Health and Community Care

On the Borderline?
People with Learning Disabilities and/or Autistic Spectrum Disorders in Secure, Forensic and Other Specialist Settings

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ON THE BORDERLINE?
PEOPLE WITH LEARNING DISABILITIES AND/OR
AUTISTIC SPECTRUM DISORDERS IN SECURE,
FORENSIC AND OTHER SPECIALIST SETTINGS

Fiona Myers
Scottish Development Centre for Mental Health

Scottish Executive Social Research
2004
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<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACT</td>
<td>Act and Care the Scottish Prison Service Suicide Risk Management Strategy</td>
</tr>
<tr>
<td>ASD</td>
<td>Autistic Spectrum Disorder(s)</td>
</tr>
<tr>
<td>AWIA</td>
<td>Adults with Incapacity (Scotland) Act 2000</td>
</tr>
<tr>
<td>CRF</td>
<td>Case recording form</td>
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<tr>
<td>CPA</td>
<td>Care Programme Approach</td>
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<tr>
<td>CPN</td>
<td>Community Psychiatric Nurse</td>
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<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
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<tr>
<td>MDT</td>
<td>Multi-Disciplinary Team</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PAMs</td>
<td>Professions Allied to Medicine</td>
</tr>
<tr>
<td>RMHN</td>
<td>Registered Mental Handicap Nurse</td>
</tr>
<tr>
<td>RMN</td>
<td>Registered Mental Nurse</td>
</tr>
<tr>
<td>RMO</td>
<td>Responsible Medical Officer</td>
</tr>
<tr>
<td>SACRO</td>
<td>Scottish Association for the Care and Resettlement of Offenders</td>
</tr>
<tr>
<td>SER</td>
<td>Social Enquiry Report</td>
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<tr>
<td>SPS</td>
<td>Scottish Prison Service</td>
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<tr>
<td>STOP</td>
<td>Sex Offenders Treatment Programme</td>
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EXECUTIVE SUMMARY

INTRODUCTION AND BACKGROUND

- *The same as you?* the review of services for people with learning disabilities published by the Scottish Executive in 2000 recommended that the Scottish Executive should commission research into the numbers of people with learning disabilities in prison or secure accommodation and the arrangements for assessing and providing them with care. In response the Scottish Executive Health Department commissioned the study which forms the basis of this report.

- For the purposes of the research secure accommodation comprises the State Hospital, the 16 prisons in Scotland, the 6 secure accommodation units for children, and 24 secure, forensic or other specialist in-patient settings for people with learning disabilities and those for people with mental health problems.

- The study was concerned with children, young people and adults with learning disabilities and those with Autistic Spectrum Disorders (ASD). The defining characteristics the study took as being associated with learning disabilities and with ASD are described in Annex 1.

- Different policy streams can affect people with learning disabilities and/or ASD in different secure settings. These include: overarching policies and initiatives such as mental health legislation; policies with implications for children and young people, including those with learning disabilities and/or ASD who require secure accommodation; and policies with implications for young people and adults with learning disabilities and/or ASD who offend, or whose behaviour puts them at risk of contact with the criminal justice system.

- A literature review undertaken as part of the study revealed the definitional and methodological difficulties associated with measuring the prevalence of people with learning disabilities and/or ASD in secure settings.

- Nine key themes emerged from the literature reviewed including: the under-identification of people as having a learning disability and/or ASD among those who come into contact with the criminal justice system; the multiply deprived backgrounds of this group of people; the risk of some people in this group falling between service and policy responsibilities.

- To inform policy and practice development research needs to be undertaken in a number of areas. In particular more needs to be understood about people with ASD who offend or come into contact with the criminal justice system. Research is also needed which compares the routes to, and the experiences of, men and women with learning disabilities and/or ASD in secure settings and of people from minority ethnic communities. The outcomes for people with learning disabilities and/or ASD in secure settings also need further investigation.
STUDY DESIGN AND METHODS

- The study comprised 2 stages. The first stage involved a scoping exercise across 57 secure settings: identifying the numbers of people with learning disabilities and/or ASD in each of the settings and the services available. The brief for the research project specified the need to include at this stage all 16 prisons in Scotland, the 11 wards on the State Hospital site and the 6 secure accommodation units for children. In addition the researchers included 24 hospital in-patient units selected because they accommodated people with learning disabilities and/or ASD who had offended or engaged in offending behaviours, or who were a risk to themselves and/or others.

- The first stage involved the completion by the selected units of 3 forms: a unit level profile; a unit level recording form; and individual level case recording forms. Social Enquiry Reports (SERs) prepared by criminal justice social workers in 2 local authority areas were also reviewed.

- The response rate to this stage was extremely good: 52 units returned unit profile and unit recording forms - a response rate of over 90%. Over two-thirds of the case recording forms distributed were completed and returned.

- The second stage involved an in-depth investigation of 7 secure settings. The research brief indicated that this stage should include the State Hospital, St Mary’s and Rossie secure accommodation units for children and 4 prisons. The 4 prisons were selected by the researchers to ensure that the sample included establishments holding women, young offenders, sex offenders and prisoners serving shorter sentences. Each of the prisons selected had someone currently resident who was believed to have a learning disability and/or ASD. In each setting interviews took place with service managers and staff and, where possible, people with learning disabilities and/or ASD. One relative also took part in an interview.

- The design and methods employed established the numbers of people identified or assessed as having a learning disability and/or ASD across the different secure settings. The perception was held, particularly by prison staff and managers, that there was, in addition, an indeterminate number of people who may have a learning disability and/or ASD who had not been identified. This meant that it was not possible to determine prevalence rates.

IDENTIFYING PEOPLE WITH LEARNING DISABILITIES AND/OR ASD IN SECURE SETTINGS

- The data suggest that there are 3 ‘triggers’ for identifying people with learning disabilities and/or ASD within the secure settings: information made available prior to or at referral; information collected in the course of routine assessments following admission; and information collected or assessments undertaken in response to problems or concerns arising.
• The value of pre-admission information depends upon whether people have been identified prior to referral as having a learning disability and/or ASD and whether this information is available to the secure setting.

• Post admission, the secure settings described different routine assessment mechanisms and processes which, though not specific to screening for, or identifying, whether someone has a learning disability and/or ASD, could flag up the need for specialist assessment. This requires people to be aware of learning disabilities or ASD as a possible explanation for someone’s behaviour or responses.

• Assessment tools for identifying someone as having a learning disability and/or ASD may be less significant than access to professionals with specialist expertise in these areas.

• The use of tools and the availability of expertise in assessing or diagnosing ASD appears to be limited.

• The data suggest that the range of different agencies and professionals within and outwith the secure settings may not necessarily result in improved identification but, in some cases at least, a risk of people slipping between the different ‘nets’.

HOW MANY PEOPLE?

• A self-completion pro-forma distributed to secure settings asked respondents to indicate the numbers of people currently accommodated who had been formally assessed or diagnosed as having, or were strongly believed to have, a learning disability and/or ASD. This yielded the following numbers of children, young people or adults with a learning disability and/or ASD in each of the secure settings:

  19 people across the 16 prisons in Scotland
  3 children or young people across the 6 secure accommodation units in Scotland
  26 people accommodated in the specialist ward for people with learning disabilities on the State Hospital site
  19 people accommodated in selected secure, forensic or other specialist settings for people with mental health problems, including 9 wards on the State Hospital site
  149 people in selected secure, forensic or other specialist settings for people with learning disabilities

• Although across the prison estate only a small number of people were formally identified, the perception among prison respondents was that this represented only a proportion of a larger number of prisoners who had a learning disability and/or ASD, but who had not been identified, assessed or diagnosed

• The figures underline questions concerning the processes for identifying and assessing children, young people and adults prior to and post-admission to a secure setting.
PEOPLE IN SECURE SETTINGS: CHARACTERISTICS, HISTORIES, RISKS AND VULNERABILITIES

• The sample of 49 for whom case recording forms were completed comprised a white, predominantly male population.

• The majority of the sample had a learning disability only, 4 people had an ASD, and 7 both learning disabilities and an ASD.

• The majority of the sample for whom information was available had an assessed IQ of between 60 – 70. Eight people had assessed IQs of over 70, and 9 had IQs under 60. The majority of the latter were in learning disability units.

• At least 24 people also had mental health problems. Among the prison population this tended to be depression. People in learning disability units tended to be diagnosed as having psychotic illnesses.

• A number of people also had chronic physical health conditions. Communication difficulties were noted in relation to 28 people.

• Available information on past histories indicates that the majority of people had been in local authority care at some time. A large proportion had been in-patients of learning disability or psychiatric units at some time in the past. Across the sample 19 people had had periods in both learning disability and psychiatric units.

• Lengths of stay were variable in and across the secure settings, though for adults in prison these tended to be shorter on average than in healthcare settings. The young people had been in secure accommodation for between one year and 20 months.

• Information on index offence and risks posed to others indicate that a number of the sample had committed quite serious offences, including sexual offences, culpable homicide and fire raising. Others may not have been convicted but were at risk of engaging in offending behaviour.

• The sample was also a vulnerable group of people. A number of people with learning disabilities and/or ASD were considered by staff within the units to be at risk of self-harm. People were also felt to be at potential risk from other residents. The possible risks identified by staff included being ostracised, bullied or exploited.

• A number of people had been assessed under the Adults with Incapacity (Scotland) Act 2000 (see 5.63 below). Independent Advocacy was believed to be accessible to the majority of the sample in healthcare settings and secure accommodation, although not everyone had an advocate. None of the prison sample had an independent advocate.

• The key features distinguishing the profiles of the adults in the different environments include the IQ levels of individuals, the nature of co-morbid mental illness and the routes to
the different types of setting. In other respects adults in different types of secure environment shared similar characteristics.

**ASSESSMENT OF NEED AND CARE PLANNING**

- Comparing across the settings, the secure accommodation units for children had access to the widest range of contributors to assessment from both within and outwith the units.

- Within the prisons, there is evidence of multi-disciplinary input but the range of resources appears more circumscribed. There also does not appear to be a systematic approach to actively involving users in the assessment process.

- The State Hospital and the learning disability and psychiatric units appear to have a broad range of assessment resources to draw upon. These are largely internal to the units.

- Both in relation to the State Hospital units and the in-patient units for people with learning disabilities, there may be a lack, in one form or another, of external voices to contribute to assessments. This includes independent advocacy or relatives, where appropriate.

- Co-ordinating assessments may be a single or joint responsibility. Recording mechanisms too, may be a single set of notes or profession specific.

- Risk assessments tend to be based on professional expertise or generic tools.

- The majority of people in the sample had some form of needs-led, if not person-centred, care plan.

- Care plans prepared by the State Hospital and secure accommodation for children had the dual purpose of informing current activities and interventions and planning for the future. Within the prisons the focus at the care planning stage tended to be more on the here and now.

- From the descriptions of assessment and care planning it would seem that a number of recent relevant policy initiatives, including single shared assessment, personal life plans and the involvement of local area co-ordinators do not yet have currency within the secure settings in which people with learning disabilities and/or ASD may find themselves.
MEETING ASSESSED NEEDS

Appropriateness

- The perception among prison-based professionals interviewed was that, in general, the prisons were not an appropriate environment for people with learning disabilities and/or ASD. The view expressed was that the prisons had neither the resources nor the expertise to meet the needs of this group of people.

- The responses of professionals within 2 secure accommodation units suggest that different units use different criteria upon which to judge the appropriateness of the environment for children or young people with learning disabilities and/or ASD. These criteria may relate to the severity of the disability or a child or young person’s particular combination of needs.

- The State Hospital respondents suggested that very few people with learning disabilities and/or ASD required conditions of high security. To meet the needs of this group of people efforts had been made by the hospital to enhance the service through the appointment of additional specialists and by adapting programmes.

- Women in general, and women with learning disabilities and/or ASD in particular were felt to be inappropriately placed in the high secure environment of the State Hospital. The need to mix women with mental health problems and those with learning disabilities on the one women’s ward was also felt to be less than satisfactory.

- The majority of people in the in-patient learning disability units were felt to be appropriately placed. There were, however, a small number who were felt to need ‘step down’ or community placements.

- People with learning disabilities and/or ASD on psychiatric units were felt to be inappropriately placed either because of the lack of specialist skills available or because they too required a community placement.

Resources

- Within the prisons the resources to meet the needs of this group of people included the time made available by staff, particularly health care staff, and the attempts to find activities to engage them and with which they could cope.

- There, were though limits to what the prisons could provide. Respondents described how, if staff were not available, people with learning disabilities and/or ASD may have to be locked in their cells for periods to ensure they were protected. It was also suggested that, in the absence of appropriate resources, people with learning disabilities and/or ASD may not have an opportunity to address their offending behaviour.
To meet the needs of children and young people in secure accommodation the approach was to adapt generic resources including teaching, programmes and health care. There was little evidence of direct input from specialists in learning disabilities and/or ASD.

Gaps identified by the secure accommodation units included resources for intensive input, the need to adapt programmes, and the reduced levels of support available to young people when they move on from the units.

Within the State Hospital the specialist unit for people with learning disabilities, the women’s unit and rehabilitation unit had access to psychiatric, psychological, nursing and social work expertise in learning disabilities. Hospital wide services including the Patient Activity and Recreation Services were increasingly tailoring services to meet the needs of people with learning disabilities and/or ASD. Adapted psychological intervention programmes had recently been developed and introduced.

For State Hospital respondents the perceived obstacles to meeting the needs of people with learning disabilities on the site included: the high number of people accommodated on the one ward for people with learning disabilities and/or ASD; the need to support both people with mental health problems, who form the majority, and people with learning disabilities and/or ASD on the same site, and in some cases on the same wards; and the use of some generic services which may be less sensitive to the needs of this client group. The significant gap identified, by staff was the perceived lack of appropriate community-based facilities to enable people to move on from the State Hospital.

In-patient learning disability units had access to a wide range of professionals with specialist learning disability expertise.

Although not drawing on the same range of specialists, the psychiatric units appeared to have developed very individualised packages, including social work and voluntary organisation input.

One service gap identified by learning disability and psychiatric units was the lack of appropriate accommodation to enable people to move on.

Three themes emerge from the overview of ways in which the settings meet the needs of people with learning disabilities and/or ASD.

First, that people with learning disabilities in general, and women and people with ASD in particular, do not fit easily into what is perceived by respondents to be the core business of the different secure environments.

Second, respondents perceived there to be a lack of appropriate resources outwith the secure settings.

Third, different strategies are used to respond to the needs people present: using specialist resources; using generic resources; and adapting generic resources.
MOVING ON: THROUGHCARE AND AFTER CARE

• For people in prison arrangements for throughcare and after care are contingent on whether they are remand or sentenced, and, if sentenced, the length of sentence and/or whether they will be going out on licence or under a supervision order.

• For people on remand and those eligible for voluntary after care, arranging support on release is a largely informal process involving prison healthcare or social work staff making contact with outside agencies on behalf of the person.

• ‘Formal’ mechanisms for after care and throughcare planning include the criminal justice social work led process for people going out on licence and the health care led Care Programme Approach.

• The formality of the process for people going out on licence may ensure continuity of care, but may place requirements on an individual that they are unable to fulfil. The informal approach for people who are not under licence may mean they do not receive follow up or support in the community, potentially increasing the likelihood of re-offending.

• The secure accommodation units for children appear to be forward focused and proactive in planning for throughcare and after care. There is also an emphasis on multi-disciplinary and multi-agency working, involving unit based and external professions and agencies.

• Discharge planning for people on the State Hospital site was multi-disciplinary but primarily involved professionals from within the hospital.

• In the few cases where discharge planning was in progress for people on in-patient units outwith the State Hospital there appeared to be greater involvement by external agencies and services.

• Respondents felt that one of the fundamental barriers faced by people ready to move on from healthcare settings was the lack of appropriate resources beyond the secure setting, including a range of types of accommodation and activities and interventions.

• Community-based health and social care resources may also be reluctant to take on responsibility for people, particularly those moving from the State Hospital. State Hospital staff suggested that local units may feel they do not have the capacity to cope with the risks someone poses.

• Interviews with people with learning disabilities and/or ASD revealed their hopes and aspirations but also their frustrations as they wait for appropriate places to become available so they can move on.

• The lack of integrated care networks, clarity of agency responsibilities and a perceived lack of appropriate resources can have a number of implications for people with learning disabilities and/or ASD in secure settings. Some people may have to wait a number of years...
before they are able to move; some may have to move to units even further away from their family and friends; the risk of recidivism may increase when people move out of prison without timely and appropriate support. For people in the community inadequate or inexperienced support may mean admission or re-admission to the State Hospital.

- A number of recent policy initiatives may assist to break down some of the barriers encountered by people in secure settings. This, however, hinges on the preparedness of ‘external’ agencies to accept responsibility for these individuals, and the capacities and confidence of mainstream services to respond to their complex needs.

DISCUSSION

- The evidence from the study suggests that children, young people and adults with learning disabilities and/or ASD could find themselves on the ‘borderline’ not just in terms of the ways in which their capacities and abilities are defined, but in policy and service terms. As a result they may be perceived as not fitting in with what providers see as the core business of the different secure environments. Some people, particularly women and people with ASD may be doubly on the margins.

- To begin to understand the implications for people with learning disabilities and/or ASD the different approaches to identification, assessment and care planning, service provision and after care planning are summarised. Drawing on the comments of respondents a range of possible outcomes for people beyond secure care are described. A number of illustrative scenarios are presented to suggest that unless these different elements of the process are in place, appropriate and in balance, some people may become ‘entrapped’ within a secure environment while others may find themselves on a revolving door between community and custody.

CONCLUSIONS

Policy implications

- At policy level it is suggested that there is scope for linking the different policy initiatives as they impact upon people with learning disabilities and/or ASD in secure settings.

Planning implications

- In service planning terms secure environments could be linked in to appropriate planning and development networks for people with learning disabilities and/or ASD.

- Local area co-ordinators may also have a role in managing and co-ordinating the care of people with learning disabilities and/or ASD in secure environments.
Practice implications

- In practice terms there is scope for raising awareness about people with learning disabilities and/or ASD across the different disciplines in non-healthcare settings, including health, social work, social care, education and security staff.

- Consideration could be given to the development of a screening tool for use in non-healthcare settings.

- There is scope for greater co-ordination of information and assessment, particularly within prison environments. Consideration could be given to introducing a single shared assessment model within secure settings.

- Perceived resource constraints were described. These related to the capacity to provide appropriate services within secure environments and to the resources available outwith these settings to provide after care.

- There may be scope for greater involvement of, and integration with, specialists in learning disabilities – statutory and voluntary/independent - not just as service providers, but in an advisory capacity. This includes access to Speech and Language Therapists.

- The feasibility of people with learning disability and/or ASD in secure environments having the opportunity to have a personal life plan could be considered.

- Within each unit there may be a value in identifying a key person with responsibility for issues relating to learning disability and/or ASD. This could, for example, be a RMHN in a prison, or a designated teacher in a secure accommodation unit.

- A number of areas for further research are identified which could assist policy, service and practice development.
CHAPTER ONE       INTRODUCTION AND BACKGROUND

INTRODUCTION

1.1 The same as you? the review of services for people with learning disabilities, published in 2000, included as one of its recommendations:

The Scottish Executive should commission research into the number of people with learning disabilities in prison or in secure accommodation and the arrangements for assessing and providing them with care (Scottish Executive, 2000)

1.2 This arose from the review’s concern that there was insufficient information on the numbers, needs and vulnerabilities of people with learning disabilities and/or autistic spectrum disorders (ASD) in prison and secure accommodation.

1.3 To begin to piece together a picture of the numbers of people with learning disabilities and/or Autistic Spectrum Disorders (ASD) accommodated in secure settings, the means by which they are identified, and their needs assessed and met, the Scottish Executive Health Department commissioned the 11 month study which forms the basis of this report.

1.4 For the purposes of the project secure accommodation comprises the State Hospital at Carstairs, the 16 prisons in Scotland, the 6 secure accommodation units for children and 24 secure, forensic or other specialist in-patient settings for people with learning disabilities and those for people with mental health problems.

1.5 The study was concerned with children, young people and adults with learning disabilities and those with ASD. The defining characteristics the study took as being associated with learning disabilities and with ASD are described in Annex 1. People with learning disabilities have a significant, life long condition that started before adulthood, that affected their development and which means they need help to: understand information; learn skills; and cope independently (Scottish Executive, 2000; Holland et al, 2002). The characteristics associated with ASD, including autism and Asperger’s syndrome are: difficulty with understanding verbal and non-verbal communication; difficulties with social relationships and understanding social behaviour; and ritualistic behaviour or obsessiona l interests (Wing, 1996). Some people can have both a learning disability and ASD.

1.6 Although the study itself is set within the policy context of the review of services for people with learning disabilities, the different secure settings are shaped by other policy influences which may impact upon the ways in which they are able to respond to the needs of people with learning disabilities and/or ASD. This opening chapter begins by sketching out these different policy influences. This is followed by a summary of themes drawn from a review of literature. The literature review provides an evidence base against which to compare the research findings.
POLICY CONTEXT

1.7 The study focuses on a number of quite distinct secure settings: prisons, high secure in-patient care, specialist in-patient care for people with learning disabilities and those with mental health problems and secure accommodation for children. Each has different core objectives, or a different balance of objectives, for example, custodial, therapeutic and/or protective. The idea of a ‘secure setting’ is therefore, in many respects, an artificial construct. Further, the study combines a focus on both learning disabilities and ASD as well as on children, young people and adults. As a result different policy streams will be influential on the different settings and the people for whom they provide a secure environment. To begin to identify the ‘bridges’ between these different streams policies and initiatives have been grouped into 3 categories:

- Overarching policies and initiatives with implications for people with learning disabilities and/or ASD
- Specific policies and initiatives with implications for children and young people, including those with learning disabilities and/or ASD, who require secure accommodation
- Policies and initiatives with implications for adults with learning disabilities and/or ASD who offend or whose behaviour puts them at risk of contact with the criminal justice system

Overarching policies and initiatives with implications for people with learning disabilities and/or ASD

‘Universal’ policies

1.8 At a universal level, human rights legislation, disability discrimination legislation and social justice and social inclusion policies, all have implications for people with learning disabilities and/or ASD. They may take on a particular resonance in this context both while people are in secure settings and when they move on.

Mental health legislation

1.9 The current Mental Health (Scotland) Act 1984 and the Mental Health (Care and Treatment) (Scotland) Act 2003 both include learning disabilities within the definition of mental disorder. When implemented the new legislation will have implications both for people with learning disabilities and/or ASD and for services. Changes introduced by the new Act include: the extended role of Mental Health Officers, including the preparation of reports for offenders subject to a compulsion order; the capacity for individuals to challenge continued detention at a level of security they are assessed as no longer requiring; the role of the Mental Health Tribunal, including its role as an appeal mechanism for mentally disordered offenders; and the right to advocacy.

1.10 The main provisions of the new Act will become effective in April 2005. The right of appeal for patients detained in excessive security will be implemented in May 2006.
Adults with Incapacity (Scotland) Act 2000

1.11 The Adults with Incapacity (Scotland) Act 2000 (AWIA) enables decisions to be made on behalf of adults who lack the legal capacity to do so themselves due to either mental disorder or an inability to communicate. As in the case of mental health legislation ‘mental disorder’ includes learning disabilities. Of particular relevance in relation to people with learning disabilities and/or ASD in secure settings is part 5 of the legislation which deals with decisions relating to medical treatment and research, and part 6 which makes provision for intervention orders and guardianship orders relating to financial and/or welfare decisions. Part 6 supersedes arrangements for guardianship, tutors, and curator bonis, previously contained in the Mental Health (Scotland) Act 1984. The Criminal Procedure (Scotland) Act 1995 has also been amended to reflect the arrangements for welfare guardianship introduced by the AWIA.

1.12 Both the Mental Health (Care and Treatment) (Scotland) Act 2003 and the AWIA are based on sets of principles that encourage consideration of issues of benefit, least restrictive intervention, non-discrimination and participation. As fundamental principles they are therefore applicable to all those who come within the scope of the respective legislation, including people with learning disabilities and/or ASD in secure settings.

Reviews of services for people with learning disabilities and/or ASD

1.13 In addition to the legislative context the key policy statement, and the one which provides the framework for the study which follows is *The same as you?*, the review of services for people with learning disabilities published by the Scottish Executive in 2000. For the current study 3 elements of the review have particular significance. First, the 7 values and principles the review embodies. Set out in Figure 1.1, one of the questions the study raises is how these are, or can be applied in secure settings: not just health care settings, but environments such as prisons.

![Figure 1.1](image-url)

**Seven principles from ‘The same as you?’ A review of services for people with learning disabilities (Scottish Executive, 2000)**

- People with learning disabilities should be valued
- People with learning disabilities are individual people
- People with learning disabilities should be asked about the services they need and be involved in making choices about what they want
- People with learning disabilities should be helped and supported to do everything they are able to
- People with learning disabilities should be able to use the same local services as everyone else, wherever possible
- People with learning disabilities should benefit from specialist school, health and educational services
- People with learning disabilities should have services which take account of their age, abilities and other needs.

1.14 Second, the inclusion in the review of both people with learning disabilities and those with ASD as well as children and adults. The inclusion of children implies that secure accommodation comes within the remit of the policy. The inclusion of people with ASD is particular salient in environments where this group of people may comprise a minority within a minority.
1.15 Third, a number of the specific recommendations made in the review are of particular relevance. The recommendation to close long stay hospitals for people with learning disabilities by 2005 has a number of implications. As discussed in chapter 7, the prisons felt that hospital retraction had meant that in the apparent absence of alternative forms of support prison had become the only option for some people. For people in hospital who have been assessed as continuing to need 24-hour supervision in a secure environment the data suggest that retraction for some may be experienced as being moved from one hospital to another.

1.16 The review’s recommendations for health board and local authority Partnership in Practice agreements, the appointment of local area co-ordinators, the options for individuals to have personal life plans, and the setting up of a Scottish service network for people with autistic spectrum disorders should all provide opportunities for ensuring on-going responsibility for children, young people and adults who enter secure environments. As the following chapters demonstrate, however, these mechanisms do not yet feature in the descriptions given of the processes of identification, assessment, service provision and after-care for this client group.

1.17 A further initiative specifically concerned with improving services for people with learning disabilities and/or ASD is the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities, Promoting Health, Supporting Inclusion (Scottish Executive, 2002c). The review specifically draws attention to the needs of children in secure accommodation and people with learning disabilities in prison. The review emphasises the importance of ensuring “that their everyday and special needs are appropriately addressed” (p.41). Although not specific to these 2 groups of people, the review’s proposals to enhance the skills of non-specialist learning disability nurses and to improve access to appropriately trained specialist nurses at local and regional levels have particular saliency. As discussed in chapter 7, in the prisons and secure accommodation, responsibility for the care of children, young people and adults with learning disabilities falls heavily on largely ‘generic’ health care staff, with little direct input from learning disability specialists.

**Single shared assessment**

1.18 Among its recommendations the Scottish Executive Joint Future Group (2000) proposed the introduction of single shared assessment: a mechanism for streamlining and co-ordinating needs assessments across and within disciplines and agencies. Although a ‘generic’ initiative, the introduction by April 2004 of single shared assessment across all community care groups will impact upon people with learning disabilities and/or ASD in the community. What cannot be predicted is the extent to which it is applied in relation to people in secure settings. Chapter 6 below suggests that single shared assessment has yet to fully enter the consciousness of these environments.
Policies and initiatives with implications for children and young people, including those with learning disabilities and/or ASD who require secure accommodation

For Scotland’s Children

1.19 Of the policies and initiatives aimed at children the baseline is perhaps *For Scotland’s Children* published in 2001 (Scottish Executive, 2001a). In response to concerns that current children’s services were poorly integrated and that some children were ‘invisible’ to services, the report sets out an Action Plan covering 6 areas including preparation of a joint children’s service plan, inclusive access to universal services, co-ordinated needs assessment, co-ordinated interventions and targeted services. It is outwith the scope of this study to assess the extent to which these objectives have been implemented in ways which include children with learning disabilities and/or ASD in general, or those in secure accommodation in particular. The aims, however, are not dissimilar to those set out in *The same as you?* (Scottish Executive, 2000).

Looked After Children

1.20 The Children (Scotland) Act 1995 provides the legislative framework for local authority responsibilities toward looked after children.

1.21 Children and young people can be admitted to secure accommodation on remand or following conviction under the Criminal Procedures (Scotland) Act 1995. The other route is via provisions in the Children (Scotland) Act 1995. Under the Act children may be referred through the Children’s Hearings on a Place of Safety Warrant for up to 22 days, or under a supervision requirement valid for up to 3 months. In addition a child may be kept in secure accommodation for 72 hours on an interim placement. Section 70 (10) of the Act sets out the criteria for admission to secure accommodation i.e. that the child:

- having previously absconded, is likely to abscond unless kept in secure accommodation, and if he absconds it is likely that his physical, mental or moral welfare will at risk; OR
- is likely to injure himself or some other person unless he is kept in such accommodation

1.22 *A Secure Remedy* (Scottish Office, 1996) reviewed the role, availability and quality of secure accommodation in Scotland. Its recommendations include improving co-ordination of assessment and information sharing, the development of needs led programmes of care, treatment and education for each child, agreed standards between local authorities for arranging after care and education for children leaving secure care, consideration of staffing levels and staff training, consideration of the design and physical environment of the secure units. In addition the report proposed that there should be further research in to the mental health needs of children in secure accommodation. The report also recommended that units develop plans for dealing with challenging behaviour. The report does not, however, refer to the specific needs of children and young people with learning disabilities and/or ASD in secure care.
To address the after care needs of looked after children, including those in secure accommodation, Sections 17 and 29 of the Children (Scotland) Act 1995 sets out the duties on local authorities in terms of preparing a child for a time when they are no longer ‘looked after’ and in relation to people above school leaving age. In response to research on the poor outcomes for young people leaving care a report from the Working Group on the Throughcare and Aftercare of Looked After Children in Scotland made a number of recommendations for improving arrangements and services (Scottish Executive, 2002d). These include ensuring a throughcare and aftercare plan and a nominated key worker/adviser for all young people leaving care. For young people with learning disabilities and/or ASD, however, the issue may not be leaving care, but of transitions between children’s services and adult services, or between local authority and health care services. How these transitions are managed is discussed in chapter 8 below.

Learning with Care

Guidance to the Children (Scotland) Act 1995 states that “children who are looked after should have the same educational opportunities as all other children for education, including further and higher education, and access to other opportunities for development” (quoted in Learning with Care, Scottish Executive (2001b)). The inspection report Learning with Care on the education of looked after children, however found variations across local authorities in the extent to which these objectives were being met. The report also highlighted the consequent educational disadvantage experienced by looked after children. Following the report local authorities were set targets for improving the educational attainment of looked after children including: ensuring they receive full time education; have a care plan which addresses educational needs; and there is a teacher designated to champion the interests of these children.

Again, although not a specific focus of the initial report or the subsequent recommendations, children and young people with learning disabilities and/or ASD in secure accommodation may be doubly disadvantaged: both in being ‘looked after’ and in having specific learning and educational needs. The ways in which secure accommodation units attempted to cope with these needs are described below in chapter 7.

Additional Support for Learning

Future educational provision for children with special needs, including those with learning disabilities and/or ASD in secure accommodation, will be informed by the proposals set out in the Education (Additional Support for Learning) Bill, published in October 2003. The bill anticipates replacing the current Record of Need system with a new duty on local authorities to identify and assess children with additional support needs (ASN) and provide them with individually tailored education packages.

Youth Justice

Throughout the course of the research project a number of policies and initiatives were launched focusing on youth justice. These include: Scotland’s Action Plan to Reduce Youth Crime 2002 (Scottish Executive, 2002e); the 10 point plan proposed by the Ad Hoc Ministerial
Group on Youth Crime (Scottish Executive, 2002a); and the publication of a set of National Standards for Scotland’s Youth Justice Services by the Improving the Effectiveness of the Youth Justice System Working Group (Scottish Executive, 2002b). The proposed national standards include, as one objective “To target the use of secure accommodation appropriately and ensure it is effective in reducing offending behaviour”. During the course of the research the Secure Accommodation Advisory Group also made public its 2001 interim report on the use and development of secure accommodation (Scottish Executive, 2003a).

1.28 To implement the proposals a number of new funding streams have been made available including: the Youth Crime Prevention Fund, the Youth Justice Teams Fund and the Intensive Support Fund. The latter aims to increase the level of community based supervision of young offenders and improve support for those returning to their communities from secure accommodation.

1.29 Across these initiatives the common themes are early intervention/prevention, responding to offending behaviour, tackling the effects of youth crime on individuals and communities and preventing re-offending. All of these have potential implications for children and young people with learning disabilities and/or ASD who engage in offending behaviour. In the context of the research, however, the 2 key themes are the expansion of the secure estate and the emphasis on programmes to prevent offending and re-offending.

1.30 In March 2003 proposals to create an extra 29 secure accommodation places were announced. In addition to improving the geographical spread across Scotland, the aim is to provide a wider range of accommodation including dedicated places for girls and women and support for young people with mental health problems. At this stage it cannot be predicted what effects, if any, the dual approach of targeted use and the expansion of the estate will have on the referral of young people with learning disabilities and/or ASD. As indicated in chapters 3 and 4 below, at present the numbers identified are extremely small. It is possible that improved identification, particularly of children and young people with ASD may create a demand for further specialisation across the expanded estate, analogous to the increased provision for those with mental health problems.

1.31 To prevent youth offending and re-offending the different initiatives emphasise the role of programmes or interventions targeted at offending behaviour. Objective 2 of the proposed national standards, for example, seeks to “Improve the range and availability of programmes to stop youth offending” (Scottish Executive, 2002b). This extends to improving the range of programmes provided in secure accommodation. Chapter 7 below, however, suggests that unless these programmes can be tailor made or re-designed they may prove to be less than effective in helping children and young people with learning disabilities and/or ASD who engage in offending behaviour.
Policies and initiatives with implications for young people and adults with learning disabilities and/or ASD who offend or whose behaviour puts them at risk of contact with the criminal justice system


1.32 For adults with learning disabilities and/or ASD who engage in offending behaviour the key policy document is NHS MEL (1999) 5 Health, Social Work and Related Services for Mentally Disordered Offenders in Scotland. This sets out the roles and responsibilities of statutory agencies to meet the care, treatment and security needs of people with mental health problems, learning disabilities or a personality disorder who come into contact (or are at risk of contact) with criminal justice services. The policy excludes children on the basis that the needs of children and adolescents “are very specific and every effort should be made so that they are dealt with separately” (p.4).

1.33 The pattern of future services proposed specifically for people with learning disabilities include a range of accommodation with different levels of security including secure, semi-secure, potentially lockable, and staffed community accommodation, as well as input from a range of health, social work and voluntary sector providers. Recognising the vulnerability of people with learning disabilities in prison, the review recommends the availability of diversion schemes when appropriate.

1.34 Following a review of the implementation of the policy, the Scottish Executive issued a care pathway framework to enhance integrated working between the different agencies at different stages of an individual’s route through the criminal justice, health care and social work systems (NHS HDL (2001) 9). The need to improve the integration of the different elements of the service system also emerged from a consultation focusing on the governance and accountability of the State Hospitals Board. Plans are now in progress to set up a national forensic managed care network.

Criminal justice legislation and sex offending

1.35 Other legislative changes or policy initiatives whose impact upon people with learning disabilities and/or ASD who engage in serious offending behaviour is untested include the Criminal Justice (Scotland) Act 2003. This introduces the Order for Lifelong Restriction for serious offenders and sets up a Risk Management Authority. This legislation builds on the work of the Expert Panel on Sex Offending (Scottish Executive, 2001c) and the MacLean Report on Violent and Sexual Offenders (Scottish Executive, 2000). Specifically in the context of sex offending, an expert group was set up in March 2003 to consider how agencies can work better together to manage the risk presented by sex offenders. As described in chapter 5, a number of people within the sample for the study had engaged in offending of a sexual nature.
Scottish Prison Service policies

1.36 Within the prisons 2 policies are of specific relevance to understanding the resources available to support people with a learning disabilities and/or ASD in secure settings. First, the SPS Positive Mental Health Strategy (2002a) sets out objectives for responding to the mental health needs of prisoners and creating an environment which enhances positive mental health. Key to realising these objectives is the role of prison based multi-disciplinary mental health teams. Among the target groups identified are people with “cognitive impairments” including those associated with a “learning disability”. The policy recognises, however, that some areas are not yet fully addressed and require further needs analysis and research. Learning disability is specifically included as one such area.

1.37 The second policy of relevance is the SPS Sentence Management Process (2002b). This is a system of assessment, action planning and interventions geared towards reducing an individual’s offending behaviour. At a number of points in the following chapters it is suggested that as a process it provides an opportunity to identify or flag up needs relating to an individual’s learning disability and/or ASD. However, because of the limited scope for tailoring interventions, the view was also expressed by research respondents that the process may have only a limited impact on reducing offending behaviour among this group of people.

Discussion

1.38 There is no one policy encompassing children, young people and adults with a learning disability and/or ASD whose behaviour or welfare needs may lead them on the pathway to secure care. What this overview illustrates is the range of well-developed policies that impact, to a greater or lesser degree, on this “unique” group of people, either because they have a learning disability or ASD, because they are children or because they are adults who engage in offending behaviour.

1.39 It is not that these different policies are in conflict. In a number of respects they in fact overlap in their core objectives or the mechanisms they propose to meet these objectives. But to what extent are policies intended for people with learning disabilities and/or ASD translated or adapted for implementation into secure environments such as prisons or secure accommodation for children? On the other hand, how flexible and adaptable can policies intended to inform the structure and functions of secure settings be to meet the specific needs of the small numbers of people with a learning disability and/or ASD?

1.40 Some of these questions are addressed in the following chapters. But what the policy overview does suggest is the need not just for a care pathway for individuals, but a policy pathway to map the points of connection.
LITERATURE REVIEW

Issues of method

1.41 One of the specific objectives of the research was to review the literature on people with learning disabilities and/or ASD in secure settings, summarising the main findings and highlighting any gaps in information.

1.42 As with the policy context, identifying research relevant to the study meant following a number of quite different lines of enquiry. Search terms included ‘service’ terms, for example, prison, secure care, special hospital, approved schools and forensic; ‘status’ terms such as prisoner, detained, probation, convicted, remand, children, young offender; coupled with ‘clinical’ terms including learning disability, mental retardation, intellectual disability, autism/autistic and Asperger’s syndrome. The 2 inclusion criteria for the literature review were that the studies were specifically concerned with, or specifically included, people with learning disabilities and/or ASD, and, were set in, or addressed some issue relating to the security of the environment or the need for security.

1.43 Even narrowing down the review to these 2 criteria was not without its difficulties. The concept of ‘security’, for example, is difficult to pin down, including as it does relational, physical and procedural dimensions (Vaughan, 2002). Although not watertight, for the purposes of the literature review ‘secure settings’ comprised: prisons, in-patient care providing a level of physical and/or relational security over and above or instead of a locked door and secure accommodation for children. The user information sheet developed by the research project to describe to potential interviewees what the study was about summarises these different environments as “places where people can’t just go out when they want to”.

1.44 The concept of learning disability is also fluid. First, there are the different terms used, for example, intellectual disability, learning difficulty, mental retardation, to describe what may or may not be a similar set of attributes. Second, the measures used to assess these attributes, and the cut off points used to distinguish between people with and without learning disabilities make comparison difficult. The most frequently cited cut off point is an assessed IQ of 70 or below, but some services determine their own thresholds. Third, the use of different tools and measures for estimating incidence and prevalence in different environments also undermines the scope for comparison.

1.45 Whether someone is defined as an ‘offender’ may not just be dependent upon notions of intent, or the assessed capacity to tell right from wrong (Holland et al, 2002). Other factors, such as service responses may determine whether similar behaviours are processed via the criminal justice system or contained within service systems (Lyall et al, 1995).

1.46 Each of these 3 definitional problems have implications not just for the literature review, but for the research as whole in terms of the range of healthcare environments included (chapter 2), the ways in which people are identified (chapters 3 and 4), and the routes by which people arrive in the different settings (chapter 5).
Emerging themes

1.47 Despite the difficulties of definition and comparison 9 key themes emerged from the literature reviewed.

- The under-identification of people as having a learning disability and/or ASD among those who come into contact with the criminal justice system. Petersilia (2000) and Flynn and Bernard (1999) point to the difficulties the police and others in the criminal justice system have in recognising that someone may have a learning disability, particularly where this is mild or borderline. Even in clinical settings the findings from a number of settings suggest that among trained professionals outwith specialist services there may not be an awareness, knowledge or consideration of the possibility of a diagnosis of learning disability or, in particular, of ASD (Gunn et al, 1991; Scragg and Shah, 1994; Hare et al 1999; Siponmaa et al, 2001)

- Studies focusing on prison populations have found only very small proportions of people with an IQ of less than 70. However, the different methods employed, populations sampled, together with contextual factors such as criminal justice policies, mean that there is no one figure that can be used as a benchmark. For example, estimates for remand prisoners range from 2.0% to 5.0% (Woods and Mason, 1998; Holland et al, 2002). For sentenced prisoners the prevalence rate can vary widely from 0.4% of adult males (Gunn et al, 1991) to 28.8% (Murphy et al, 1999).

Even if the proportion of people with an IQ of less than 70 is small, there is felt to be a high proportion of people with low educational levels. A study of remand prisoners in Scotland, for example, found that only 0.3% of the sample had an IQ below 70. In total, however, 11% had an IQ of 80 or below (Davidson et al, 1995). Murphy et al (1995) and Winter et al (1997) both found that although very small proportions had an IQ of 70 or below there were men among their sample prison populations who were likely to have major difficulties with adaptive behaviour or who were very vulnerable psychologically.

Where identified those in contact with the criminal justice system tend to have mild or borderline learning disabilities (Cullen, 1993; Thomas and Singh, 1995; Clare and Murphy, 1998; Petersilia, 2000; Mason and Murphy, 2002). This has implications for early identification.

No studies were found indicating the prevalence of ASD among young offenders or adults committed to prison. Murrie et al (2002), however found that people with Asperger’s syndrome in forensic settings have little or no experience of drug or alcohol misuse and little or no prior contact with the criminal justice system

- Studies suggest comparatively high proportions of people with mild or borderline learning disabilities in forensic/secure in-patient settings (Kearns and O’Connor, 1988; Puri et al, 2000; Alexander et al, 2002)
The socio-demographic characteristics and life circumstances of people with learning disabilities and/or ASD in secure settings reveal a multiply deprived group of people. Many will have experienced abuse or disrupted early lives, poverty, unemployment, prior institutionalisation and contact with statutory services (Winter et al, 1997; Flynn and Bernard, 1999; Glaser and Deane, 1999; Simpson and Hogg, 2001; Alexander et al, 2002; Holland et al, 2002). A number will also have alcohol and drug related problems (Winter et al, 1997; Glaser and Deane, 1999).

A high proportion of people with learning disabilities in secure settings have been found to also have a diagnosable mental illness (Alexander et al, 2002; O’Brien, 2002).

Research has pointed to the vulnerability of young people with learning disabilities to the risk factors implicated in mental illness (Foundation for People with Learning Disabilities, 2002; PHIS, 2003). Young offenders are also vulnerable to mental health problems (Mental Health Foundation 2002) as are ‘Looked after Children’ (ONS, 2003). As a result children and young people with learning disabilities and/or ASD in secure settings, particularly as a result of their offending behaviour, may be particularly vulnerable to mental health problems.

The routes to secure settings may be contingent not upon behaviours per se, but on factors such as whether or not they are known to services. If known to services carers may be reluctant to call the police. If they are not known then they may be referred to the criminal justice system (Lyall et al, 1995; Clare and Murphy, 1998; Flynn and Bernard, 1999).

Whether in forensic/secure in-patient settings or in penal settings, people with learning disabilities and/or ASD can be differentially disadvantaged. Higher proportions who have not committed offences have been found to have been admitted to these specialist settings, compared with people with mental health problems (Woods and Mason, 1998). They may also have longer average lengths of stay in these secure settings (Butwell et al, 2000). In the prisons, people with learning disabilities may not be able to take part in programmes and this may limit their opportunities for early release. They may find it more difficult to understand the prison rules, which may also mean they are involved in more incidents within prisons. People in prison may also be particularly vulnerable. But, if accommodated in segregation or protection units this may further limit their opportunities to take part in education or other activities (Gunn et al, 1991; Davison et al, 1994; Flynn and Bernard, 1999; Glaser and Deane, 1999; Petersilia, 2000).

People with learning disabilities and/or ASD who offend, or engage in offending behaviours fall between different service stools: between prison and in-patient care; between health and social work responsibilities; between learning disability and mental health services (Winter, 1997; Coid, 1998; Smith, 1998; Murphy, 2000; Purie, et al, 2000).
Children too can be caught on the edge of service systems, Kurtz et al (1998) describe how specialist services can lack confidence in dealing with children in secure settings who have mental health problems: child and adolescent psychiatrists feel they lack confidence in dealing with violent behaviour; forensic psychiatrists lack experience in dealing with children and families. The authors argue the case for specialist resources for consultation and training to support children in secure settings with mental health problems. Further evidence is needed to establish whether the same applies to children with learning disabilities and/or ASD in secure accommodation.

- Other studies have found that services are not always available, or not available in ways that meet the needs of this group of people (Clare and Murphy, 1998; Coid, 1998; Smith, 1998; Purie et al, 2000; Barron et al, 2002; Murrie et al, 2002). A consistent argument is that because of their specific treatment and therapeutic needs as well as the management issues they pose people with learning disabilities and/or ASD accommodated in existing secure in-patient care or in prisons need specialist services (Mayor et al, 1990; Holland, 1991; Thomas and Singh, 1998; Murphy and Fernando, 1999; Puri et al, 2000).

Specifically in relation to people with ASD in secure in-patient settings, Hare et al (1999) comment that although people with ASD comprise only a comparatively small proportion of the special hospital population (in England), they pose particular management, treatment and placement problems.

1.48 From the literature reviewed people with learning disabilities and/or ASD present a distinctive set of needs. Although possibly having mild or borderline learning disabilities, their backgrounds suggest personal experience of multiple deprivation. A number may have co-morbid mental health problems and or needs relating to substance misuse. The borderline nature of their impairment may mean they go unidentified: if identified, however they may fall between service responsibilities. Wherever they end up, and by whatever route, the likelihood is that services may be struggling to meet the particular combination of therapeutic, treatment and management needs they present. As a result they may be both vulnerable and differentially disadvantaged. In the prison context in particular this may mean, as Petersilia comments:

“*It appears that offenders with mental retardation do more time, do harder time, and get less out of their time, and are more likely to be returned to prison after release than person’s who are not mentally handicapped.*” (1997, in Linhorst et al, 2002, p.41)

**Gaps in the evidence base**

1.49 Despite the fairly extensive literature identified and reviewed a number of gaps in the evidence base are apparent. The picture is still, in some respects, incomplete. In particular the missing pieces include:
• Limited evidence relating specifically to people with ASD who offend or engage in offending behaviour
• Limited evidence relating specifically to the experiences of, and responses to, children or young people with either learning disabilities and/or ASD in secure settings
• Few studies comparing the experiences of, and the routes to, secure care for men and for women with learning disabilities and/or ASD in secure settings
• Limited evidence on the experiences of people with learning disabilities and/or ASD from minority ethnic communities who offend or engage in offending behaviour, or their routes to secure settings
• Very little research comparing the care pathways of offenders and non-offenders to secure in-patient settings, and the long-term outcomes for individuals
• Beyond issues of recidivism there is little evidence exploring the outcomes for people with learning disabilities and/or ASD in secure settings and the people who care for and about them
• The majority of studies are quantitative. A study by Flynn and Bernard (1999) was one of the few identified that gave a voice to people with learning disabilities in secure settings. More qualitative work needs to be undertaken to explore the experiences and perceptions of people with learning disabilities and/or ASD in secure settings, and that of their families or informal carers.

1.50 The following chapters describe the findings from the research that begins to fill some of these gaps. But much has still to be learned.

**STRUCTURE OF THE REPORT**

1.51 The research design and methods are described in the next chapter. This is followed by a discussion in chapter 3 of ways in which people in the different secure settings are identified as having a learning disability and/or ASD. This sets in context the findings presented in chapter 4 on the numbers of people with learning disabilities and/or ASD in each setting at the time of the study. The characteristics of a sample of this group of people are described in chapter 5. These characteristics provide a framework for understanding the processes of identification, assessment, service delivery and throughcare and after care planning described in chapters 6, 7 and 8. Chapter 9 discusses the emerging themes and issues. These inform the conclusions set out in chapter 10.
CHAPTER TWO STUDY DESIGN AND METHODS

AIMS AND OBJECTIVES

2.1 The 2 core aims of the research were to:

- Explore the number of people in secure settings in Scotland who are known to have a learning disability and/or Autistic Spectrum Disorders (ASD)
- Explore the means used to identify, assess need and provide services for people with a learning disability and/or ASD in secure settings.

2.2 To meet these aims the detailed objectives were to:

- Identify the numbers of people with a learning disability and/or ASD in secure settings
- Describe the ways in which people are identified
- Explore the ways in which people are assessed
- Explore the health, welfare and educational services available to meet people’s needs
- Explore procedures for release/discharge planning
- Identify gaps in services
- Identify examples of practice
- Explore the views and experiences of detained people with a learning disability and/or ASD
- Explore the perceptions of the families of people with learning disabilities and/or ASD in secure settings.

2.3 To both describe the numbers, needs of, and service responses to, people with learning disabilities and/or ASD in secure settings, and to explore and explain the factors which influence the processes for identifying, assessing and meeting the needs of this group of people, the study comprised 2 stages. Stage one comprised a quantitative scoping exercise across a range of secure settings in Scotland. Stage 2 adopted a qualitative case study approach focusing on 7 settings.

STAGE ONE: SCOPING EXERCISE

Stage One: Scoping pro-forma

2.4 The scoping exercise comprised 3 pro-forma for completion by each of the identified secure units in Scotland. The purpose behind the pro-forma was to obtain a snapshot of the numbers of people currently accommodated with a learning disability and/or ASD, the methods available for identifying and assessing the needs of this group of people, and the services available.
2.5 The 3 forms comprised:

- **A Unit Profile Form.** This was concerned with background information about the secure setting including the function of the unit, the level of security and staffing.

- **A Unit Recording Form.** This form focused on the numbers of people currently in the setting with a learning disability and/or ASD, and the ways in which people are identified, assessed and their needs met.

- **Individual Level Case Recording Forms.** Following the completion and return of the unit recording form anonymised case recording forms were sent to the units for completion for a sample of individuals. The case recording forms provided background information on the characteristics and needs of individuals. They were also a way for describing how unit level processes for identifying, assessing and responding to need were applied in individual cases.

2.6 To reflect the different environments the **unit profile** and **unit recording form** were adapted for each of the 3 settings: in-patient units, prisons, and secure accommodation for children. The core questions however, remained the same. The **case recording form** was standard across all 3 settings, with some questions included for completion ‘as appropriate’ to the setting.

2.7 A covering letter and guidance notes accompanied the forms. The guidance notes addressed the criteria for including people for the purposes of the unit and case recording forms. These criteria are reproduced in figure 2.1. A brief description of some of the characteristics associated with people with learning disabilities and autistic spectrum disorders was also provided (see Annex 1). Respondents were, however, discouraged from actually undertaking assessments solely for the purposes of the research.

2.8 The covering letter recommended that the forms were filled in collaboratively with other disciplines/professions.

2.9 Unit profile and unit recording forms together with guidance notes were sent to identified key informants in all units in February 2003. Respondents were given 2 weeks to complete and return the forms.
2.10 Case recording forms were sent out when the earlier forms, indicating the number of people with learning disabilities and/or ASD currently in the unit had been returned. A 3-week response time was provided.

**Stage One: Unit sampling**

2.11 The Scottish Executive specification for the research required that the study include the 16 prisons in Scotland, the 11 wards on the State Hospital site and the 6 secure accommodation units for children in Scotland.

2.12 The tender submitted proposed extending the sample for stage one of the study to include secure in-patient accommodation. The focus was intended to be those in-patient units providing a ‘step-down’ from (or potentially step up toward) the State Hospital. Because of the difficulties of defining ‘secure’ in a hard and fast way the sample was subsequently further extended to include not just ‘forensic’ units, but also units accommodating people with learning disabilities and/or ASD with offending/offending behaviour or who were a risk to themselves and/or others. This includes some units for people with ‘challenging behaviour’. It also includes 2 Intensive Psychiatric Care Units (IPCU).

2.13 For the prisons and secure accommodation for children a ‘unit’ comprises the whole institution. For the State Hospital and in-patient accommodation a ‘unit’ comprises the wards providing care in a secure, forensic or other specialist setting for people with a learning disability and/or ASD. The numbers of units included within stage one of the study are indicated in table 2.1.

<table>
<thead>
<tr>
<th>Type of Secure Setting</th>
<th>Number of units included in the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prisons</td>
<td>16</td>
</tr>
<tr>
<td>The State Hospital wards</td>
<td>11</td>
</tr>
<tr>
<td>Secure, forensic and other specialist in-patient settings for people with learning disabilities</td>
<td>16</td>
</tr>
<tr>
<td>Secure, forensic and other specialist in-patient settings for people with mental health problems</td>
<td>8</td>
</tr>
<tr>
<td>Secure accommodation for children</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total units</strong></td>
<td><strong>57</strong></td>
</tr>
</tbody>
</table>

**Stage One: Individual case recording form sampling**

2.14 Case recording forms (CRFs) were designed to provide anonymised information on a sample of children, young people or adults, who met the study criteria for inclusion (see above). To provide a sample of people from each of the different types of unit without also overburdening staff in specialist learning disability units a 2-track sampling strategy was developed.
In relation to the prisons, secure accommodation units for children and psychiatric units and wards forms were distributed for completion for each individual currently resident who had been identified as having a learning disability and/or ASD.

In relation to the specialist in-patient learning disability units only a sample of wards was selected. In addition to the specialist learning disability ward on the State Hospital site, these units were selected on the basis of information collected from the unit profile and recording forms which suggested that they were a 'step down' from the State Hospital. Within each of these wards a case recording form was to be completed for every fourth person on the current ward list.

### Stage One: Distribution and response rate

Prison pro-forma were distributed to the Governors in Chief. Pro-forma for the secure accommodation for children and in-patient units were distributed to identified key informants.

The number of forms distributed and completed by type of unit is illustrated in table 2.2.

<table>
<thead>
<tr>
<th>Type of Secure Setting</th>
<th>Unit Profile and Recording Forms</th>
<th>Individual Case Recording Forms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of forms distributed</td>
<td>Number of forms returned</td>
</tr>
<tr>
<td>Prisons</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>The State Hospital</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>In-patient units – learning disabilities</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>In-patient units – mental health</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Secure accommodation for children</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Totals</td>
<td>57</td>
<td>52</td>
</tr>
</tbody>
</table>

Note

(1) Four CRFs were returned blank: 3 because people had moved on; one because, after further discussion within the prison, the person concerned was felt to have a learning difficulty rather than a learning disability. A further 7 CRFs (6 from one prison) were completed but not received by the project.

Given the number and length of the forms, the response rate is very high, and, in the case of the case recording forms would have been higher if 7 completed forms had been received by the project.

What did become apparent was that despite respondents being encouraged to complete the forms collaboratively rarely did this appear to occur. In the prisons, for example, the majority of forms were completed by health centre staff. Arguably, within a prison context,
these professionals would be key to the process of identifying and assessing people with a learning disability and/or ASD. However, social work staff may also be aware of individuals who may not be known to the health centre. This potentially underestimates the numbers of people identified. Indirectly it also points to the limits to joint working and information sharing in these environments.

Stage One: Social Enquiry Report analysis

2.21 Prior to sentencing courts can, and under certain circumstances are required to request social work departments to prepare a Social Enquiry Report (SER) on an individual. Potentially these can be a way of flagging up early on that a person has a learning disability and/or ASD. The case recording forms included questions aimed at identifying whether an SER had been prepared, whether respondents had had sight of the report and whether the reports had indicated whether the individual had a learning disability and/or ASD. To supplement this data a sample of 16 SERs prepared over a 12-month period by 2 local authorities were reviewed.

STAGE TWO: CASE STUDIES

Stage Two: Case study objectives

2.22 The objectives of the case study stage of the project were 2-fold:

- To provide an overview, building on the information collected in the course of the scoping exercise, of the mechanisms for identifying, assessing and supporting people with learning disabilities and/or ASD in 7 secure settings
- To explore, through interviews with people with learning disabilities and/or ASD, keyworkers and, where appropriate, families, their perceptions and experiences of the ways in which secure settings identify and are able to respond to need.

2.23 Using a semi-structured interview approach the aim was to explore the perceptions of 3 groups:

Service managers in each institution
Service level staff including health (medical, nursing, psychology and PAMs), social work/social care, education and security staff
The person with a learning disability and/or ASD, their key worker and (where appropriate) members of their family

Stage Two: Design

2.24 Based on the project’s core themes of identification, assessment, service response, service gaps and forward planning 5 topic guides were developed:
User Topic Guide
Keyworker Topic Guide
Family/Welfare Guardian Topic Guide
Service Managers’ Topic Guide (including one especially adapted for the State Hospital)
Service Level Staff Topic Guide

Stage Two: Sampling

Unit sample

2.25 The specification for the project required the inclusion of 7 units as case studies including: The State Hospital; Rossie and St Mary’s Kenmure secure accommodation units for children; and 4 prisons to be selected on the basis of the findings from the scoping exercise, but to include establishments holding women, young offenders, sex offenders and prisoners serving short sentences.

2.26 Using the data supplied on the unit recording forms 3 State Hospital wards were selected for more detailed study:

- Cromarty Ward, for people with learning disabilities
- Earn Unit, comprising rehabilitation flats, including provision for 4 people with learning disabilities and/or ASD
- Alexandra Ward, the one female ward on the site, accommodating both women with mental health problems and those with learning disabilities and/or ASD

2.27 The 4 prisons were selected on the basis both of the criteria indicated above plus they currently contained people who were believed to have a learning disability and/or ASD. These comprised:

- HMP Edinburgh – Male young offenders (remand and convicted); male adult offenders (remand and convicted). This prison was used to pilot the interview schedules
- HMP Cornton Vale – Female young offenders (remand and convicted); female adult offenders (remand and convicted)
- HMP Perth - Male young offenders (remand and convicted); Male adult offenders (remand and convicted)
- HMP Peterhead – Male, adult convicted sex offenders

Person-centred samples

2.28 From the case recording form sample it was proposed to identify a small number of individuals with a learning disability and/or ASD (who were aware of their diagnosis) to obtain a more detailed analysis of individual experiences. It was intended to interview the individual, their key worker, and where appropriate, members of their family. While it was hoped to use
criteria to ‘select’ the sample, in terms, for example, of diagnosis and gender, in practice, the limited numbers of people identified in some settings did not make this practicable.

2.29 Nine ‘users’ were interviewed, including one woman. Six key-workers took part in a telephone interview. A total of 6 relatives were approached to take part in a telephone interview, but only one agreed to take part. To protect the anonymity of relatives sealed letters were addressed and sent by the secure settings. It is therefore not known why the majority did not respond. The sensitivity of the subject matter may be one explanation.

**Stage Two: Obtaining informed consent**

2.30 Ethical approval was obtained from the Multi-Centre Medical Research Ethics Committee for Scotland, and from 5 Local Medical Research Ethics Committees.

2.31 As part of ensuring informed consent on the part of individuals with a learning disability and/or ASD, consent forms, information sheets and a covering letter were designed to be as easily understandable as possible. Advice on the wording and layout of the consent form was also obtained from a speech and language therapist via a Research Advisory Group member. To meet the requirements of Section 5 of the Adults with Incapacity (Scotland) Act 2000 (AWIA) an information sheet and assent form were designed for the appropriate proxy. A letter, information sheet and consent form were also developed for relatives.

2.32 To protect the anonymity of people who did not want to take part a 2-step procedure for obtaining consent was developed and implemented. Key workers were supplied with the consent forms and accompanying documentation and asked to go through these with the individual concerned. If the individual then agreed to take part the researchers were informed. In the course of the site visits the individuals were invited to be interviewed. Before the interview commenced the consent form was again discussed with the individual who was given an opportunity at that point to either consent or withdraw.

**DISCUSSION**

**Ensuring informed consent.**

2.33 A number of authors have commented on the ethical difficulties, including ensuring informed consent, of involving people with learning disabilities in research (Brown and Thompson, 1997; Stalker, 1998). As described above, a rigorous procedure was adopted by the study to enable people to consent or withhold their consent from taking part in the research. On each occasion consent was given by the users approached (no one refused). However, a lingering doubt remains as to how much people really understood what ‘research’ was, or what this project in particular, was seeking to achieve. This doubt was fuelled by misunderstandings, despite repeated assurances on the part of the researchers, that the interview was part of a parole or transfer process, or would effect their own circumstances.
2.34 In addition, as noted by Hayes (2002, in Lindsay, 2002) this is very much a ‘captive’ audience. In this respect giving key workers (and this could be a social care worker, a nurse, or a personal officer in a prison) the task of first contact can have both advantages and disadvantages. On the one hand the people approached could withhold consent without being made known to the researchers. On the other hand, the environment may compel people to feel they have to take part. The procedure for going over the consent form again with the individual, prior to starting the interview does, however, provide another opportunity for people to withhold their consent.

2.35 These difficulties should not, however, be regarded as insurmountable, or a reason for not including people with learning disabilities and/or ASD in research such as this. It is important that people with learning disabilities and/or ASD are given a voice to describe their experiences and express their perceptions and views.

Estimating prevalence

2.36 It was not proposed in either the research specification issued or the research tender submitted to undertake assessments across a sample population to identify the prevalence of learning disabilities and/or ASD. As noted above, respondents were asked to indicate those people for whom an assessment/diagnosis had been made, or whose past histories, strongly suggested a learning disability and/or ASD.

2.37 Discussions with units in the course of distributing and discussing the pro-forma and during site visits, raised questions as to the complete accuracy of the numbers, particularly outwith health care settings. First, despite encouraging disciplines and professions to collaborate in completing the forms, this does not appear to have occurred routinely. As already noted this may reflect existing patterns of joint working and information sharing. It may also reflect the realities of these environments that make it impractical to expect this level of collaboration outwith day to day practice.

2.38 Second, discussions also revealed that within prison environments in particular the numbers of people formally identified may only be a proportion of the people who are ‘known’ or believed to have a learning disability and/or ASD but who have, to the knowledge of respondents, never been formally assessed. As a result, while the figures identified may appear low, they may be an accurate picture of people formally assessed, but an underestimate of a larger group of people with learning disabilities and/or ASD.

2.39 As discussed in chapter 1, there are difficulties in defining ‘learning disability’ and assessing prevalence. These difficulties may be magnified in relation to adults with ASD.

2.40 To try and estimate the numbers beyond those who have been formally assessed or diagnosed as having a learning disability and/or ASD using the type of indirect method employed in the current study may risk the inclusion of people who, for example, are unable to read or write for a multitude of reasons, or who are affected by a history of drug or alcohol misuse, or who have a range of behavioural problems. To ensure a more reliable estimate of
prevalence may therefore necessitate systematic assessment of a sample population using validated methods.

2.41 The figures indicated in the following chapters can therefore be regarded as indicative of the numbers assessed as having a learning disability and/or ASD, rather than definitive of the prevalence rate of all people who, if assessed, may be found to have a learning disability and/or ASD. The research is therefore not a prevalence study.

**KEY POINTS**

- The study comprised 2 stages: A quantitative scoping exercise across 57 secure settings; and qualitative case studies of 7 units

- The first stage involved the completion by the selected units of 3 forms: a unit level profile; a unit level recording form; and individual level case recording forms. SERs in 2 local authority areas were also reviewed

- The response rate to this stage was extremely good: 52 units returned unit profile and unit recording forms a response rate of over 90%. Over two-thirds of the case recording forms distributed were completed and returned

- The second stage of the study comprised in-depth analysis of 7 settings through interviews with service managers, staff, people with learning disabilities and/or ASD, and their key workers. One relative also took part in an interview

- The study draws attention to the difficulties of ensuring informed consent on the part of people with learning disabilities and/or ASD to participate in the research

- The design and methods employed established the numbers of people identified or assessed as having a learning disability and/or ASD across the different the secure settings. The perception was held, particularly by prison staff and managers, that there was, in addition, an indeterminate number of people who had a learning disability and/or ASD who had not been identified. This meant that it was not possible to determine prevalence rates
CHAPTER THREE IDENTIFYING PEOPLE IN SECURE SETTINGS

BEING MADE AWARE: MECHANISMS FOR IDENTIFYING PEOPLE

3.1 The study objectives included establishing the numbers of people with learning disabilities and/or ASD in secure settings and describing the ways in which people were identified. The 2 objectives are inextricably linked. To set in context the numbers of people identified it is necessary to understand the mechanisms and processes of identification in each of these settings.

3.2 ‘Identification’ has been taken here to include:

- Tools or processes used to formally assess or diagnose someone as having a learning disability and/or ASD
- Other assessments or processes which may serve as an initial screening or alert that someone may have a learning disability and/or ASD
- The ways in which this information is made available to inform action or formal assessment

3.3 Combining these 3 different elements the first stage unit recording forms asked each setting to indicate the means by which they would become or be made aware that someone had a learning disability and/or ASD. Table 3.1 illustrates the mechanisms within each type of setting.

Table 3.1 Means for being made aware that someone had a learning disability and/or ASD by type of secure setting

| Means for being made aware that someone had a learning disability and/or ASD⁽¹⁾ | Type of secure setting | number of units |
|---|---|---|---|---|---|---|---|
| | Prisons (n=16) | Secure Accommodation for children (n=4) | State Hospital - all wards (n=10) | In-patient units for people with learning disabilities (n=16) | In-patient units for people with mental health problems (n=6) |
| SER or other Court Reports | 13 | 3 | 6 | 8 | 5 |
| Medical case records | 14 | 2 | 9 | 16 | 6 |
| Other social work records | 11 | 4 | 8 | 7 | 3 |
| Routine health checks on admission | 9 | 3 | 7 | 4 | 3 |
| Education assessment prior to admission | 13 | 4 | 5 | 6 | 0 |
| Education or programme assessment following admission | 11 | 3 | 7 | 6 | 1 |
| Referral to a social worker, clinical psychologist or psychiatrist following admission | 14 | 3 | 6 | 8 | 2 |
| Other means | 7 | 0 | 1 | 7 | 0 |

Note
⁽¹⁾Units could indicate more than one mechanism
3.4 On this basis it would appear that the prisons have access to a number of different sources of information, including health, social work and educational records as well as through referrals to specialists. One mechanism that features less frequently is identification through routine health checks on admission. This is surprising given that all prisoners on admission are given a health check that includes current and past mental and physical health. The ‘other’ ways include information provided to prison health centres by external agencies or legal agents, referrals from other prison staff, families and even ‘self referral’.

3.5 The secure accommodation for children similarly has to hand a number of sources that could alert the unit to the possibility that a young person has a learning disability and/or ASD.

3.6 ‘Identification’ takes on a different cast in the health care settings compared with the prisons and children’s units. For the in-patient units with an assessment function ‘identification’ is fundamental to their role. As one specialist learning disability unit commented, “We would often make the diagnosis following assessment”. Outwith the admission/assessment units people will have largely been referred from other in-patient units. As a result people will have been identified as having a learning disability and/or ASD prior to referral.

3.7 Not surprisingly, medical records are pre-eminent as a source of information for the in-patient units. Of lesser significance, particularly for the learning disability in-patient units are social work records and educational assessments. Referral on to other specialists also does not feature very highly. Again this may reflect the fact that a number of units are, or have, the specialist resources to which people are referred for assessment and diagnosis.

**PROCESSES OF IDENTIFICATION**

3.8 This overview of mechanisms suggests that each of the different types of settings has access to a range of health, social work and educational resources that might alert them to the possibility that someone has a learning disability and/or ASD. The value of these information sources is, though, dependent upon whether the learning disability and/or ASD is specifically identified and the extent to which this information is shared with service providers. Drawing on data obtained from case recording forms, in the course of site visits and from the Social Enquiry Reports (SERs) reviewed, it is possible to get a better sense of how identification processes operate in practice: what information is available, at what stage and to whom.

3.9 The data suggest there are 3 ‘stages’ or ‘triggers’ to identification: information made available at the point of referral or admission, for example in Social Enquiry Reports (SERs); identification in the course of routine or other assessments following admission; and identification in response to problems or concerns arising.
Background information at the point of referral or admission

Social Enquiry Reports

3.10 For people entering secure settings via a criminal justice route, SERs prepared for the courts by criminal justice social work departments are a key potential source for identifying early on that someone has a learning disability and/or ASD.

3.11 A review of 16 SERs across 2 local authority criminal justice social work departments revealed how the reports can be used to both indicate to the courts that the person has been assessed as having a learning disability, and the implications of this in relation to the index offence, risk of re-offending and disposal options. One SER, for example noted that:

“X is diagnosed as being learning disabled: assessment of the latter indicates he is considered to be well below average intelligence. Consequently he has limited verbal, cognitive and intellectual functioning.”

3.12 In relation to another person the SER author concluded that “X could not survive within a prison environment and would be vulnerable to exploitation and scapegoating due to his limited ability and lack of awareness”. These examples may be atypical of SERs in general. The 2 local authority areas are served by a Forensic Community Mental Health Team with a learning disabilities and mental health remit that has actively sought to increase awareness among criminal justice teams. Nonetheless, they illustrate the potential for SERs to be a useful tool both for the courts and for the secure settings if a custodial disposal is pursued.

3.13 However, SERs are only mandatory under certain circumstances if, for example, a custodial sentence is being considered for someone aged under 21 years. As a result, not everyone will have an SER. Further, the SER, or the information it contains may not be shared with, or made available to those responsible for the person’s care. This is suggested by table 3.2. Drawing on the case recording forms the table shows how many people in each setting were believed to have an SER or similar report prepared for the courts and whether the person completing the case recording form had seen this report.
Table 3.2  Whether an SER or similar report was prepared for the court and whether seen by respondents: case recording form sample

<table>
<thead>
<tr>
<th>Types of secure setting (n=number of cases)</th>
<th>Whether a social enquiry report or similar court report was prepared</th>
<th>Whether respondents have seen the report&lt;sup&gt;(1)&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Prisons (n=9)</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Secure accommodation for children (n=3)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>State Hospital - all wards (n=11)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>In-patient units for people with learning disabilities (n=20)</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>In-patient units for people with mental health problems (n=6)</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

Note
<sup>(1)</sup>Missing data means that columns will not total to the number of cases

3.14  Two people in the prison sample gave consent to the research having access to social work reports. Of these, one had an SER relating to the index offence. Although not seen by the researchers, discussion with the person’s key worker revealed that reference was made in the report to the person’s learning disability. Ironically in this case, there was some doubt as to whether the person actually had a learning disability. Of the 4 State Hospital patients in the sample who had been admitted via the criminal justice system and gave permission for the researchers to access social work reports, only one had an SER, written in the 1970’s.

3.15  The fact that SERs for people coming through a criminal justice route are not mandatory solely for social or welfare reasons may therefore limit their scope as an early warning system.

3.16  The other key finding is that, even when prepared, this information is not necessarily shared with or within the secure settings, particularly, it appears with health care staff whether in prison or hospital.

3.17  One team of community based criminal justice workers described a risk alert system. If someone with a learning disability for whom they had prepared an SER were given a custodial sentence the court social worker would be informed. The court social worker would notify the relevant prison social work team.

3.18  The possibility that people would still fall through the net was, though, suggested in the course of site visits to several prisons. One prison based criminal justice social work team described how they would get copies of SERs for people going out on licence, otherwise the reports would be kept with the prisoner’s warrant in the prison general office. Health care staff in another prison also pointed out that the SER would accompany the warrant, and while social
work may have sight of it, it would not automatically be available to health care staff at admission. The social work department would only pass it on to the health centre if they felt it was necessary.

3.19 In the course of data collection for the study it was also found that SERs may not be made available routinely to the social work staff within a secure health care setting.

3.20 Even if the documentation is made available, social work staff in one prison pointed out that the SER authors would not necessarily know if someone had a learning disability and/or ASD. Unless an assessment was initiated or undertaken previously they may not have information on, for example, IQ level that would enable them to state that someone had a learning disability. They may instead use ambiguous expressions like “low average ability”. This does in itself raise a question about the role and responsibilities of SER authors in recommending to the court the need for specialist assessment.

3.21 In effect, SERs are a useful means for early identification, but only if the information is available to the authors and this is subsequently noted and shared.

**Pre admission identification**

3.22 In addition to SERs a number of other pre-admission mechanisms could assist early identification, including assessment by the secure unit prior to admission and referral information.

3.23 The State Hospital specialist unit for people with learning disabilities and the women’s ward would undertake assessments of individuals prior to admission. This would primarily involve psychiatric and nursing staff but, if informed, the hospital based social workers would also aim to be involved in these pre-admission assessments.

3.24 One secure accommodation unit anticipated that a child or young person with a learning disability and/or ASD of a severity that they could not cope independently would be identified in the course of a pre-admission planning meeting or at the point of referral.

3.25 Nonetheless, in the course of site visits both secure accommodation units suggested that, in practice, little information might accompany a child or young person. While a background report might be available for a child referred through the Children’s Hearings, there may be a 6-week delay before receiving a report on someone remanded to the secure accommodation unit through the courts. As one staff member commented:

"..the young people sometimes come straight in off the streets..Sometimes we receive paperwork, but this is rare, the kids just arrive, about 50% of them come from the courts. If it’s their first time caught then there is no paperwork."

3.26 One team of psychologists based in a secure accommodation unit referred to the “impossibility” of getting a Record of Need from “outside”.

28
3.27 Even if a social work report is available it may be incomplete: secure accommodation units had found that sections of the Looked After Children documentation had been left blank. In one secure accommodation unit 2 respondents felt the need to check the validity of any information that was supplied, on the basis that “sometimes social work are selective about the information they supply, they angle it to get what they want”. Where claims of a learning disability or ASD were made, the unit psychologist would try to obtain more information.

3.28 But the issue is not just the availability of information, but, more fundamentally, whether the children or young people were actually identified pre-admission as having a learning disability and/or ASD. A member of staff in one of the secure accommodation units suggested that some children and young people were admitted who did not appear to have a learning disability but this was revealed through testing. The implication is that it is not children and young people with moderate to severe learning disabilities or ASD who are slipping through, but those with borderline or mild learning disabilities and/or ASD: children whose behaviours may have been interpreted as “attitudinal” rather as resulting from a learning disability and/or ASD.

3.29 The 3 case examples of children and young people in secure accommodation included in the study are indicative of the difficulties of early identification. Despite 2 of the children having a Record of Need and all 3 having a Future Needs Assessment, only one person had been identified as having a learning disability prior to admission to the secure accommodation unit.

**Identification following admission to a secure setting**

3.30 Even if relevant information is missing or unavailable at the point of admission or referral, at various stages at, or after admission, opportunities exist in the routine processes used by secure settings to assess people’s needs that could act as further triggers to identification. This section focuses on the use of these processes for identifying whether someone may have a learning disability and/or ASD. More detailed examination of assessments of need, post identification, are discussed in chapter 7 below.

**Post admission identification in health care settings**

3.31 As noted above, identification in the health care settings is of a different order compared with the secure accommodation units and prisons. The sample of health care settings for people with learning disabilities included secondary or tertiary services to which someone already identified as having a learning disability and/or ASD would be referred for specialist assessment or treatment, or because they required a level of security not available in another health care environment.

3.32 People referred to specialist psychiatric units, including mental health wards on the State Hospital site, may only be identified as having a learning disability and/or ASD following admission and assessment. It was suggested, for example, that despite the State Hospital care pathway for assessment that there could still be gaps in the process.
3.33 Across healthcare settings people with ASD in particular may go unidentified. Studies undertaken in English secure hospitals in the 1990s found that only a proportion of those identified in the course of the research had actually been diagnosed as having ASD (Scrapp and Shah, 1994; Hare et al, 1999). It is possible that a similar situation pertains across the Scottish hospitals. One State Hospital respondent, for example suggested that the number of people across the hospital with ASD was not known.

*Post admission identification in secure accommodation for children*

3.34 Within the secure accommodation units multi-agency and multi-disciplinary case conferences are held 72-hours after a child or young person is admitted and then again at 14 days. These provide an opportunity for information gathering and information sharing between the referrer and the secure accommodation unit and within the unit. They were described by one respondent as a chance to “tease out educational/psychological issues and social concerns”.

3.35 The secure accommodation units described a range of psychological, educational and health assessments that would be undertaken in respect of all children or young people referred. Potentially these provide another opportunity for early identification. Education tests will identify how far children and young people have developed in terms of their education. On their own, however, the tests may not be able to distinguish between a child with dyslexia, one who has missed out on their education, or someone with a learning disability.

3.36 It was indicated in one secure accommodation unit that the unit psychologist would see all new admissions. In addition, preparatory to undertaking offending based programmes the psychologists undertake IQ and psychometric tests. Again this has the potential to identify a child with a low IQ.

3.37 Secure accommodation units could also refer children or young people to other specialists. For all 3 young people for whom a case recording form was completed this was one of the ways in which the learning disability/ASD was assessed.

3.38 The data from the case recording forms and site visits suggest that, post referral, the units’ education, health, social care and psychology professionals work together. But even with this level of joint working and the mechanisms in place, some people may slip through. One secure accommodation unit, for example, acknowledged that there may be more people with Asperger’s than they were aware of.

3.39 To provide more systematic ‘baseline’ data the psychologists supporting one secure accommodation unit were proposing to undertake an audit to establish baseline information, of which learning disability/ASD would be one component.

*Post admission identification in prisons*

3.40 Within the prisons there are at least 5 formal mechanisms which could trigger identification: In the course of the reception assessment; through routine health checks on admission; educational assessments; and psychological assessments preparatory to undertaking
offence-related programmes. In addition, for convicted prisoners, the SPS sentence management process includes a risk and needs assessment. The focus is on addressing offending behaviour and minimising the risk of re-offending. However, the process of assessment and consultation with the different disciplines and staff may open up a further opportunity for identification.

3.41 Reception managers who allocate people to particular halls or wings on admission made the point in one prison that although they assessed residential care need, or suicide risk, they were not routinely screening for learning disability and/or ASD at this early stage. Furthermore, they did not have “a set of tools or system” to be able to identify people and assess the degree of impairment. They suggested that the availability of these tools at the reception stage might prevent people “slipping through the net”.

3.42 All new prisoners undergo a routine health screening on reception to the prison. Undertaken initially by a nurse, the screening is followed up after 24-hours by a medical assessment by the prison medical officer. For 5 of the 9 people for whom case recording forms were completed the routine health check was one of the ways in which the individual’s learning disability and/or ASD was identified. However, current procedures for routine screening may be limited as a means for identifying people with learning disabilities and/or ASD. First, information on past hospitalisation may not be available at this early stage. Further, the process relies on self-report, but some people will not know, or will not wish to admit they have difficulties. One nursing assistant described how, in relation to one individual with learning disabilities they had had to do “detective work” to obtain information. Mirroring the reference made by the reception managers to the lack of screening tools this nursing assistant posed the question “what could you ask of a person that would identify learning disabilities?”.

3.43 Adult Basic Education assessments undertaken by prison Learning Centre staff to assess learning skills are a further potential trigger for identifying difficulties. But these can be something of a “blunt instrument” unable, on their own to distinguish someone with “lapsed skills”, dyslexia or learning disabilities.

3.44 Prison based forensic psychologists, responsible for setting up and evaluating offence based group programmes will undertake assessments, including IQ to establish someone’s suitability for a specific programme, but would not routinely be referred someone as part of a process of identifying learning disabilities. One commented: “People with learning disabilities and/or ASD don’t really come to the attention of forensic psychologists”. One prison’s experience was that obtaining an assessment by a clinical psychologist could be delayed by a lengthy waiting list.

3.45 The sentence management process requires a risk and needs assessment to be completed by a trained residential officer within 6 months of sentence. A multi-disciplinary case conference is then held and an action plan developed. Unit managers in one prison suggested that if problems were identified in the course of the assessment a referral could be made to the visiting psychiatrist.

3.46 Within the prisons there are a number of different resources using different means and with different purposes that could potentially flag up or trigger the need for further assessment.
But, as with the secure accommodation units, the different elements do not necessarily add up to a whole system. In part this may be because within the prisons no one ‘provider’ was seen as having responsibility specifically for screening for learning disabilities and/or ASD.

3.47 Perhaps as a corollary of this, information sharing is limited and unsystematic between the different service elements. This has already been touched upon in the context of SERs, but is perpetuated post admission. Interviews in the course of site visits suggest that prison education departments might identify someone as having a problem but not necessarily have a route to pass this on to other agencies such as social work or psychology; prison forensic psychologists would not necessarily have case-specific links with clinical psychologists; prison health care centres and criminal justice social work teams may not initially share information. For the purposes of identification each may have pieces of information but the systems in place do not appear to encourage joining these up until something occurs or the person poses a management problem.

**Responsive identification**

3.48 The previous sections have described the opportunities available in each type of setting for identifying someone as having a learning disability and/or ASD. What becomes apparent from the data, particularly in the context of the prisons, is that in some cases despite these formal routes identification can still almost be by chance: in response to concerns or issues arising. The triggers here may be more ‘informal’: the “instinct” of a prison based nurse, or teacher, or a hall officer knowing when something is not right, for example if someone cannot comprehend instructions or has “unusual” behaviour. One open prison described how they picked up that someone had “slight autistic tendencies” because of his behaviour in the communal dining room. To minimise the risk of bullying from other prisoners the person was referred back to the more restrictive environment of a closed prison but one with a health care unit. In another prison the healthcare team included a number of RMHN-trained nurses who were able to draw on their expertise to identify people who might not otherwise be identified.

3.49 Such ‘informal’ mechanisms are important as a source of identification, but unreliable. Several respondents felt that, in a prison context, people with a learning disability may be less easily identifiable than, for example, someone with a psychosis. Managers in one prison questioned how skilled the staff would be in identifying a problem if someone was not “forthcoming”.

3.50 Both informal and more formal mechanism may be moot for people on remand or those on short sentences: people who may “come in and go out”. Comments of an anecdotal nature suggest that some at least of these are on a revolving door of breach of the peace charges, prison and discharge, subsequently re-offending and returning to prison. Although believed to have a learning disability they may have never been formally assessed.
ASSESSING/DIAGNOSING LEARNING DISABILITIES AND/OR ASD

3.51 The previous sections have described the formal and informal routes and mechanisms by which the different secure settings can become aware that someone has a learning disability and/or ASD. These include assessment procedures intended for other purposes but which may pick up the need for a specialist assessment to be undertaken. Questions included on both the unit and case recording forms indicate the specialist tools available ‘in-house’ to formally assess or diagnose someone as having a learning disability and/or ASD post-admission.

3.52 The data suggest that for formal assessment or diagnosis tools were less significant than professional expertise. For example, 3 of the 9 people in prison for whom case recording forms were completed were assessed by a clinical psychologist using a version of WAIS (Weschler Adult Intelligence Scale), a validated tool for assessing for learning disabilities. But in these and other cases assessments by prison medical officers and psychiatrists were combined with more informal methods: “RMHN and RMN nursing staff identified quite quickly, but without formal assessment”.

3.53 None of the secure accommodation units for children had access to specialist in-house tools for formally identifying if someone had a learning disability and/or ASD. However, of the 3 young people identified by one of the secure units, 2 had been assessed using WAIS III. A psychiatrist and an educational psychologist had assessed the third person. In another secure accommodation unit referrals for assessment would be made to the visiting clinical forensic psychologist.

3.54 Where formal assessment was undertaken on the in-patient units WAIS III tended to be used. One patient on a psychiatric unit was assessed using Nylander’s Screening Questionnaire for ASD in psychiatric patients. The case recording forms also reveal however, that tools would not always be used but assessments undertaken by a range of specialists.

3.55 The specialist learning disability unit on the State Hospital site noted that ‘screening’ would be undertaken prior to admission to the ward. Another ward on the site indicated that the unit “would refer to learning disability specialists within hospital e.g. CNS [clinical nurse specialist in learning disabilities]”.

3.56 One in-patient unit for people with learning disabilities did not use an “exact screening tool”, but described a team screening coupled with pre-admission screening information. Psychology, nursing, medical/psychiatric assessments would be included.

3.57 On the basis of the data ‘tools’ for formal identification may be less significant than staff in the different settings knowing and having access to professionals who do have the relevant experience and expertise.

3.58 The one area where such expertise may be lacking is in identifying and diagnosing ASD. Several clinicians referred to their own lack of expertise in the area and the lack of specialist expertise generally.
EXAMPLES OF PRACTICE

3.59 The study found a number of examples of practice aimed at improving systems for identifying people with learning disabilities and/or ASD in secure settings. These include:

- The SERs reviewed within 2 local authority areas. These illustrate the role the reports can play in alerting not just the courts, but also the secure settings to which people may be referred that the individual has a learning disability and/or ASD
- The proposed audit of children’s needs in one secure accommodation unit
- One prison respondent stressed the importance of providing staff with information to improve their confidence in managing people. In this establishment a prison officer who has a child with Asperger’s syndrome would attend a case conference for someone with Asperger’s. The officer would be in a position to describe the presentation of someone with this syndrome “officer to officer”.

DISCUSSION

3.60 From this analysis of the mechanisms and processes for identifying someone as having a learning disability and/or ASD 4 key findings emerge.

3.61 First, people may be referred to secure accommodation without having been previously identified as having a learning disability and/or ASD. The Scottish Executive care pathways framework (NHS HDL (2001) 9) indicates the need for access to specialist and generic mental health and learning disability services prior to, and at the different stages of contact with the criminal justice system. Yet, for those coming through criminal justice routes in particular, the data from the study raise questions about the procedures in places to ensure early identification. This has policy and practice implications that go beyond the scope of the current study.

3.62 Second, the prisons and secure accommodation for children do not undertake initial screening specifically for learning disabilities and/or ASD. Nonetheless, each setting has a number of different assessment processes that could flag up the need for more formal assessment or diagnosis. In effect, the need may be not for more screening tools, but enhanced awareness of the possibility of learning disability and/or ASD as an explanatory variable, and the availability of referral routes for specialist assessment.

3.63 Third, across settings, people with an ASD in particular may go unidentified. Resources in terms of both tools and expertise appear to be in short supply.

3.64 The need for information collected through different routes to be made available to, or shared with, those who have a role in providing care, treatment and support for individuals in each setting is fundamental. The data suggest that at this early identification stage information may not be shared across boundaries.
3.65 In this context ‘slipping through the net’ may take on a different meaning. In environments where there are a number of comparatively discrete ‘nets’, for example, community based social work, criminal justice social work, health care and education services, prison or secure care based health, education and social work services as well as custodial services, then without a more systematic approach to information sharing or a single provider with responsibility, the risk of people falling between nets may be high. This may be particularly the case for people on remand or in secure settings for short periods.

3.66 As a result at any one time across the different secure settings the population may comprise:

- Children, young people and adults who have been appropriately identified as having a learning disability and/or ASD
- People who have not been formally diagnosed or assessed but ‘known’ or believed to have a learning disability and/or ASD
- Children, young people and adults with a learning disability and/or ASD who have not been identified
- Potentially, too, there may be people who are inappropriately identified as having a learning disability and/or ASD

3.67 Arguably, it is those who are not identified who are the most concern. For individuals it may mean not having access to the same range of ‘in-house’ resources as others because they are not tailored to their needs. It may mean not having access to appropriate after care, with implications for re-offending and re-admission. For people in prison it may mean being disciplined for breaching rules they do not comprehend, or losing out on privileges such as a tobacco allowance because they are unable to complete the required form. An individual may also be exposed to bullying or manipulation by peers: not just in the prisons, but also in the secure accommodation units for children and in forensic psychiatric inpatient units. As managers in one prison commented: “Because only 2 have been identified they don’t pose a management problem for the prison. But there may be problems that the prison doesn’t know about”.

KEY POINTS

- The data suggest that there are 3 ‘triggers’ for identifying people within the secure settings: information made available prior to or at referral, for example, SERs; information collected in the course of routine assessments following admission; and information collected or assessments undertaken in response to problems or concerns arising
- The value of pre-admission information depends upon whether people have been identified prior to referral as having a learning disability and/or ASD and whether this information is available to the secure setting
- Post admission, the secure settings described different routine assessment mechanisms and processes which, though not specific to screening for, or identifying, whether someone has a
learning disability and/or ASD, could flag up the need for specialist assessment. This requires people to be aware of learning disabilities or ASD as a possible explanation for someone’s behaviour or responses

- Assessment tools for identifying someone as having a learning disability and/or ASD may be less significant than access to professionals with specialist expertise in these areas

- The use of tools and the availability of expertise in assessing or diagnosing ASD appears to be limited

- The data suggest that the range of different agencies and professionals within and outwith the secure settings may not necessarily result in improved identification but, in some cases at least, a risk of people slipping between the different ‘nets’
CHAPTER FOUR  HOW MANY PEOPLE?

HOW MANY PEOPLE?

4.1 One of the main aims of the research was to estimate how many people were currently accommodated in the selected secure settings. The literature review (chapter 1) underlined the difficulties of measuring prevalence: different measuring tools and different criteria generate different results. Health and social care policies as well as criminal justice policies will also influence prevalence rates making comparison across and within countries difficult. These complexities are compounded in relation to people with autistic spectrum disorders, particularly adults (MRC, 2001; PHIS, 2001).

4.2 The approach used in the current study, described in chapter 2 was to ask respondents in each secure setting how many people were currently resident who had been formally assessed or diagnosed as having a learning disability and/or ASD, or whose past histories strongly suggested the person has a learning disability and/or ASD. This approach relies heavily on the ways in which people are identified. As discussed in chapter 3, although there are a number of different mechanisms or processes that may assist to identify people, they can be ad hoc and unconnected, leaving some people to fall between service ‘nets’. It is against this background that the numbers identified in the course of the scoping exercise have to be interpreted and understood. Table 4.1 summarises the responses for each type of secure setting.

Table 4.1 Number of people assessed/diagnosed as having a learning disability and/or ASD by type of secure setting

<table>
<thead>
<tr>
<th>Disability</th>
<th>Prisons (n=16)</th>
<th>Secure accommodation for children (n=4)</th>
<th>State Hospital – ward for people with learning disabilities (n=1)</th>
<th>State Hospital – other wards (n=9)</th>
<th>In-patient units for people with learning disabilities (n=16)</th>
<th>In-patient units for people with mental health problems (n=6)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disability Only</td>
<td>17</td>
<td>2</td>
<td>19</td>
<td>9</td>
<td>123</td>
<td>6</td>
<td>176</td>
</tr>
<tr>
<td>ASD Only</td>
<td>2</td>
<td>1⁽¹⁾</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>LD and ASD</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>26</td>
<td>0</td>
<td>34</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>3</td>
<td>26</td>
<td>10</td>
<td>149</td>
<td>9</td>
<td>216</td>
</tr>
</tbody>
</table>

Note
⁽¹⁾Described as ‘ASD other’ on the pro-forma

4.3 The method used by the research revealed a total sample of 216 people with learning disabilities and/or ASD in secure, forensic or specialist settings. Not surprisingly, the in-patient units for people with learning disabilities account for the lion’s share.
4.4 Only a very small proportion of the total identified had a diagnosis of ASD only i.e. did not also have a learning disability. If people with ASD ‘only’ and those with a ‘dual’ diagnosis of learning disabilities and ASD are combined they comprise just under 20% of the total sample.

4.5 Focusing on specific settings, the data suggest that out of an average daily prisoner population of 6475 (Scottish Prison Service, 2003), only 19, or around 0.3% were identified as having a learning disability and/or ASD. This proportion, which includes people with ASD, is lower than Gunn et al’s (1991) comparatively low estimate of prevalence of 0.4% for sentenced adult males with a learning disability. Further, the numbers of those identified are not distributed evenly across the estate: half of the prisons had no-one currently who met the study criteria. Of the remainder one prison alone accounted for 6 out of the 19.

4.6 The secure accommodation units, too, appear to have identified only a small proportion of children with a learning disability and/or ASD. Although 2 units did not complete the study’s forms, informal discussions with these units suggest that neither had children or young people who met the criteria at that time. On this basis only 3% of children or young people, out of an estate of 96 places, were identified as having a learning disability and/or ASD.

4.7 A small, but, in policy terms, significant number of people were also identified in psychiatric in-patient units. This includes Intensive Psychiatric Care Units (IPCU), the mental health wards on the State Hospital site, and psychiatric units including those which, formally at least, specifically exclude people with learning disabilities.

ISSUES ARISING FROM THE NUMBERS OF PEOPLE IDENTIFIED

4.8 Table 4.1 raises 3 issues. First, the apparently small proportion of people across the prison estate identified as having a learning disability and/or ASD. On the one hand, the data suggest that there are few people with moderate to severe learning disabilities within prison settings. On the other hand, discussions with respondents as the study’s forms were being returned and subsequently in the course of site visits suggest that this figure may represent only a proportion of a larger number of people with learning disabilities and/or ASD throughout the prison estate. This includes people who are informally ‘known’ or believed to have a learning disability, but who have not been formally assessed or diagnosed, or not known to have been formally assessed. The comparatively high number of people identified in one prison where the forms were completed by a nurse with specialist qualifications in learning disabilities appears to confirm that the numbers are an under-estimate. As described in chapter 3, there is a lack of systematic information available to the prisons to more accurately assess the numbers involved. In one unit, for example, health care staff described how they might “hazard a guess” that someone had a learning disability, but there may be nothing in their casenotes. In another unit the comment was made on a unit recording form that “it would be difficult to get this accurately without trawling through the notes of everyone ever in”.

4.9 Using specifically defined inclusion criteria and a reliance on the knowledge base and familiarity of respondents with the prison population, the research has been unable to pin down this apparently floating population beneath the surface. As suggested in chapter 2, to inform
strategic policy there may be an argument for assessing a sample population with validated tools in order to be able to estimate more accurately the prevalence of learning disability and/or ASD among the prisoner population. In terms of operational policies and practices, as chapter 3 has argued, there are issues around accurate screening and identification, including information sharing and joint working within these settings.

4.10 Second, although only a small proportion of children and young people were identified by the secure accommodation units for children, from interviews and discussions there is not the same sense of the figures representing a small proportion of a larger pool of people with learning disabilities and/or ASD. Potentially there may be others who are unidentified, particularly given the multiple needs that children referred to secure care often present. A respondent in one secure accommodation unit also felt that the number of children with Asperger’s syndrome was not really known. The perception among respondents, however, was that those with a learning disability and/or ASD would either be identified before admission to the secure setting, and, in the case of one unit “are not ordinarily taken”, or would be identified through assessments once admitted.

4.11 The third issue raised by table 4.1 is the small, but not insignificant number of people identified as having a learning disability and/or ASD accommodated in secure, forensic or other specialist in-patient settings for people with mental health problems. Several factors may account for this finding.

4.12 First, a number of people within the sample had both a learning disability and a mental health problem. It may therefore not be inappropriate for someone to be placed on a psychiatric unit. Second, inconclusive or inaccurate diagnosis at the time of admission may result in people being “misplaced”. For example, one person was admitted to a forensic psychiatric in-patient unit with a diagnosis of “chronic schizophrenia”. It was the unit which, following assessment, identified the person as having a learning disability.

4.13 A third reason may be the lack of appropriate alternative facilities. This may result, for example, in someone requiring secure care being accommodated “inappropriately” on an IPCU.

4.14 On the State Hospital site, the one female ward cares both for women with mental health problems and those with learning disabilities. Earn Unit, a rehabilitation ward on the hospital site accommodates 4 people with a learning disability moving on from the specialist learning disability ward, together with 14 people with mental health problems.

4.15 The issues of service delivery and of service gaps raised by this use of psychiatric resources are addressed in chapter 7 below.
KEY POINTS

- A self-completion pro-forma distributed to secure settings asked respondents to indicate the numbers of people currently accommodated who had been formally assessed or diagnosed as having, or were strongly believed to have, a learning disability and/or ASD. This yielded the following numbers of children, young people or adults with a learning disability and/or ASD in each of the secure settings:

  19 people across the 16 prisons in Scotland
  3 children or young people across the 6 secure accommodation units in Scotland
  26 people accommodated in the specialist ward for people with learning disabilities on the State Hospital site
  19 people accommodated in selected secure, forensic or other specialist settings for people with mental health problems, including 9 wards on the State Hospital site
  149 people in selected secure, forensic or other specialist settings for people with learning disabilities

- Although across the prison estate only a small number of people were formally identified, the perception among prison respondents was that this represented only a proportion of a larger number of prisoners who had a learning disability and/or ASD, but who had not been identified, assessed or diagnosed

- The figures underline the questions raised earlier concerning the processes for identifying and assessing children, young people and adults prior to and post-admission to a secure setting
CHAPTER FIVE  PEOPLE IN SECURE SETTINGS: CHARACTERISTICS, HISTORIES, RISKS AND VULNERABILITIES

5.1 The following chapters outline the processes that impact upon the lives of people with learning disabilities and/or ASD in the different secure settings. This chapter sets these processes in context, describing the socio-demographic characteristics, past histories, risks and vulnerabilities of the sample of 49 individuals for whom case recording forms were completed.

SOCIO-DEMOGRAPHIC CHARACTERISTICS

Gender

5.2 All but 2 of the sample of 49 for whom case recording forms were completed were men. The exceptions were one girl in secure accommodation for children, and one woman in a prison setting. At the time of the study a further 4 women with learning disabilities were resident on the women’s ward on the State Hospital site. Unfortunately completed case recording forms were not returned by this unit.

5.3 Given the issues around identification discussed in chapters 3 and 4, there may be more women both in Cornton Vale and the local prisons with capacity to accommodate women than have been formally diagnosed or assessed as having a learning disability and/or ASD. Women, however, comprise only a small (though increasing) proportion of all offenders (Scottish Office, 1998; Scottish Executive, 2002f; SPS, 2003). The prevalence of mild and severe learning disabilities and ASD is also higher among boys and men than girls and women (Foundation for People with Learning Disabilities, www.learningdisabilities.org.uk; PHIS, 2001). It is, therefore perhaps not surprising that women should comprise such a small proportion of the sample.

5.4 Unfortunately with so little information it is difficult to compare the characteristics, routes into secure care, risk posed and vulnerabilities of women and men. Although Hayes (2002) argues that women in secure settings have significantly different characteristics from their male counterparts, the literature review was unable to identify other studies that specifically compared the pathways to, and experiences of, men and women with learning disabilities and/or ASD in secure settings.

5.5 Nonetheless, as a sub-group (women) of a sub-group (people with learning disabilities and/or ASD in secure settings) the small numbers do make the provision of appropriate services even more problematic.
Ethnicity

5.6 All of the sample of 49 were described as ‘white’. It is therefore not possible to identify the specific needs and service responses to people in secure settings from minority ethnic communities.

Age

5.7 The age range of people in The State Hospital and the psychiatric in-patient units was similar: 23 – 56 years and 24 – 56 years respectively. Within the learning disability units the age range extended from 18 – 71 years, reflecting the inclusion of both long stay and admission/assessment units within the sample.

5.8 The average age of the sample of 9 people in prison was 34 years. The range extended from 19 – 49 years. Offenders tend, on average to be younger which perhaps explains the slightly younger profile compared with those in healthcare settings.

5.9 The young people in secure accommodation were all aged under 20 years.

Nature and levels of impairment

5.10 Table 5.1 shows the nature of impairment of the sample of people for whom case recording forms were completed in each type of setting.

Table 5.1 Number of people with learning disabilities and/or ASD by type of secure unit: case recording form sample

<table>
<thead>
<tr>
<th>Disability</th>
<th>Prisons</th>
<th>Secure accommodation for children</th>
<th>State Hospital - learning disability unit</th>
<th>State Hospital – mental health unit</th>
<th>In-patient units for people with learning disabilities</th>
<th>In-patient units for people with mental health problems</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability only</td>
<td>7</td>
<td>2</td>
<td>5</td>
<td>3</td>
<td>16</td>
<td>2</td>
<td>35</td>
</tr>
<tr>
<td>ASD only</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Learning disability and ASD</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Other ASD</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>19&lt;sup&gt;11&lt;/sup&gt;</td>
<td>5&lt;sup&gt;11&lt;/sup&gt;</td>
<td>47</td>
</tr>
</tbody>
</table>

Note

<sup>1</sup>One case each of missing data
5.11 The majority of the sample had a learning disability only. In 7 cases this was combined with an autistic spectrum disorder.

5.12 Of the 32 people for whom information on level of impairment was available 15 had an assessed full scale IQ of between 60 – 70 or were described as having a “mild” or “borderline” learning disability. Several people were assessed as having “high functioning autism”. A further 8 people had an assessed IQ of over 70, including one person with Asperger’s syndrome who was described as having a ‘normal’ IQ. Within the prisons one person was assessed as having ‘high functioning autism’ and a full scale IQ of 85, another person was described a having a ‘mild level’ learning disability and a third person had an assessed full scale IQ of 67. No information was available on the level of impairment of the remaining 6 people within the prison sample.

5.13 The majority of the 9 people with an assessed IQ of under 60 were in healthcare settings, specifically the units for people with learning disabilities outwith the State Hospital. The exception was one young person in secure accommodation who was assessed as having a full scale IQ of 53. Information was not available in relation to the other 2 young people.

5.14 As noted in chapter 1, studies of people with learning disabilities in secure and forensic in-patient settings and in contact with the criminal justice system have noted that people in these environments tend to have mild or borderline learning disabilities, rather than moderate or severe levels of impairment. With the exception of the in-patient learning disability units, this pattern is largely replicated even within this small sample. It is the mild or borderline nature of the impairment which may mean some people slip through unnoticed, particularly in non-healthcare settings (see chapter 3).

Additional mental and physical health problems and communication difficulties

5.15 Commentators have noted high rates of co-morbid mental health problems both within the general population of people with learning disabilities, including children and young people, and among offenders with intellectual disabilities (Foundation for Learning Disabilities, (2002); O’Brien (2002); Smith and O’Brien (unpublished)).

5.16 Evidence of this is also found among the sample of 49 of whom at least 24 were believed to have a mental health problem. This includes 8 of the 9 people in prison, 9 people in learning disability units, 4 in psychiatric units, and one young person in secure accommodation. Only 2 people, however, out of 11 in the State Hospital were noted as having mental health problem.

5.17 Depression was the most frequent mental health problem among the prison sample. People in the learning disability units tended to be diagnosed as having psychotic illnesses including schizophrenia. Insufficient information was available for people in the other units.

5.18 A number of people across secure settings also had chronic physical health care conditions including epilepsy, diabetes, cardiac problems and Chronic Obstructive Airways Disease.
5.19 Communication difficulties were noted in relation to 28 people out of 49, including 5 people out of the sample of 9 in prison. In the majority of cases the cause was perceived to be due to cognitive impairments or was speech related. In several cases hearing impairments were also noted.

5.20 Clearly this is a multiply impaired group of people, some of whom have mental and physical health care needs and communication difficulties. Furthermore, these individuals are not just found in healthcare settings but in secure accommodation and penal settings. How the different environments assess and respond to these multiple needs is discussed in chapters 6 and 7 below.

PAST HISTORIES

5.21 Two themes emerge from an analysis of the data on the past histories of the sample of 49. First, is the extent to which some of this background information was not available to the respondents completing the forms. Although to a degree an inevitable consequence of relying on self-completion questionnaires by people with competing demands on their time, it also perhaps reflects some of the problems of multi-agency information transmission. The accumulated histories of individuals may not follow them into, or across, different secure settings. The implications for early identification are discussed in chapter 3. Second, where this information was available it revealed the degree of prior contact people within the sample had had with health, education and social work services.

5.22 Nearly 90% of the people for whom information was available had been ‘Looked After’ by the local authority at some point in their lives (37 out of 42). This includes all 11 people in the State Hospital for whom case recording forms were completed, all 3 children in secure accommodation and the majority of people in learning disability, psychiatric in-patient units and in prison where this information was known. This is clearly a significant finding which raises further questions about the experiences of, and outcomes for, ‘looked after’ children, which extends beyond the scope of the current study.

5.23 A high proportion of the sample were known to have attended special schools – 35 people out of 41. Again the numbers were particular high among State Hospital patients and people in learning disability and psychiatric in-patient units. Among prisoners the figure is lower, 2 out of 5.

5.24 The data also indicate the level of usage of specialist health care resources in the past. Just under 80% of the sample of 46 for whom this information was available were believed to have been a patient of a hospital for people with learning disabilities at some point. This includes all the State Hospital patients in the sample, and 16 out of 20 people currently resident in learning disability units. But it also includes 6 people in prison (out of 8 for whom information was available). On the other hand, only one out of the 4 people in psychiatric in-patient units, for whom this information was known, had previously been in a learning disability unit.
5.25 In addition, 24 people in the sample had had prior contact with a Community Learning Disability Team or similar specialist team. This includes 3 people in prison.

5.26 The high level of psychiatric morbidity within the sample noted above, is given further emphasis by the finding that 26 people were known to have been patients of a psychiatric unit. Of these 6 were currently in prison, and 5 in psychiatric units.

5.27 Across the sample as a whole, 19 people had had periods as in-patients in both psychiatric and learning disability units, including 5 out of the sample of 9 people in prison. This is equivalent to the proportion with similar institutional histories in the State Hospital, where 6 out of 11 people had been in-patients of both types of unit at some point.

5.28 The past histories of in-patient care suggest that this group present significant challenges to services. For some people this is reflected in periods in different types of care: progressing along a pathway from residential care, to or from admission to local psychiatric or learning disability units or to high secure in-patient care. People in prison appear at some point to have slipped off this pathway and have ended up on a criminal justice route that has ultimately resulted in their imprisonment.

5.29 The perception held by a number of prison-based respondents was that as the large hospitals have closed so the prisons have increasingly had to accommodate people who would in the past have been admitted to, or remained in hospital. The study is not in a position to support or disprove this view. But the number of people within the prison sample with previous admissions to either hospitals for people with learning disabilities and/or psychiatric inpatient units suggests that for some people prison represents yet another institutional response to the needs they present and the risks they pose.

**ROUTES TO SECURE CARE**

*Routes to secure care*

5.30 The routes to secure care reinforce the sense of a cohort moving from one institutional environment to another. Only 6 people out of the sample of 49 were admitted direct from their current place of residence: 5 to learning disability in-patient units and one to a psychiatric unit outwith the State Hospital.

5.31 Admission to the prisons was, as would be expected, through the courts or from other prisons.

5.32 The State Hospital admitted people straight from the criminal justice system, but also from other hospitals.

5.33 None of the sample within the learning disability in-patient units came direct from prison or the courts. The majority were referred from another hospital, including 3 people moving on from the State Hospital. A number of those moving from other hospitals were being transferred
because of hospital closure programmes. This appears to have affected at least 8 people out of the sample of 20.

5.34 As well as the one person admitted from their current place of residence, the psychiatric in-patient units admitted people from the State Hospital (3 people) and from the courts (one person).

5.35 Of the 3 children in secure accommodation, 2 were admitted from other residential care settings, and one from prison, via a short stay in a residential school. Two of the children had been placed following a Children’s Panel hearing the third was a criminal justice disposal.

5.36 Leaving aside the people admitted to the current setting for ‘administrative reasons’ relating to hospital closure, those who crossover between environments comprise 3 groups. First, people moving from conditions of lesser to higher security, for example, from other hospitals to the State Hospital, or from a residential placement to secure accommodation for children, or from home to hospital, or to prison. Second, people moving in the opposite direction from higher security to lesser security, specifically from the State Hospital to other in-patient units. The third group comprise those taking a step sideways: from prison to high secure or other secure in-patient care, or to secure accommodation for children.

5.37 None of the sample crossed over from a health or social care setting to a prison setting. But, as described above, people in prison may have a history of local authority care and hospital admissions.

Current legal status

5.38 Although people may not be admitted direct from courts or prisons, data on current legal status reveals that a number of people in healthcare settings were detained under sections of the Criminal Procedures (Scotland) Act 1995. This applied to 8 of the State Hospital sample, 3 out of 20 people in units for people with learning disabilities and half of the 6 people in psychiatric units. A further 16 people were detained under the Mental Health (Scotland) Act 1984, 11 of whom were in the learning disability units.

5.39 In effect, people detained under criminal justice legislation were more likely to feature among the State Hospital and psychiatric populations, those for whom mental health legislation is applied feature more significantly among the population in the learning disability units.

5.40 Of the 3 young people in secure accommodation, one person on probation was detained under the Criminal Procedures (Scotland) Act 1995. The remaining 2 were placed under Sections 70 and 73 of the Children (Scotland) Act 1995.
Length of stay in secure settings

5.41 How long people stay in secure settings once admitted is affected by a number of factors, not all relating to changes in need. Obviously, for prisoners, the length of stay will reflect the sentence or length of period on remand. Estimating the length of stay from the point of admission to the date the case recording forms were completed reveals a range extending from one month to 29 months. Two people on remand had been in prison one month and 5 months respectively. For convicted prisoners the length of sentence varied from 16 months for one person to 10 years for 2 people.

5.42 The shortest length of stay to date among the State Hospital sample was 7 months, the longest 19.5 years.

5.43 The person with the longest period in a hospital setting was an individual in a unit for people with learning disabilities who had been a patient for over 22 years. This person was one of the sub-group of 8 people who had recently been transferred following hospital closures. Excluding the distorting affect of this group of people, the range of lengths of stay in learning disability units extended from one month to over 5 years. This reflects the inclusion of settings with different functions including assessment and continuing care. A narrower range is found in the psychiatric units: from 17 months to just under 3 years.

5.44 The 3 young people had spent between one year and 20 months in secure accommodation at the time of data collection.

5.45 The degree of movement, the variability between cases, together with incomplete data on transfer dates, particularly across and within health care settings, makes it difficult to draw firm conclusions on length of stay. The one impression that does emerge, however, is that for many people secure care is not a short stay option.

RISK TO OTHERS

5.46 Why people are in secure settings, and the lengths of time they stay, once admitted, can not be divorced from the risks they are felt to pose, both to themselves and to other people.

5.47 For people who are offenders the nature of the index offence is an indicator of the anticipated risk an individual poses towards others.

5.48 Table 5.2 summarises the offences with which people had been charged or convicted at the time of admission to the secure setting. For some people more than one offence was indicated. No information was available in relation to the children in secure accommodation.
Table 5.2  Index offence by type of secure setting: case recording form sample

<table>
<thead>
<tr>
<th>Index Offence</th>
<th>Prison – units combined</th>
<th>In-patient units for people with learning disabilities</th>
<th>In-patient units for people with mental health problems</th>
<th>Total Offences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offences of a sexual nature</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Homicide</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Fire raising</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Threatening behaviour</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Assault</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Drug Offence</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Theft</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Reckless conduct</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Breach of Peace</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Breach of Order</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total Offences</td>
<td>12</td>
<td>9</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Total Offenders</td>
<td>9</td>
<td>7</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Total CRF sample (ex children)</td>
<td>9</td>
<td>11</td>
<td>19</td>
<td>5</td>
</tr>
</tbody>
</table>

5.49 What the table reveals is the seriousness of some of the offences perpetrated by this group of people, including culpable homicide, sexual offences, including rape and sexual assault, and fire raising. Further, the people committing these offences are distributed across the different secure settings for adults, including in-patient units for people with learning disabilities.

5.50 Looked at from another perspective, what the table also indicates is the numbers of people in different health care settings who have not been convicted or charged of an offence. The literature, however suggests that there is a level of under-reporting of offences by people with learning disabilities, particularly among those known to services (Lyall et al, 1995; Clare and Murphy, 1998). One health care respondent also suggested that in terms of their behaviours everyone in one secure unit was, in effect, an ‘offender’:

“Although they will not necessarily have been through the criminal justice system they will have perpetrated acts which would be classified as offending..if someone has a clear learning disability and IQ of 50 and is unable to control their impulsive behaviour and is assultative then they won’t be taken to court. There would be no point going to court they will already have been civilly detained and if they are taken to court they will just be assessed as unfit to plead and returned to hospital.”

5.51 The comment made on one case recording form for a patient on an in-patient unit for people with learning disabilities serves to illustrate that, even if reported, the threshold for prosecution may be higher than for someone who is not learning disabled:

“No action taken for sexual offence but Procurator Fiscal said it would be taken into account if further offences.”
5.52 If the index offence is an unreliable indicator of behaviour the data on the nature of the risk posed to others provides further evidence of the challenges this group of people present. Of the sample of 49, at least 31, or over 60% were believed to present a risk to others. Of these only 4 were in prison. It may be that some prison respondents interpreted risk within the context of the prison environment which, by its very nature, may minimise the opportunities to engage in certain behaviours.

5.53 The risks described on case recording forms ranged from “unpredictable violent outbursts” to “impulsive, verbal abuse, threatening and sexually inappropriate physical assault”.

5.54 They are, though, not just a high risk group in terms of behaviours directed towards others, but also in terms of the harm they effect upon themselves, and the harm others in secure environments may effect upon them. In other words this is both a high risk and an ‘at risk’ or vulnerable group of people.

VULNERABILITIES

5.55 At least 24 of the sample were felt to be vulnerable in their current environment. This includes people in prison, in secure accommodation and on in-patient units.

5.56 Vulnerability stems from the risks people pose to themselves and the risks they are exposed to in their current environments from other people. Risks to self include self-harming or suicidal thoughts, self-neglect or non-compliance with medication. Risks from others include bullying, manipulation, abuse, or negative responses to their behaviour by other residents.

5.57 At least 17 of the sample were felt to be a risk to themselves. People with self-harming behaviour or suicidal thoughts were found across secure settings.

5.58 Several people in health care settings were at risk because of alcohol or, in one case, drug abuse.

5.59 Several prison respondents spoke anecdotally of prisoners taking someone with a learning disability “under their wing”. But the data from the case recording forms suggests that they are more like to be shunned or at risk of exploitation. In environments where to stand out or appear “odd” could be a risk factor people with learning disabilities and/or ASD could be particularly vulnerable. In the prisons and secure accommodation for children, for example, there was an awareness that people with learning disabilities were at risk of being bullied or “ostracised” or of being ridiculed by others. This is underlined by the comments of one prisoner interviewed in the course of the study. When asked what was the worst thing about being there the response was: “Getting bullied by other prisoners”.

5.60 People with learning disabilities were also at risk of being exploited. In several different secure environments respondents were conscious of the fact that people in the sample with learning disabilities could be used by more able residents to handle illegal substances or blamed for others’ “wrong doings”. In a prison context sexually inappropriate behaviour on the part of
an individual with learning disabilities may also put them at risk. It was also suggested, anecdotally, that some people could be at risk of sexual abuse even within secure settings.

5.61 Chapter 7 describes in more detail how, in different contexts, people with learning disabilities and/or ASD can be outsiders or on the periphery of the environments within which they find themselves. What this means for the individuals themselves is summed up in the comments of one interviewee with a learning disability:

“\textit{The people here slag you and take liberties with you...People here are dangerous to themselves and to me...People intimidate you. People pass stuff on to you like hash or dope or take stuff off you. They take me for a ride. They take my CD and don’t return it to me. It’s terrible, horrible here.}”

\textbf{SUPPORTING PEOPLE}

5.62 Notwithstanding the degree of vulnerability of this group of people, only 12 were known to have been assessed under the Adults with Incapacity (Scotland) Act 2000 (AWIA). The majority of these people (10) were in-patients of the learning disability or psychiatric units. Two people in psychiatric units had a welfare guardian. Although no one in the prison sample was known to have been assessed under the AWIA, in response to a question on the unit recording forms regarding services available to meet social welfare needs one prison included “Adults with Incapacity Act”. This suggests a degree of awareness of the legislation.

5.63 Ironically, however, it may be that the capacities of this group of people preclude the use of this legislation: 3 people in hospital settings who had been assessed under the AWIA were found to be “capable”. Capacity, under the AWIA, is not all or nothing, but context or issue specific for example in relation to managing financial affairs, or consenting to medical treatment. Unfortunately it is not known what aspect of capacity was assessed in these cases.

5.64 One young person in secure accommodation was described as having a ‘guardian’, but no further information was available from the case recording forms to indicate their nature or status.

5.65 Across the sites information from the unit recording forms indicates the availability of independent advocacy services. Across the 16 prisons, 7 believed independent advocacy would be available for someone identified as having a learning disability and/or ASD. Four prisons suggested that this would not be available, the remainder did not know. In fact, for the 9 prisoners for whom more detailed information was available, none had an independent advocate. In one prison a RMHN was looking at ways of bringing in an independent advocacy agency for people with learning disabilities.

5.66 All the secure accommodation units had access to independent advocacy services. Of the 3 young people in the sample 2 had their own advocate.

5.67 All 11 people in the State Hospital sample were believed to have an advocate. This may reflect the activities of the on-site patient advocacy service.
5.68 All but 2 of the learning disability and psychiatric units outwith the State Hospital suggested that individuals would be able to obtain access to independent advocacy. One of the exceptions may have interpreted the words “in this setting” to mean on site, rather than accessible. In the second case, a unit for people with severe learning disabilities and challenging behaviour, the respondent commented that advocacy was “difficult to obtain for this group”. Reflecting a gap in service provision.

5.69 In fact out of the sample of 20 people in learning disability units half had an independent advocate, as did 2 of the 6 people in psychiatric units.

DISCUSSION

5.70 In common with a number of other studies (Winter et al, 1997; Flynn and Bernard, 1999; Glaser and Deane, 1999; Alexander et al, 2002), the data reveal a multiply disadvantaged, high risk and at risk group of people.

5.71 Although information is not available on socio-economic status, past histories indicate a common pattern of previous institutionalisation and contact with statutory services.

5.72 They are also a vulnerable group of people. This vulnerability stems, on the one hand, from the combination and complexity of the behaviours they present, including self harm, physical and mental health problems and communication difficulties. On the other hand, the environments within which they find themselves may exacerbate their individual vulnerabilities. People with learning disabilities and/or ASD may be at risk of being bullied, exploited or even abused in environments where they are perceived not to ‘fit in’ or are seen as different.

5.73 But they are also a high risk group: some have committed, or are at risk of committing serious offences.

5.74 Given the multiple needs and risks identified across the sample the data do raise questions about the distinguishing characteristics of the populations in the different settings. The small sample size together with limited case-specific clinical information or detailed information on offending behaviours or histories means it is not possible to draw firm conclusions. The small number of women, and the absence of any people from minority ethnic communities also makes it difficult to compare experiences by gender and ethnicity. Nonetheless it is possible to identify some of the dimensions which distinguish the populations and those areas where they overlap.

5.75 The secure accommodation for children is something of a special case. The small number of young people identified makes it difficult to draw any within-group conclusions, other than to reflect on the heterogeneity of this small group in terms of their routes to secure care and their individual characteristics. What they share with each other and with the sample in secure settings for adults is the complex combination of needs, risks to self and/or others and vulnerabilities.
Focusing on secure settings for adults, the key distinguishing features include the level of IQ, the nature of co-morbid mental illness and the routes to secure settings.

In the 32 cases where this information was available, the majority of the sample had an assessed IQ of 60 and over, one-quarter of these have an IQ of over 70. The majority of people with an assessed IQ under 60 tend to be found in the units for people with learning disabilities outwith the State Hospital. This, though, is not hard and fast. Several prison respondents suggested that people with assessed IQs in the 50s have been found within the prison system.

The other distinguishing feature is the nature of co-morbid mental health problems, where identified. For people in prison this was most frequently depression. The sample of people in learning disability units with mental health problems tended to have psychotic illnesses.

The third distinguishing feature is the route to a secure environment. People referred to the State Hospital and psychiatric in-patient units came through the criminal justice system, other hospitals and occasionally direct from home. The prison sample, of necessity came through the courts or other prisons. Those in learning disability units came predominantly from other hospitals, with a few admitted from home.

Along the dimensions of index offence, or other indicators of risk to others, past histories of institutional care, combinations of mental and physical health problems and communication difficulties, there is, however, little to distinguish between the samples in the different secure settings. The prisons, the State Hospital and the in-patient units are providing care for people with histories of institutional care, with multiple impairments, who may pose significant risks to other people and/or towards themselves.

It has been suggested that responses to alleged offending can be dependent upon existing contact with services (Lyall et al, 1995; Clare and Murphy, 1998). Other research has also described how people with learning disabilities and/or ASD who engage in offending behaviour do not fit within the remit of mental health or learning disability services. As a result they may fall between service responsibilities (Winter et al 1997; Mason and Murphy 2002). The apparent overlaps in the characteristics of a sample of people in the secure settings suggest that for some individuals the routes to different secure settings may be contingent on factors such as whether they are known to services and the preparedness, or otherwise, of different services to take on responsibility for these people.

For the individuals themselves the outcomes of these contingencies may however be distinct. For example, there is evidence of greater lengths of stay for people in the State Hospital and in-patient units for people with learning disabilities. Further, as will be discussed in greater detail in chapter 7 below, the vulnerabilities of people with learning disabilities and/or ASD may be exacerbated by the environments within which they find themselves.
KEY POINTS

• The sample of 49 for whom case recording forms were completed comprised a white, predominantly male population

• The majority of the sample had a learning disability only, 4 people had an ASD, and 7 both learning disabilities and an ASD

• The majority of the sample for whom information was available had an assessed IQ of between 60 – 70. Eight people had assessed IQs of over 70, and 9 had IQs under 60. The majority of the latter were in learning disability units

• At least 24 people also had mental health problems. Among the prison population this tended to be depression. People in learning disability units tended to be diagnosed as having psychotic illnesses

• A number of people also had chronic physical health conditions. Communication difficulties were noted in relation to 28 people

• Available information on past histories indicates that the majority of people had been in local authority care at some time. A large proportion had been in-patients of learning disability or psychiatric units at some time in the past. Across the sample 19 people had had periods in both learning disability and psychiatric units

• Lengths of stay were variable in and across the secure settings, though for adults in prison these tended to be shorter on average than in healthcare settings. The young people had been in secure accommodation for between one year and 20 months

• Information on index offence and risks posed to others indicate that a number of the sample had committed quite serious offences, including sexual offences, culpable homicide and fire raising. Others may not have been convicted but were at risk of engaging in offending behaviour

• The sample was also a vulnerable group of people. A number of people were considered by staff to be at risk of self harm

• People were also felt by staff to be at potential risk from other residents within the secure environment. The possible risks identified by staff included being ostracised, bullied or exploited

• A number of people had been assessed under the Adults with Incapacity (Scotland) Act 2000. Independent Advocacy was believed to be accessible to the majority of the sample in healthcare settings and secure accommodation, although not everyone had an advocate. None of the prison sample had an independent advocate
• The key features distinguishing the profiles of the adults in the different environments include the IQ levels of individuals, the nature of co-morbid mental illness and the routes to the different types of setting. In other respects adults in different types of secure environment shared similar characteristics
CHAPTER SIX ASSESSMENT OF NEED AND CARE PLANNING

6.1 Chapter 3 described the processes and mechanisms for identifying someone as having a learning disability and/or ASD. This chapter explores the ways in which, once identified an individual’s needs are assessed and care plans developed. Assessments are distinguished between: specialist clinical assessments following initial screening or identification; assessment of additional health, social care, education/training and offending/behaviour related needs; and risk assessment.

SPECIALIST ASSESSMENTS

6.2 The unit recording forms indicate that across the secure settings assessment or diagnosis of learning disabilities and/or ASD was seen as a role for clinical psychologists, clinical forensic psychologists, or, in the prison service, forensic psychologists, and, less frequently, consultant psychiatrists.

6.3 From the more detailed case recording forms, however, 2 findings emerge in relation to non-health care settings. First, in some instances assessment or diagnosis did not seem to involve psychiatric or psychological input. Second, where there was clinical input it was only occasionally from a specialist in learning disabilities.

6.4 In secure accommodation for children, for example, assessment may be undertaken by a psychiatrist in learning disabilities, but it may also be made by an educational psychologist.

6.5 Similarly, in the prisons, there was evidence in one case of the assessment being undertaken by a Forensic Learning Disability Team, including a psychiatrist specialising in learning disabilities. Others had been assessed or diagnosed by consultant psychiatrists or clinical psychologists, or the person’s GP and/or the prison medical officer.

6.6 The route to learning disability services for people in prison would be via the prison mental health teams. Visiting psychiatrists would refer on to specialist services. For example, one person identified by the prison as having an IQ of 50, was being referred to the local learning disability service with a view to transfer to a specialist in-patient unit. This person had, however, been convicted. Two prisons raised the difficulties of obtaining specialist input for someone who was only in for a short period. One visiting psychiatrist described how, if someone was “not in for a long sentence, or not detainable, and had no prior contact with learning disability services, then they may not be seen by learning disability services”.

6.7 One prison expressed the view that rather than referring to a forensic psychiatrist they should be able to refer direct to “psychiatrists who are specialists in learning disabilities”. Potentially this could ensure not just specialist but also timely input.

6.8 No specialists in ASD were referred to in either the non-health care or health care settings.
6.9 In any specific case there may not be a demand for input from a specialist in learning disabilities or ASD. There may though be a case for arguing that the involvement of specialist learning disability services at the point of assessment may also encourage ‘ownership’ or ongoing responsibility by these services, where appropriate, for people identified within the secure settings.

ASSSESSMENTS OF NEED

Additional assessments

6.10 From a pre-selected list on the unit recording forms secure settings were asked to indicate the range of additional assessments that, in principle, would be available. The list included physical health care, mental health care, offending and/or other challenging behaviour, social welfare and education and training. In general, all units responding anticipated being able to access the range of assessments. In-patient units for people with learning disabilities (outwith the State Hospital) were less sure about being able to obtain assessments of social welfare or education/training needs.

6.11 Across the different settings just under two-thirds of the 39 units responding to the question on the unit recording form felt that arrangements for obtaining these additional assessments ‘worked well’. For a significant minority, however, this was felt to work ‘less well’.

6.12 Unit recording forms also asked respondents to indicate whether additional assessments were undertaken once someone was identified as having a learning disability and/or ASD.

6.13 Of the units responding to this question a few indicated that they would not undertake additional assessments. These include: one long stay rehabilitation unit for people with learning disabilities; 5 of the psychiatric units on the State Hospital site; and 3 of the 6 psychiatric units. It is not evident why these units would not anticipate undertaking additional assessments. It may be that the wording of the question, which referred to additional assessments following identification, may have misled respondents. Alternatively, it may be that once admitted the focus in these units would be on treatment following prior assessments.

6.14 The data from the case recording forms present a less ambiguous picture. The forms asked for information on additional assessments undertaken either in the previous 12 months or since admission, whichever was most recent. Table 6.1 summarises the responses for the sample of people in each setting for whom case recording forms were completed.
Table 6.1 People receiving additional assessments following identification, by type of secure setting

<table>
<thead>
<tr>
<th>Type of secure setting</th>
<th>Additional assessments undertaken</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Prisons</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Secure accommodation for children</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>State Hospital (all units)</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>In-patient units – learning disabilities</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>In-patient units – mental health</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>8</td>
</tr>
</tbody>
</table>

6.15 The majority of people appear to have had additional assessments. The ‘Don’t Know’ responses perhaps again reflect a misunderstanding. From interviews with staff of the secure accommodation units, for example, it is clear that children and young people routinely undergo extensive multi-disciplinary assessment of need and this is regarded as a core function.

6.16 All 4 of those in learning disability in-patient units who had not had additional assessments had recently been transferred following the closure of other units. Assessments of need may have been undertaken prior to transfer.

6.17 Of the 4 people within the prisons who had not had additional assessments 2 were on remand. This may limit opportunities for the units to arrange more detailed assessments.

6.18 The data from the case recording forms suggest that additional assessments would be undertaken for 5 overlapping reasons:

- To obtain information on someone newly referred, including to provide information to a court or Children’s Hearing panel to inform decision-making
- In response to a specific need, or a change in need
- To inform care or treatment plans
- As part of on-going routine assessment
- To inform discharge or future planning

Scope of assessments

6.19 From the case recording information data it appears that across settings mental health and physical health care needs were being assessed. Offending behaviour and/or ‘other challenging behaviour’ were also reviewed. Fewer people however appeared to have their social welfare and education/training needs assessed. This is illustrated in table 6.2.
### Table 6.2  Social work and education/training assessments undertaken by type of secure setting

<table>
<thead>
<tr>
<th>Type of secure setting Numbers of people</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prison</td>
<td>Secure accommodation for children</td>
<td>State Hospital learning disab. unit</td>
<td>State Hospital other units</td>
<td>In-patient units for people with learning disabs.</td>
<td>In patient units for people with mental health probs.</td>
</tr>
<tr>
<td>Total CRF sample</td>
<td>9</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>20</td>
<td>6</td>
</tr>
<tr>
<td>CRF sample having additional assessments</td>
<td>4</td>
<td>1</td>
<td>7</td>
<td>4</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Total having assessments of social welfare needs</td>
<td>2</td>
<td>1</td>
<td>7</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Total having assessments of education/training needs</td>
<td>0</td>
<td>1</td>
<td>7</td>
<td>4</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

6.20 It can not be assumed that everyone requires a social welfare or education/training assessment, but given the reasons cited for undertaking assessments the comparatively infrequent assessment of social welfare and education/training needs is significant. A number of inter-linked reasons may account for this emerging pattern, and may also begin to suggest why, for some units, obtaining additional assessments is felt to work ‘less well’.

6.21 First, resource availability. The specialist unit for people with learning disabilities on the State Hospital site, has a level of on-site social work input described as double that available to the continuing care wards. This may partly explain the greater number of social welfare assessments. Within the prisons, criminal justice social work departments may not have the capacity to routinely assess people identified as having a learning disability and/or ASD, especially if they are not being released on licence. Other in-patient units, outwith the State Hospital, particularly those providing long stay care may also not have ready access to social work resources for assessment.

6.22 Across settings, issues of capacity and the limited links with and between different agencies may mean that there are fewer opportunities for cross-agency joint working at the point of assessment. This emerges particularly in relation to the prisons where education and social work departments, for example, may undertake their own independent assessments.

6.23 A number of these issues are underlined when attention turns to contributors and coordinators of assessments of need.
Contributors to assessments of need

6.24 Across settings there is evidence of multi-disciplinary assessment, but the number and range of contributors is variable.

Secure accommodation for children

6.25 The secure accommodation units included within the sample shared an ethos of seeking internal and external multi-disciplinary/multi-agency working. This is demonstrated by the range of people involved in assessing the needs of one young person. These included the young person, their family and GP, community social work team, consultant psychiatrist, clinical forensic psychologist, educational psychologist and unit teaching and nursing staff. In addition contacts were made with health, education and social work professionals involved with the person before they were admitted.

6.26 Staff within the units commented not just on the involvement of different disciplines but the integration of different inputs:

“The beauty of X school is that they work in a multi-disciplinary way. For any one case they will get together as a team ... Don’t just do one’s own bit but identify things to refer on or discuss.”

The prisons

6.27 Within the prisons there is an evident aspiration, across disciplines, to take a multi-disciplinary approach. But there are barriers limiting the breadth and depth of joint working. The quantitative and qualitative data suggest 2 patterns: joint assessment across a small core of disciplines; and independent assessment.

6.28 Data from the case recording forms reveal that the core disciplines involved in additional assessments were prison nursing staff, medical officers and prison officers. In addition, in some cases, social work/criminal justice social work and consultant psychiatry contributed. In one case study prison the RNMH-trained nurse would be able to contribute to assessments of people identified as having a learning disability. There may also be contact with professionals known to the individual prior to incarceration. But beyond this core the range of those involved in assessments appears limited.

6.29 Of the sample of 4 people who received additional assessments only in one case was it indicated that they contributed to their own assessment. No families were involved. Also absent were assessments by clinical psychology, education/training and speech and language therapy. The latter is especially significant given that 5 out of the 9 people for whom case recording forms were completed were believed to have communication difficulties. For 3 people these difficulties were seen as being due to both cognitive and speech difficulties.

6.30 The second pattern within the prisons is of independent, rather than joint assessments. Unless someone was on ACT, the SPS suicide strategy, contact between health care and social
work may be “limited”. Prison unit managers in one prison also alluded to what they perceived to be the constrained capacity of the prison social work department to attend “team meetings”.

6.31 Prison-based education staff may undertake their own assessment and develop a learning plan, but the prison health care centre would not necessarily know if individual prisoners were using the education centre.

6.32 Criminal justice social workers based in one prison raised another obstacle to jointness: a lack of clarity over responsibility for undertaking community care assessments for prisoners. The prison team related how the local social work department community care team saw these assessments as being the responsibility of criminal justice team. The prison-based team, however, felt that they had neither the expertise nor the knowledge base to undertake community care assessments. Further, they were not clear whether these assessments came within the scope of the social work department’s service contract with SPS.

The State Hospital

6.33 Across the State Hospital units the data suggest a breadth of clinical input to assessment, including medical, nursing, psychology, OT and speech and language therapy, as well as teaching/training and security staff. Hospital social workers would also anticipate undertaking assessments on all admissions. The breadth of contributors may be a testament to the introduction of integrated care pathways, enabling each discipline to contribute to the “pool” of assessments. But, although there was some contact with professionals who had known individuals prior to admission, there may be an argument for saying that assessment is largely ‘inward facing’ – reflecting the disciplines and expertise available on the State Hospital site.

6.34 Given the length of stay of many of the State Hospital patients the apparently limited input from external agencies in ‘assessment’ may not be surprising. But, as in the context of the prisons, it may raise questions about on-going ‘ownership’ and responsibilities for individuals. This may have implications for forward planning.

6.35 All 7 people in the sample from the specialist learning disability unit on the State Hospital site and their families were described as contributing to the assessments. This was less in evidence on the other wards. No advocates were involved in relation to people on the learning disabilities unit, one, however, contributed to an assessment on another ward.

In-patient units for people with learning disabilities and for people with mental health problems

6.36 The in-patient learning disability units shared a similar pattern to the State Hospital units in terms of the breadth of in-house clinical input to assessment. Speech and language assessments had, however, only been undertaken in relation to 3 of the 8 people believed to have communication difficulties. Given the length of stay of some people it may have been that these assessments had taken place at some prior point in time. In 2 cases community based social workers were involved in the assessments. There was also some contact with professionals who had known the individuals before admission.
6.37 The majority of the sample of people in the learning disability units had contributed to their own assessments, but in only 4 cases were families also involved. This could be in part due to the inappropriateness of relative involvement, or lack of on-going contact. In only one case was an independent advocate involved.

6.38 Across the small number of cases in psychiatric units outwith the State Hospital, the range of contributors to additional assessments was quite extensive, including medical, nursing, psychology, OT and social work members of clinical teams. In addition to external contacts familiar with the individual, 3 people and their families, out of 5, contributed to the assessments. Independent advocates were involved in 2 cases, the welfare guardian of one of these was also involved.

Co-ordinating and recording assessments

6.39 Having access to a range of different assessments does not necessarily add up to a whole picture. To ensure integration as well as joint working also relies on mechanisms for co-ordinating and recording additional assessments.

Co-ordinating assessments

6.40 The case recording form data suggest that across settings 3 different approaches were adopted to co-ordinating the assessment.

- Multi-disciplinary team responsibility. The majority of the prisons and the wards on the State Hospital site interpreted ‘co-ordination’ as a joint function, albeit in the case of the wards, one that was led by the Responsible Medical Officer
- A medical or nursing responsibility. In the majority of the learning disability units medical or nursing staff were seen as responsible for co-ordinating assessments
- The function of a specific individual. The additional assessments of one young person in secure accommodation were co-ordinated by the assessment unit manager; an MHO and a social worker were responsible for co-ordinating the assessments of one person each in the psychiatric units. “Keyworkers” were described as co-ordinators for 2 people in learning disability units

Recording assessments

6.41 In the policy context of Joint Future and the gradual introduction across all community care groups of single shared assessment, the mechanisms used to record assessment is a further indicator of joint working.

6.42 Across the sample, 2 of the in-patient learning disability units and 2 of the psychiatric units specifically referred to using single shared assessment. One State Hospital unit also referred to “shared assessment”. Elsewhere reference tended to be made to multi-disciplinary team notes or treatment plans. For one person in prison, and 11 people in in-patient learning disability units, however, information was recorded in medical and/or nursing notes only.
RISK ASSESSMENT AND OTHER TOOLS

6.43 The case recording forms asked respondents to indicate what, if any, risk assessments, had been undertaken in relation to the individual over the previous 12 months, or since admission (whichever was most recent).

6.44 Suicide/self harm was the most frequently cited form of risk assessment across the sample. For example, 8 of the 9 people in the prison sample had been assessed under ACT, the SPS suicide prevention strategy.

6.45 Risk assessment is also a central function of the SPS sentence management process. One prison for example, described the work of the multi-disciplinary risk management group in obtaining risk reports. A psychologist on the group, however, had not to date been asked to undertake an assessment on someone with a learning disability.

6.46 In the majority of cases and secure settings the ‘tools’ used were the ‘clinical team’ or local assessment tools. One in-patient learning disability unit referred to RAMAS (Risk Assessment and Management System). One secure accommodation unit in the sample made specific reference to using YLSI – a needs and screening tool adapted for adolescents for use by non-clinical staff.

6.47 The secure accommodation units described a battery of different assessments. One unit indicated that for children or young people with sexually aggressive behaviour this would include risk assessments specific to sex offenders.

6.48 Although not a specific focus of this study, 2 themes emerged from an overview of the risk and other assessment tools used. First, the expertise vested in clinical teams or individuals tends to be the main ‘tool’ used. Second, where specific tools are used they tend to be ‘generic’. It is not clear to what extent they can, or are able to be adapted for people with learning disabilities and/or ASD.

CARE PLANNING

Care planning

6.49 The above outlines the assessment processes in each of the selected secure settings. In chapter 7 the responsiveness and capacity of settings to meet identified needs is described. The link between these 2 is the care plan. Unit recording form responses indicate that for the majority of units care planning was an aspect of their work that they felt worked well.

6.50 No definition of a care plan was given in the case recording forms, but across secure settings the majority of the sample for whom forms were completed had what respondents regarded as a care plan. The proportion was slightly lower in the prisons, but even here 5 out of 9 people had some sort of plan of action.
6.51 Convicted prisoners also have the option of participating in the SPS sentence management process. An action plan will be developed following a needs and risk assessment. Although the focus is on offending behaviour and risks of re-offending, as suggested earlier, the process provides an opportunity to identify and address specific care needs as well as pre-liberation planning.

**Person-centred care planning**

6.52 There are clearly attempts to prepare plans in response to identified individual needs. In the prisons, for example, attempts may be made, in liaison with hall staff, to adapt a routine to meet the needs of an individual with learning disabilities and/or ASD.

6.53 Within the secure accommodation units the emphasis was on tailor-made care planning. As the respondent in one unit commented:

“The care plan is geared towards the young person, their own strengths and needs.”

6.54 Treatment plans for people on the State Hospital include a nurse based plan formulated by the keyworker and the patient. The Patient Activities and Recreation Service (PARS) was also increasingly tailoring services to meet individual needs. Describing how one of the PARS staff now attends clinical team meetings one practitioner commented:

“This did not happen in the past. This is an enormous change and is of great value. Staff are now sitting down with patients to find out personal likes and dislikes and any deficits to address..and, with the OT looking at specific activities. Feeding back assessments then forms part of the treatment plan.”

6.55 With the exception of the secure accommodation units for children, what does not come across strongly is a sense of the plans produced by the different settings being person-centred: that is, part of a collaborative process which is informed by the individual, as far as practicable. The information collected for the current study is perhaps insufficient to draw conclusions, but as the example from the State Hospital suggests, processes may be in transition and approaches with a common currency ‘outside’, may be slower to take a foothold in secure settings. It was suggested in one secure setting, for example, that person-centred approaches in the context of planning for discharge may be an unfamiliar concept with which some staff may still feel uncomfortable.

**Care plan function**

6.56 The care plans for children and young people in secure accommodation would include health, education, care and relationships/contact needs. Once formulated the plan was seen as serving 2 functions: to inform the sessional work to be carried out in the areas identified; and to begin the process of forward planning. One secure accommodation unit, for example, described
how an “exit plan is sought from day one so that people do not feel they have been taken from the community and left in [unit]”.

6.57 The ‘treatment plans’ for people in the State Hospital were similarly dual purpose, including informing current activity and discharge planning. One respondent described how treatment plans were now a mechanism for “starting to plan discharge from the point of admission”.

6.58 Within the prisons the care plans focused on supporting and managing the person in the secure setting.

Monitoring and reviewing care plans

6.59 In healthcare settings responsibility for monitoring the care plans was seen as a medical or nursing and/or multi-disciplinary team responsibility. In 3 health care settings, outwith the State Hospital, a social worker or ‘care manager’ was identified as solely or jointly responsible for monitoring the care plan.

6.60 Social workers from a child or young person’s area of residence would be responsible for monitoring the care plans of their clients in secure accommodation.

6.61 Within the prisons responsibility for monitoring plans lay with prison officers and/or nursing teams. In one case social work, nursing and prison officers were seen as jointly responsible.

6.62 The frequency with which plans were reviewed varied from ‘on-going’, particularly in the prisons through weekly, quarterly, 4-monthly, to annually for 6 people in learning disability units.

6.63 Looked After Children reviews would be held in relation to young people in secure accommodation. For those referred via the Children’s Panels a multi-disciplinary review would be held to formulate recommendations for the hearing.

6.64 The State Hospital reviews, held quarterly or 4-monthly, would involve patients and their families to the extent that they are informed of the review in advance and subsequently receive feedback. A feedback form has been designed so that someone with a learning disability can understand what is discussed. In the feedback session with the RMO the individual can also have their advocate present. Nevertheless, neither the individual nor their family are invited to attend the reviews. This is in contrast to the ethos in the secure accommodation for children where young people are “actively encouraged” to attend reviews, as are families, where appropriate.
EXAMPLES OF PRACTICE

6.65 Across the settings there are examples of joint assessment and multi-disciplinary working:

- In one prison, for example, in response to the identified needs of one person with Asperger’s syndrome, the prison healthcare centre was proactive in contacting the court based social worker and the psychiatrist preparing a report. On the basis of the information jointly provided the court placed the person in a specialist resource on a supervision order
- The holistic approach to assessment described by the secure accommodation units
- The State Hospital integrated care pathway

6.66 A number of examples were given where care planning was used to effect change:

- State Hospital staff described how, following a visit to observe an approach used in the US they undertook a comprehensive review of one person’s care and treatment. This then informed the care plan
- One secure accommodation unit described how in developing a care plan they would seek to “manipulate success” for a child, planning the day to avoid areas which might cause difficulties such as stimulating the child to throw a tantrum

DISCUSSION

6.67 From this review of the processes of assessment and care planning in secure settings 4 key issues emerge.

6.68 First, people with learning disabilities and/or ASD across the secure settings are to a great extent receiving additional assessments.

6.69 The second finding, however, is the variable depth and breadth of those contributing to the assessment and care planning. This has a number of dimensions. Across non-health care settings there is apparently limited involvement of specialists in learning disabilities. This may have implications insofar as assessment, including risk assessment, tends to draw on expertise and tools not specific to the needs of people with learning disabilities and/or ASD. A lack of input at the stage of assessment may also have implications for on-going responsibility for people once they leave the secure care setting. The State Hospital and learning disability units appeared to be able to draw on the greatest range of professions to contribute including specialists in learning disabilities, but to a lesser extent agencies and professionals from outside. Again this may have implications in respect of forward planning for people.

6.70 A third finding relates to the degree of ‘jointness’ or partnership working in assessment. This too has a number of dimensions. First, although there is multi-disciplinary working in the sense of contributions to assessment and care planning, what comes across is a series of multiple, rather than a single, shared assessment. Further, there is still the potential for different
components of a service to undertake multiple assessments, for example prison health care, social work and education. In addition, with the exception of the secure accommodation units, there is variable involvement of the person with learning disabilities and/or ASD, their advocate or their relatives in these processes.

6.71 Finally, what does emerge is a sense of parallel processes in operation for people with learning disabilities and/or ASD in secure settings and those available, or proposed for people living in the community. As already noted, the mechanism of single shared assessment has yet to make an impact in these environments. The review of learning disability services, The same as you? (Scottish Executive, 2000) proposed the development of Personal Life Plans for everyone who has a learning disability and wants such a plan. Even more than single shared assessment, this has yet to appear in the discourse of these units. The one exception is the annual report prepared by the specialist unit for people with learning disabilities on the State Hospital site. This refers to the development of Personal Life Plans as one of a number of “specific issues yet to be addressed”. The same as you? also recommends the appointment of Local Area Co-ordinators to support people and ensure services are in place to meet their needs. The implications of this too for people in secure settings could warrant further consideration.

KEY POINTS

• Comparing across the settings, the secure accommodation units for children had access to the widest range of contributors to assessment from both within and outwith the units

• Within the prisons, there is evidence of multi-disciplinary input but the range of resources appears more circumscribed. There also does not appear to be a systematic approach to actively involving users in the assessment process

• The State Hospital, learning disability and psychiatric units appear to have a broad range of assessment resources to draw upon. These are largely internal to the units

• Both in relation to the State Hospital units and the in-patient units for people with learning disabilities, there may be a lack, in one form or another, of external voices to contribute to assessments. This includes independent advocacy or relatives, where appropriate

• Co-ordinating assessments may be a single or joint responsibility. Recording mechanisms too, may be a single set of notes or profession specific

• Risk assessments tend to be based on professional expertise or generic tools

• The majority of people in the sample had some form of needs led, if not person-centred, care plan

• Care plans prepared by the State Hospital and secure accommodation for children had the dual purpose of informing current activities and interventions and planning for the future. Within the prisons the focus at the care planning stage tended to be more on the here and now
From the descriptions of assessment and care planning it would seem that a number of recent relevant policy initiatives, including single shared assessment, personal life plans and the involvement of local area co-ordinators do not yet have currency within the secure settings in which people with learning disabilities and/or ASD may find themselves.
CHAPTER SEVEN MEETING ASSESSED NEEDS

7.1 People may have their needs assessed but to what extent do secure settings have access to the resources to meet these needs? This chapter begins to address this question in 2 ways. First, by looking at the perceived appropriateness of the different environments for people with learning disabilities and/or ASD. Second, by describing both the range of services available in each setting and the perceived gaps in the web of care, treatment and support.

THE APPROPRIATENESS OF THE SECURE SETTINGS

The prisons

7.2 SPS is obliged to hold in custody securely and safely all those incarcerated by the Scottish courts. At one, level therefore, whether or not prison is perceived by respondents as an appropriate environment for people with learning disabilities and/or ASD, it is a legal requirement for them to be there if they have been remanded to prison or given a custodial sentence.

7.3 Notwithstanding this legal context, the dominant theme emerging from the recording forms and from discussions in the course of site visits was the perception among prison respondents that, in general, prisons were not the most appropriate place for people with learning disabilities and/or ASD who engage in offending behaviour. But, it was suggested, for some people, in the absence of alternative resources, it may be the only environment.

7.4 A number of respondents suggested that the prison environment can provide a degree of routine and support otherwise lacking for some people. The view was also expressed that a period of imprisonment might help some people to understand the consequences of their offending. On the other hand, the lack of appropriate resources can mean that prisoners with a learning disability and/or ASD are not able to address their offending behaviour: the prisons may contain, but not reduce the risk. Further, individuals who are vulnerable may be held on protection or segregation wings, or locked in their cells for long periods, as in the following example:

“Both [people with learning disabilities] get bullied – their behaviour probably leads to that. For example, X becomes an object of fun...he only knows how to deal with it up to a point, then he doesn’t know how to deal with it, which means being up behind his locked door for long periods. It helps to keep him out of trouble, but doesn’t provide treatment or support for him.”

7.5 Prisons may also struggle within existing resources to meet the individual care needs of someone with a learning disability and/or ASD.
7.6 This sets in context the finding that of the 9 prisoners for whom case recording forms were completed 5 were regarded as inappropriately placed in prison and 8 were considered vulnerable: at risk from bullying, sexual abuse or being manipulated by other prisoners.

**Secure accommodation for children**

7.7 In the context of secure accommodation for children the concept of ‘appropriateness’ has 2 meanings. First, whether the structure, function and operation of the unit are appropriate for any child or young person with learning disabilities and/or ASD. Second, whether the unit is appropriate to meet the needs of a specific child or young person with learning disabilities and/or ASD.

7.8 One secure accommodation unit suggested that in terms of the physical environment and the focus and approach of its working methods, it would not be a suitable environment for a child with learning disabilities and/or ASD, particularly if the learning disability was of a severity that the child could not function independently.

7.9 In a second secure accommodation unit it was the specific configuration of the child or young person’s needs or abilities that might determine whether the unit was appropriate or not: not the presence of a learning disability and/or ASD, *per se*.

**The State Hospital**

7.10 For the State Hospital respondents ‘appropriateness’ also had 2 dimensions: whether or not the individual requires conditions of high security; and whether the resources available on site were sufficiently adaptable or responsive to the needs of people with learning disabilities and/or ASD.

7.11 Learning disabilities are included within the definition of mental disorder in both the current Mental Health (Scotland) Act 1984, and in the new Mental Health (Care and Treatment) (Scotland) Act 2003. As such the State Hospital as a hospital providing conditions of high security for people with a mental disorder is, in a legal sense, an appropriate environment for people requiring that level of security.

7.12 An on-going issue, however, for the State Hospital is the number of ‘entrapped’ patients. These are defined by the hospital as people who have been clinically assessed as ready for transfer to a less secure environment but who have been waiting for somewhere to become available for 3 months or more. Data made available by the State Hospital indicate that at the beginning of April 2003, 13 patients of the learning disability service had been assessed as ready to move on. A further 6 restricted patients were awaiting transfer. Of the sample of 11 people for whom case recording forms were completed as part of the study 3 had been assessed as appropriate for moving on but were still waiting for resources elsewhere to become available.
7.13 For a number of the State Hospital respondents, it was not just a question of the appropriateness of the State Hospital for specific individuals, but whether the hospital was an appropriate environment for people with a learning disability and/or ASD per se. This argument was couched in several ways. First, the view was expressed by professionals based on the site that only a small number of people with learning disabilities and/or ASD required the conditions of high security provided by the State Hospital. It was felt that, with appropriate levels of staff and other resources, the majority could be accommodated in local secure units.

7.14 Second, the point was made that many of the activities and therapeutic interventions available on site were designed around the needs of people with mental health problems. Although, as discussed below, more opportunities were being made available through increased specialist input, State Hospital respondents felt that there was not such an immediate linkage with the range of other supports that people with learning disabilities and/or ASD require, including social, educational and housing needs. Meeting the needs of people with ASD was also still felt to pose a challenge.

7.15 A further issue raised by State Hospital staff concerned the mix of people with mental health problems and those with learning disabilities and/or ASD not just on the same site, but in some cases on the same wards. It was suggested that not only may people with learning disabilities be vulnerable to exploitation by other patients on a mixed ward, it may also mean they do not have the same access to specialist resources as people on the learning disabilities unit.

7.16 Some of these same arguments were used both in relation to women on the State Hospital site in general, and women with learning disabilities and/or ASD in particular. It was suggested that the majority of women did not require to be cared for in conditions of high security, but needed “special intensive care”.

7.17 On the one hand it was suggested that mixing women with learning disabilities and/or ASD and those with mental health problems on the one ward for women on the State Hospital site meant that women with learning disabilities were not further marginalised or stigmatised. On the other hand, their different care needs could pose significant management problems for the clinical team. As one respondent commented:

“The ward has 12 women who have mental illness and 3 or 4 with a learning disability which pulls the Team apart in terms of skills and models of care. It is difficult in a clinical setting.”

7.18 The routes by which women are admitted to the hospital are also dissimilar. Unlike women with mental health problems, women with learning disabilities and/or ASD are far less likely to come through the criminal justice system.

7.19 As a result the State Hospital resources designed with one set of needs and one gender in mind i.e. men with mental health problems, have to be adapted, not just for women, but for women with learning disabilities and/or ASD.
Other health care settings

7.20 Out of a sample of 20 people in in-patient units for people with learning disabilities for whom case recording forms were completed only 4 were felt by staff to be inappropriately placed. Within this group the environment was felt to be producing disbenefits for 2 people either because it was more restricted than the one from which they had been transferred, or because they were learning inappropriate behaviours. The remaining 2 people were felt to be inappropriately placed because of specific needs such as challenging behaviour.

7.21 For one additional person the placement was felt to be appropriate for meeting their healthcare needs and for the managing their challenging behaviour, but because of their autism they were felt to require a placement in a specialist unit.

7.22 Of the 6 people with learning disabilities and/or ASD in the psychiatric units, 4 were felt by staff to not be in the right place. In 2 cases it was stated that this was specifically because the units concerned were not set up for, or staff trained in, learning disabilities. The remaining 2 people were felt to need a different living environment: one in the community and one in a secure but more domestic setting.

7.23 A distinguishing feature of the 2 people for whom the environment of a psychiatric unit was felt by staff to be appropriate was that both had ASD. It is too small a sample to draw conclusions, but it may suggest that in-patient psychiatric units feel they have more to offer people with ASD, particularly Asperger’s or high functioning ASD, than they do for people with a learning disability.

Discussion

7.24 The ‘appropriateness’ of all of the selected secure settings hinges on 2 overlapping dimensions: context and resources. ‘Context’ relates to the perceived core role or function of the secure setting, and the extent to which people with learning disabilities and/or ASD fit into the institution’s ‘core business’. The data suggest that there are a number of ways in which people with learning disabilities and/or ASD do not fit in to the secure environments within which they are placed. For example:

- In non-healthcare environments whose core functions such as providing custody, addressing offending behaviour or providing a secondary education are designed around the needs of the majority population who do not have a learning disability and/or ASD
- Healthcare settings in which the focus is on mental illness
- People with learning disabilities and/or ASD in a healthcare setting such as the State Hospital which may provide care in conditions of security higher than required
- Women with learning disabilities and/or ASD across all the secure settings for adults
- Children, young people and adults with ASD across all secure settings
On the basis of the evidence it could be argued that across the selected secure settings, people with learning disabilities in general, and women and people with ASD in particular, are on the periphery, or borderline, rather than the central focus of these environments.

7.25 Respondents perceptions of the appropriateness of an environment may also depend upon what is or is not available ‘in-house’ and what is or is not available outwith the secure setting. For example, respondents described the State Hospital or prison as appropriate in the absence of suitable alternative accommodation outwith these environments: a second best, if not a best fit.

7.26 Given the ‘minority’ status of people with learning disabilities and/or ASD across the different secure settings, the following sections explore in more detail the resources the different environments can draw upon to meet the needs of this group of people and also the gaps in provision.

MEETING NEEDS IN SECURE SETTINGS: ADAPT TO PROVIDE

7.27 The resources available in each setting include ‘direct’ services such as the availability of appropriately trained staff, activities and therapeutic interventions, and ‘indirect’ services, for example, the physical and social environment, the time made available for individuals and the awareness and understanding of staff.

7.28 Within each setting the particular configuration of direct and indirect resources will be distinct, though the needs they address may be similar.

Meeting need in the prisons

Services to meet needs

7.29 At the time of the study all the prisons had a healthcare centre and 11 of the 16 had a mental health team. The mental health teams comprised health care centre staff, for example RMN and RMHN trained nurses, social work staff, prison medical officers and visiting psychiatry. Day care places for vulnerable prisoners were available in 3 prisons, and in the process of being developed in one. In-patient beds, including observation cells in the prison health centre were available in 6 prisons.

7.30 The majority of prison nursing staff, whatever their specialist backgrounds, were employed as practitioner nurses undertaking the range of generic healthcare duties. However, over one-half of the prisons had health care staff with training or expertise in learning disabilities and/or ASD, the majority of whom were nursing staff. Although functioning as generic nurses their specific expertise or skills may still be utilised. One prison, for example, described the RMHN as a “well used resource…able to contact practitioners outside and [know] what questions to ask”. Another prison had appointed a number of RMHNs who were not only able to assist in the identification and assessment of people with learning disabilities, but also to work with them and with prison officers to provide support.
7.31 Across the prisons the core direct care for people with learning disabilities and/or ASD was the support provided on a day to day basis by the prison health care staff, whether acting as ‘generic’ nurses or in their role as members of a prison mental health team. This is illustrated by the case recording form data. Physical health care, for example for epilepsy or asthma, was provided by the prison health care staff. Mental health care needs were being met by members of the health care staff functioning as a mental health team. This care might include one to one counselling or “on going support: brief intervention”. For one person whose behaviour included banging on their cell door for 4 to 5 hours nursing staff provided “diversional therapy”.

7.32 The procedures relating to ACT, the prison service suicide prevention strategy, had been applied in relation to a number of the sample who had a history of self-harm.

7.33 One prison had set up a day care group run by an OT and a prison officer to help people who find it difficult to understand prison routine. The group included people with learning disabilities.

7.34 To address offending behaviour another prison ran an adapted programme for sex offenders. The programme was intended for people who were unable to take part in the core sex offenders programme STOP, because they had an assessed IQ of less than 80. In another prison the forensic psychologist had undertaken one-to-one work on anger management with 2 women with learning disabilities.

7.35 Social welfare needs were met by the prison social work departments, particularly in terms of planning for liberation, but also, as in one case, for “constant reassurance”. In this case the prison social worker was responding to referrals being made by the person “virtually every day”. In addition the social worker had had a lot of contact with the community-based social worker for the prisoner’s ex-partner.

7.36 The prison based learning centres or education departments were seen as responsible for meeting education/training needs. Within the sample one person whose needs were identified as “structured participation in educational routine” was taking part in education “enjoying mainly creative activities”. Although it had not occurred in practice the education centre in one prison described how it would be able to draw on the resources of the parent college’s Access Centre if someone with a learning disability needed special input.

7.37 Several prisons described how they would aim to tailor interventions or activities to meet the individual’s needs or in ways the person would understand. This is illustrated in the account of one prison health care respondent:

“If [someone has] a learning disability or is vulnerable it can be difficult to find something appropriate. So [we] hold a case conference or identify specific needs and identify appropriate activities e.g. craft shops, specialist painting jobs, physical work placement, simple work placement...so can find a range of individual and structured routines they can cope with and can change activities until we find one thing that suits. [We] can split the routine over a week so they...
can attend education on some days, work programmes and activities on other
days. So routine can effectively become the course of treatment.”

7.38 Respondents in 2 other prisons described how people with learning disabilities might be
given more “sheltered” jobs such as “passman” or cleaning jobs. These tasks perform the dual
function of enabling people to get out of their cells, but also brought the individuals into contact
with staff “so they won’t be bullied” by other prisoners.

7.39 Indirect resources include accommodating people in protection or segregation wings, or
in the health centre, for part or all of the day, if they are unable to cope with a mainstream hall.

7.40 The one ‘resource’ that respondents across prisons and disciplines felt people with
learning disabilities and/or ASD needed was time. Nurses described how they would spend time
trying to explain things, or help people, whose retention of information may be poor, to
understand things. A social worker described the need for “patience”. In one health centre time
was seen as perhaps the only specific resource that was made available for people with learning
disabilities:

“[Nurses] look after individuals’ basic health, attend ACT case conferences,
supervise their medication and will see them if they have other problems. But
that’s it. Otherwise they get the same as other prisoners. But if issues arise they
will spend a lot of time with them.”

7.41 Another health care respondent suggested that while people with learning disabilities
and/or ASD comprised only a small percentage of the total prison population they needed a
disproportionate amount of nursing input.

Service gaps

7.42 The problem is that time and patience may be in short supply.

7.43 However committed to meeting the needs of this client group staff within the prisons may
face competing imperatives. Health care staff in several prisons commented that the size of the
prison population did not give scope for intensive input. One prison healthcare respondent made
the point that:

“[Nurses] will spend more time with both men because of their problems. So
will their Personal Officers, but it is limited. There may only be 2 nurses on
duty to provide for 320 prisoners.”

7.44 As this comment suggests, the impact is not just on healthcare staff, but on prison
officers. Personal Officers, allocated to convicted prisoners on long sentences for sentence
management, may spend longer with someone with a learning disability and/or ASD, but they
may also have responsibilities towards 5 other prisoners. Hall, or wing officers, too may have
limited capacity to respond to the specific needs of people with learning disabilities:
“There is such a pressure on staff to deliver other things that they can’t put in the level of input that people need. So, if they are working with someone who needs constant watching and the staff member has to go off to do something else, then the person may have to be locked up because they don’t have that level of resource intensiveness.”

7.45 As a result, people with learning disabilities and/or ASD are at risk of losing privileges available to other prisoners, not because of indiscipline, but as a result of needs arising from having a disability.

7.46 The other component of ‘time’ relates to the length of time people are in prison. For people on remand or short sentences there is even less scope for services to respond. Several people, for example, were described on the case recording form as having a whole range of social welfare and education/training needs but “due to short sentence few can be addressed”. For women, in particular, the short time periods they were in prison precluded what could be usefully provided by the different resources such as education, psychology and nursing.

7.47 Respondents also felt that there was a lack of expertise to draw on. Several mental health trained nurses felt that “lacking a background” they did not know what treatment would be useful for a prisoner with learning disabilities. They suggested that this was an area where an RMHN would be helpful. Three people were felt by staff to need input from forensic learning disability nurses to help them address their mental health needs, but this service was not available.

7.48 A further direct care service gap identified was the lack of clinical psychology input both for assessment/diagnosis and for treatment.

7.49 It was not just specialist clinical expertise that was identified as a gap, but a need for greater awareness of learning disabilities and/or ASD across staff groups within the prisons. Several prison health care respondents, for example, made the point that awareness of learning disabilities and/or ASD needed to be greater among prison officers. RMHNs in several prisons described how they would advise hall staff on how to communicate with someone with a learning disability so that they would understand what was expected. Without this level of understanding officers might take “firmer action”, or people may become “alienated” by other staff. As commented by health centre staff in one prison:

“The [hall staff] have a difficult enough job but dealing with those that don’t learn makes it even more difficult. There is a possibility that the 2 men are alienated by other staff.”

7.50 A further service gap relates to the generic programmes used within the prisons to address offending. Using group methods, and written work, the programmes were not suitable for people with learning disabilities (or for people who are unable to read and write). Even the Adapted STOP programme for sex offending was not suitable for everyone. As described by one prison officer:
“One person had a low IQ and was impulsive but had limited retention. It was unfortunate because he was keen, wanted to change, but it proved difficult in practice.”

7.51 Other programmes may be available at different times, in different prisons, to address different offence related needs, including, anger management, relationships, alcohol, cognitive skills and the social work programme ‘Breaking the Cycle’ for sex offenders against children. None, however, was adapted for people with low IQs or who could not read or write.

7.52 Unable to address their offending behaviour, the risk of recidivism may be higher: with implications for the person with learning disabilities and/or ASD and, potentially, for society.

Filling the gaps

7.53 Several prisons referred to the lack of policy or anything “written down” to help them address the specific needs of people with learning disabilities and/or ASD. One health care centre described how they “used mental health care and adapted best principles in relation to the individual”. In different ways respondents expressed a need for a defined policy, both as a way of ensuring the availability of resources and to increase awareness across the service.

7.54 A need for specialist input, for example a clinic, or direct links with psychiatric specialists in learning disabilities was felt to be required, and more opportunities for one to one working.

7.55 Respondents in 2 prisons, however, proposed more radical options. Staff in one prison suggested that what was needed was a separate hall within the prison for people with learning disabilities and/or ASD and for people with acquired brain injury. This would have access to different programmes and interventions and have a different regime. In a second prison it was felt that what was needed was a “halfway house” between the conditions of high security of the State Hospital, and local secure units, providing one to one individualised care in a secure environment.

7.56 Both suggestions beg a number of questions, not just practical ones, but also broader questions of social justice and social inclusion for people with learning disabilities and/or ASD. Nonetheless they do reflect the concerns of the respondents about the capacity of the prisons to be able to adapt available generic resources to meet the needs of this ‘minority’ population.

Meeting needs in secure accommodation for children

Services to meet needs

7.57 Of the 4 secure care units for children responding to the unit recording forms, 3 had staff who were believed to have training or specialist expertise in learning disabilities. This included a clinical psychologist and educational psychologist, a forensic psychiatric nurse and 2 teaching staff.
7.58 Data from the unit recording forms, case recording forms and site visits to 2 secure accommodation units suggest that to meet the specific needs of children or young people with learning disabilities and/or ASD the secure accommodation units would draw on generic or adapted generic resources, modifying what was already available rather than drawing in specialist learning disability services. For example, there is no reference to referrals to community learning disability teams. Modification or adaptation would also extend to ‘indirect’ resources such as time and styles of interaction.

7.59 In relation to mental health needs, for example, the approach might include referral to a CPN, psychiatrist or community mental health team, as well as additional care staff supervision. For example, one secure accommodation unit described allocating 3 staff to work with one young person with learning disabilities and mental health needs as a way of trying to establishing communication with the individual.

7.60 To meet physical health care needs, the secure units would use in-house health care such as the unit’s nurse, or a local health centre, or make a referral to a “paediatrician with responsibility for looked after children”. One nurse commented that although in terms of health care tasks, such as the administration of medication, what they did was no different, they did give “special attention” to the children with learning disabilities and/or ASD. The nurse gave them more time to help them “work through their fears”.

7.61 To meet educational and offending-related needs ‘tailor made’ packages or one to one working were described.

7.62 The approach to children with learning disabilities and/or ASD therefore appears to be one of ‘mainstreaming’, albeit within the segregated environment of secure accommodation. Within the expressed ethos that “every young person is an individual” the needs of a person with learning disabilities and/or ASD may be regarded as no greater, or no more complex than that of any other young person referred to the secure accommodation unit. One member of care staff remarked:

“All the young people exhibit unpredictable behaviour with some violence or aggression, in some cases worse than those with learning disabilities. Someone with a learning disability would not be treated any different, the care plan is geared towards the young person, their own strengths and needs.”

7.63 The question that remains is whether the apparently limited input from specialists in learning disabilities or ASD has implications for the child or young person in both the short and longer term. In the short term there may be scope for specialists to provide advice or consultation on the management of challenging behaviours. In the longer term staff commented on the lack of equivalent resources available to people once they leave the supportive environment of the secure accommodation unit. Linking a child or young person with learning disabilities and/or ASD with local specialist resources may help to facilitate continuity of care.
What is needed

7.64 The service gaps identified by the secure accommodation units included the level of resource available for intensive and one to one working.

7.65 As in the context of the prisons the need to adapt programmes was raised. For the secure accommodation units, though, this means not just adapting programmes for people with learning disabilities, but for younger people in general. One secure accommodation unit in the sample had been awarded funding specifically to develop programmes for adolescents.

7.66 The third gap identified by the secure units was the reduction in the level of therapeutic input for people once they moved on:

“The problem [we are] creating for the future is that we are able to bring young people up to a level of stability to the degree that we can produce measurable change. But it falls to bits when they leave because they are moving to environments which are not similarly therapeutic.”

Meeting needs in the State Hospital

Services to meet needs

7.67 As might be expected, there is a concentration of expertise available on the specialist ward for people with learning disabilities on the State Hospital site. A clinical nurse specialist in learning disabilities (CNS) and a Clinical Psychologist specialising in learning disabilities had recently been appointed to the clinical team. The Consultant Psychiatrist, OT and social worker covering the ward were both specialists in learning disabilities. The number of nurses on the ward with RMHN training was, however, comparatively low, comprising only 5 to 6 out of a complement of 26. The majority of nursing staff were RMN trained. Plans were in place to increase the number of learning disability trained nursing staff. Respondents described the “challenge” of trying to recruit people with this expertise prepared to work in a high secure setting and a “mental health context”.

7.68 In addition to the specialist ward the Consultant Psychiatrist, Clinical Psychologist and CNS also provided a service to the women’s ward and rehabilitation unit, both of which support people with learning disabilities and/or ASD. It was, however, suggested that “there is no proper support for staff” on the other State Hospital wards which have patients with learning disabilities and/or ASD.

7.69 Historically, the hospital-wide Patient Activities and Recreation Service (PARS) has tended to gear its activities towards the predominantly male population with mental health problems. It was though, increasingly tailoring services to the needs of people with learning disabilities and women both at a group and individual level. PARS vocational unit staff were also contributing to individual treatment plans in ways that had not occurred in the past.
7.70 The Psychological Therapies Service also provides a hospital wide service, but like PARS has tended to gear this towards people with mental health problems. In response, adapted programmes had been developed and were being run by staff on the specialist ward for people with learning disabilities. The first set of adapted programmes focused on sex offending and anger management. Dialectical Behaviour Therapy had also been introduced, initially on to the women’s ward, to address self-harming behaviour. The programme is suitable for men and women with learning disabilities.

7.71 A ‘positive programme approach’ was beginning to be developed both on the specialist ward and on the women’s unit. Following a visit to the US to look at the Institute of Applied Behaviour Model employed by LaVigne and colleagues (1989) it was hoped to adapt this model to meet the behaviour-related needs of one person.

7.72 Interviews with key workers and with individual patients did reinforce the sense of people being engaged in a range of different activities: work related, social, educational and therapeutic. As described by one person interviewed:

“I work in the patients’ shop, in the garden, woodwork, arts and crafts and school.”

7.73 Case recording form data gives a more detailed picture of how secure settings attempted to meet the needs of individuals with learning disabilities and/or ASD

7.74 Physical health care would be “monitored” and needs met by the on-site health centre. Although “well-served” the view was expressed that the service was “not necessarily sensitive to learning disabilities”. Recognising that the health care needs of people with learning disabilities are “unique” the specialist ward was looking at ways of improving the service.

7.75 Beyond reference to the role of clinical teams or the “special service of the State Hospital”, little information was provided on the mental health needs of people with learning disabilities and/or ASD or on service responses. It may be that in this context such needs are regarded as self-evident, or not distinguished from the range of clinical needs an individual may present, including offending behaviours.

7.76 To meet the range of offence and other behaviour-related needs reference was made to the psychological therapy groups. Difficulties were, however, experienced in relation to meeting the behaviour-related needs of one person in the sample who had autism.

7.77 A similar comment was made in relation to meeting the social welfare needs of a patient with autism. In other ways social welfare needs, including, for example, family contact were felt to be “fully met”.

7.78 Although patients had access to on site education services to meet education or training needs the service does not include specialist teachers. The perception held by some healthcare staff was that the service struggled to meet the needs of people with learning disabilities and those with autism.
Service gaps

7.79 To meet the “unique” needs of people with learning disabilities and/or ASD the State Hospital had augmented specialist services and sought to adapt generic resources. Respondents, however, drew attention to what they saw as continuing service gaps or obstacles to meeting needs. Some of these barriers relate to what can be made available on the State Hospital site, others reflect what is, or is not, available for people outwith the State Hospital.

7.80 As a ward for 26 people the specialist unit for people with learning disabilities was felt to be too large. This raised “living together” or risk related issues. This, it was suggested, was compounded by the comparatively low staff patient ratio of 5:26. Both this ward and the ward for women also had to combine the potentially competing functions of admission, continuing care and discharge preparation.

7.81 The combination of people with learning disabilities and/or ASD with people with mental health problems on site and in wards was described above in the discussion concerning the appropriateness of the environment. What it has meant is that site-wide ‘generic’ services have had to be adapted to meet the needs of people with learning disabilities and/or ASD.

7.82 As was suggested in the context of physical health care and education/training needs there may be limits to adaptability for people with learning disabilities in general, and those with ASD in particular. For example, a class may attempt to teach people how to tell the time to individuals who have no concept of time.

7.83 Even where generic services are adapted they may not be so readily available to people with learning disabilities and/or ASD on some of the mental health wards.

7.84 In terms of social welfare needs, structural factors may impede greater involvement of families. At a strategic level it was suggested that the very fact of being on the State Hospital site meant that access to family and carer involvement was not as high as the service would like for people with learning disabilities and/or ASD. At a practical level, financial constraints may limit family and carer contact. Although funds are available one relative described the financial drain of visiting, particularly since funds for petrol money appeared to have been reduced. For people coming from Northern Ireland the barrier may be raised further by the discretionary nature of payments from the Social Fund to meet travel expenses.

7.85 The perceived service gaps outwith the State Hospital reflect the lack of resources, or an infrastructure, to which people who no longer require to be cared for in conditions of high security can move. The perceived need was not just for an appropriate physical environment, but an appropriate therapeutic and social milieu. The view was expressed by State Hospital respondents that people moving to local secure units may have fewer activities and services available to them than is available on the State Hospital site.
What is needed

7.86 State Hospital staff felt that what was required was a range of resources outwith the hospital providing: an appropriate level of security; access to a range of activities and interventions; linked with a range of housing, education, training and employment resources. This, it was suggested, would not only provide opportunities for people to move on from the State Hospital, but also prevent people being admitted to the hospital in the first place and acquiring the stigma which may exacerbate their social exclusion.

Meeting needs in other health care settings

Services to meet needs

7.87 The in-patient units for people with learning disabilities have a range of specialists in learning disabilities on which they can draw including O.Ts, speech and language therapists, physiotherapists and art therapists. Some staff in these units also have forensic expertise or training.

7.88 By comparison, the unit recording form information provided by the psychiatric units appeared to suggest that the resources available to people with learning disabilities and/or ASD on these units were much more limited. However, analysis of the case recording forms illustrates the diversity of resources which the psychiatric units drew on to meet the needs of specific individuals.

7.89 In learning disability and psychiatric units physical health care needs would be met by ward medical and nursing staff, GPs or specialists such as dieticians. Learning disability units also referred to the availability of well women’s clinics, specialist women’s health and men’s health screening and health promotion.

7.90 People in both types of unit were identified as having mental health needs, including problems relating to alcohol abuse. In learning disability units resources to meet these needs included use of medication, 24-hour supervision, or referral to specialist resources such as a local alcohol misuse service. The psychiatric units would draw on ward medical and nursing staff, as well as referral to specialists in, for example, Cognitive Behaviour Therapy (CBT). One unit described as a resource the specific practices they employed with one person “Uniformity of approach: not invading personal space”.

7.91 To meet offending or other behaviour related needs the learning disability units would use a combination of protective and therapeutic approaches. For example, the response to the physical, mental health and offending-related needs of one person was “24-hour supervision to ensure the safety of others”. In other cases the service responses included “structured programme of activities”. In several cases the protective and the therapeutic were combined; “MDT [multi-disciplinary team] ensure treatment/therapeutic programmes in place to ensure person and others’ safety”.

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7.92 On the basis of a very small sample the response of the psychiatric units to offending and other behaviour-related needs was very individualised. The responses ranged from referral to a specialist learning disabilities group, making available psychology, CBT and group work, and, in one case, joint working with a care manager and voluntary organisation to undertake offence specific work together with a “multi-agency communication and support package”.

7.93 For people on both the learning disability and psychiatric units the common social welfare needs identified by staff were isolation and being misplaced.

7.94 For some people on the learning disability units isolation arose from limited family contact. It is not known, how, if at all, this need was being met. For 5 people the social welfare need was for a community-based placement, or ‘step down resource’. These resources were not currently available for any of this group.

7.95 For people with learning disabilities and/or ASD in the psychiatric units isolation and being misplaced take on a different meaning. For one person with learning disabilities the 2 were combined insofar it was felt that the individual needed to be with a “peer group of similar ability”. Although attending a therapeutic group for people with learning disabilities on another unit it was felt that this person needed a “range of social and leisure opportunities with more suitable people”.

7.96 For one person with ASD on a psychiatric unit whose social welfare needs included domestic skills acquisition as well as social isolation, a social care worker had been made available together with involvement in a social group for autistic people.

7.97 A number of people in the learning disability units had identified education/training needs. These were met by OTs, a day hospital and ward staff. In a number of cases this was in the context of a perceived lack of community based education opportunities.

7.98 For people in the psychiatric units the identified education need was for a structured daily programme. This was met by OT led activity programmes or, in one case, a correspondence course. For one person with ASD the identified language and communication difficulties were met by “staff experienced/trained in ASD”.

Service gaps

7.99 Just on the basis of the unit and case recording forms it is apparent that the perceived service gaps or obstacles to meeting needs mirror those identified by State Hospital respondents.

7.100 As already noted for a number of people in the learning disability and psychiatric units the significant ‘gap’ identified by respondents was the lack of appropriate supported ‘step down’ or community based accommodation. In effect this is the second pressure point along the care pathway for people with learning disabilities and/or ASD in secure in-patient care. For some people the absence of move on resources may mean that at some point they are re-routed to a mental health pathway: an environment which may be able to provide care, treatment and support, but which staff may feel leaves the individual socially isolated.
7.101 Other gaps identified by the learning disability and psychiatric units gaps included the lack of interventions and opportunities specifically geared to the needs of people with learning disabilities and/or ASD. For example, to address alcohol misuse, or provide adult education and work opportunities. These problems can be compounded for people with ASD.

7.102 Even where resources are available the extent of input available may be circumscribed in terms of, for example, the number of clinical psychology sessions available or the amount of funding available for social care support for someone placed on a psychiatric unit.

EXAMPLES OF PRACTICE

7.103 Across the secure settings the key strategy for meeting the needs of people with learning disabilities and/or ASD is to adapt whatever is available. Since the study does not address outcomes it is not possible to assess how successful these strategies are. It is though possible to identify examples or accounts of practice that illustrate a sensitivity to individual needs.

- One prison described how they would try and test out different activities until they found something that suited the individual and with which they could cope
- One secure accommodation unit allocated 3 staff to one person to develop a relationship and establish communication
- In relation to people with ASD on the specialist State Hospital unit for people with learning disabilities nursing, OT and PARS staff were working together jointly to develop individualised programmes of activity
- One in-patient unit for people with mental health problems described a joint package of care involving the ward and primary health care staff, criminal justice social work and voluntary organisations to support someone with ASD. The package, which involved the use of CPA included a discharge plan put in place jointly with the local autistic society

DISCUSSION

7.104 This overview does not do justice to the efforts of the secure settings to meet the very specific needs of people with learning disabilities and/or ASD. Nonetheless, 3 very clear themes emerge which suggest that meeting these needs poses a challenge for all the units, with implications for the individuals for whom they are responsible.

7.105 First, with the exception of the learning disability specific units, people with learning disabilities in general and ASD in particular do not fit easily into what is perceived to be the core business of the different secure environments. There is a pervading sense that somehow people with learning disabilities and/or ASD would have their needs better addressed ‘somewhere’ else. The perceived inappropriateness of the environment stems, on the one hand, from a lack of available and appropriate resources to meet the specific needs of this ‘minority’ group. On the other hand the nature of the environments can make the individual vulnerable to exploitation, abuse or bullying from their non-disabled peers and/or leave them socially isolated.
7.106 This sense of ‘otherness’ is compounded in relation to people with ASD, in relation to whom even the learning disability units may be struggling to adapt services.

7.107 Adult women with learning disabilities and/or ASD also emerge as a minority within a minority for whom there may be even fewer options than for men.

7.108 A second theme, following on from the first, was the perceived lack of resources outwith the secure settings, either to prevent admission to a secure unit, or provide a move on or ‘step down’ resource for someone who no longer requires the level of security of a particular setting, or has come to the end of a sentence or order. When implemented in May 2006 sections 264 - 271 of the new Mental Health (Care and Treatment) Scotland Act 2003 will provide people with an opportunity to appeal against being detained at a level of security greater than required. This may create a further pressure to develop alternative community based services.

7.109 For people in prison or on a hospital or restriction order, or on remand and not convicted, the significant issue may be the availability of support on liberation. The following chapter pursues this in more detail.

7.110 The third key theme is the way in which, within the resources they have available the different settings respond to the individual needs of people with learning disabilities and/or ASD. The data suggest 3 strategies are employed: bringing in or deploying specialists in learning disabilities; fitting people into ‘generic’ resources; or adapting ‘generic’ resources. ‘Generic’ here refers to the services available to the majority population.

7.111 The first strategy is one to which secure settings appear to have least frequent recourse. Outwith the learning disability-specific units and the State Hospital it is not surprising that few of the units have in-house or visiting specialists. Although people may be referred to specialists for assessment/diagnosis or with a view to transfer, there does not appear to be any on-going dialogue with specialist agencies or providers. The one exception was in relation to an individual with ASD in a psychiatric unit. In this instance the unit drew in the expertise of the local autistic society.

7.112 Adapting ‘generic’ resources, such as programmes to address offending or to meet education, activity or social needs is the most frequent strategy across the units. Here a number of units appeared to be innovative in putting together programmes or packages that were responsive to group or individual needs. There is also a case for saying that by adapting what is available, rather than providing something ‘special’, the individual is not further excluded. The difficulty is knowing how successful, in terms of outcomes such approaches are. A similar argument can be made in relation to the use of ‘generic’ resources, such as in-house or site wide education services or giving people less complex tasks.

7.113 Few of the resources described were felt by respondents to be able to meet the specific needs of people with ASD.

7.114 The accounts of the ways in which different settings attempt to meet the needs of people with learning disabilities and/or ASD raise a number of issues. First, the evidence raises
questions concerning equality of access to resources. This applies not only to what is available to people within different types of secure setting, but also how this compares with what is available to people with learning disabilities and/or ASD in the community. Second, there are questions about the outcomes the different settings are able to effect. If, for example, the prisons do not have the resources to help people with learning disabilities and/or ASD to address their offending behaviour does this increase the likelihood of the person re-offending and returning to prison? Third, the findings suggest that there is a risk that in seeking to protect people with a learning disability and/or ASD in environments not geared to their needs that individuals may experience indirect discrimination or even potential infringements of their rights. For example, by depriving someone of opportunities for freedom of association in a prison because of their need for supervision or because they may be vulnerable to bullying; or caring for someone in a health care setting in conditions of higher security than they need because of the lack of appropriate services to enable them to move on; or keeping someone in a closed prison while in custody rather than moving them to an open prison which may not have the resources to care or protect them. These are questions which are beyond the scope of the study to answer, but which may require further consideration at policy, planning and service levels.

KEY POINTS

Appropriateness

- The perception among prison-based professionals interviewed was that, in general, the prisons were not an appropriate environment for people with learning disabilities and/or ASD. The view expressed was that the prisons had neither the resources nor the expertise to meet the needs of this group of people.

- The responses of professionals within 2 secure accommodation units suggest that different units use different criteria upon which to judge the appropriateness of the environment for children or young people with learning disabilities and/or ASD. These criteria may relate to the severity of the disability or a child or young person’s particular combination of needs.

- The State Hospital respondents suggested that very few people with learning disabilities and/or ASD required conditions of high security. To meet the needs of this group of people efforts had been made by the hospital to enhance the service through the appointment of additional specialists and adapting programmes.

- Women in general, and women with learning disabilities and/or ASD in particular were felt to be inappropriately placed in the high secure environment of the State Hospital. The need to mix women with mental health problems and those with learning disabilities on the one women’s ward was also felt to be less than satisfactory.

- The majority of people in the in-patient learning disability units were felt to be appropriately placed. There were, however, a small number who were felt to need ‘step down’ or community placements.
• People with learning disabilities and/or ASD on psychiatric units were felt to be inappropriately placed either because of the lack of specialist skills available or because they too required a community placement

Resources

• Within the prisons the resources to meet the needs of this group of people included the time made available by staff, particularly health care staff, and the attempts to find activities to engage them and with which they could cope

• There, were though limits to what the prisons could provide. As a result people with learning disabilities and/or ASD may find they are locked in their cells for periods to ensure they are protected, they may also not have an opportunity to address their offending behaviour

• To meet the needs of children and young people in secure accommodation the approach was to adapt generic resources including teaching, programmes and health care. There was little evidence of direct input from specialists in learning disabilities and/or ASD

• Gaps identified by the secure accommodation units included resources for intensive input, the need to adapt programmes, and the reduction in the levels of support available to young people when they move on from the units

• Within the State Hospital the specialist unit for people with learning disabilities, the women’s unit and rehabilitation unit had access to psychiatric, psychological, nursing and social work expertise in learning disabilities. Hospital wide services including the Patient Activity and Recreation Services were increasingly tailoring services to meet the needs of people with learning disabilities and/or ASD. Adapted psychological intervention programmes had recently been developed and introduced

• For State Hospital respondents the perceived obstacles to meeting the needs of people with learning disabilities and/or ASD included: the high number of people accommodated on the one ward for people with learning disabilities and/or ASD; the need to support both people with mental health problems, who form the majority, and people with learning disabilities and/or ASD on the same site, and in some cases on the same wards; and the use of some generic services which may be less sensitive to the needs of this client group. For staff, however, the significant gap identified was the perceived lack of appropriate community-based facilities for people to move on to from the State Hospital

• In-patient learning disability units had access to a wide range of professionals with specialist learning disability expertise

• Although not drawing on the same range of specialists, the psychiatric units appeared to have developed very individualised packages including social work and voluntary organisation input
• One service gap identified by learning disability and psychiatric units was the lack of appropriate accommodation to enable people to move on.

Three themes emerge from the overview of ways in which the settings meet needs of people with learning disabilities and/or ASD:

• First, that people with learning disabilities in general, and women and people with ASD in particular, do not fit easily into what is perceived by respondents to be the core business of the different secure environments

• Second, respondents perceived there to be a lack of appropriate resources outwith the secure settings

• Third, different strategies are used to respond to the needs people present: using specialist resources; using generic resources; and adapting generic resources
CHAPTER EIGHT MOVING ON: THROUGHCARE AND AFTER CARE

8.1 In chapter 7 it was suggested that the appropriateness of the different secure settings for people with learning disabilities and/or ASD hinged not just on the resources available ‘in-house’, but also on the availability of appropriate resources outwith these settings. The availability of appropriate community-based resources to meet both the risks posed and the vulnerabilities of individuals in this group also has implications for throughcare and after care planning and provision. This chapter explores these implications in more detail. ‘Throughcare’ relates to preparation for moving on and ‘after care’ to longer term support.

THROUGHCARE AND AFTER CARE PLANNING

Prison throughcare and after care planning

8.2 Of the 16 prisons responding to the unit recording forms 12 felt that discharge/release planning worked well. This may, however, reflect discharge planning processes in general since a number of the prisons responding had no recent experience of release planning for anyone with a learning disability and/or ASD.

8.3 At the time of the study arrangements for throughcare and after care effectively divided prisoners into 2 groups. First, those subject to statutory supervision by criminal justice social work on release. This includes people serving sentences of over 4 years and those serving extended sentences or subject to Supervised Release Orders who serve less than 4 years but who are subject to statutory licence on release. The second group comprises people serving less than 4 years who are not subject to statutory post release supervision. This group is entitled to request advice, guidance and assistance from local authorities in the 12 months following release from prison.

8.4 The case recording form data for prisoners with a learning disability and/or ASD present a very mixed picture, reflecting not just the different arrangements for those subject to statutory licence and those entitled to voluntary aftercare, but also the difficulties of planning for someone on remand.

8.5 Of the 9 people in the prison sample a discharge plan was said to be in place for one person who was about one-third of the way through a 16 month sentence. In a further case the discharge plan was “in process of being developed”. For a further 3, including one person on remand, there seemed to be a degree of planning, if not a plan, judging from the responses to a question concerning the professionals involved in discharge/release planning.

8.6 Of the remaining 4, one person was on remand and the remainder had recently commenced sentences spanning from 3 to 10 years.
8.7 The data from the case recording forms and site visits suggest there are broadly 2 approaches to discharge planning and implementation: informal and formal. These partly, but not entirely, reflect the division of prisoners into those receiving statutory after care and those eligible for voluntary after care. Neither are specific to people with learning disabilities and/or ASD.

**Informal mechanisms for throughcare and after care planning**

8.8 ‘Informal’ mechanisms include the arrangements for individuals on remand and those eligible for voluntary after care. For people on remand the comment made on one case recording form was that it was not appropriate to prepare a discharge plan because of the potential for the person to be released at any time.

8.9 For people entitled to voluntary, but not statutory after care, ‘planning’ may be comparatively ad hoc. Health care or social work may seek out contacts in the area to which the person was returning. These contacts may be between prison social work and local social work and/or other local agencies or by prison health care staff with local agencies:

> “Sometimes it’s the health care nurses who are used to find outside support, sometimes its social workers, sometimes they work collaboratively.” (Prison health care staff member)

8.10 The view from one medical respondent was that “a lot fell to nursing staff”. One prison social work department, for example, commented that “for someone on voluntary after care the health centre might recommend contact with SACRO” (emphasis added). Nursing staff gave examples of cases where they had spent time trying to get someone supported accommodation, or arrange appointments.

8.11 Social workers would be involved with women prisoners where there were specific childcare issues.

8.12 For people with learning disabilities and/or ASD who are on remand, or who have committed less serious offences, the apparently unstructured nature of after care planning and limited move on resources can open up the possibility of people being discharged unsupported and at risk of re-offending. Drawing together issues of identification, throughcare and community resources, officers in one prison commented:

> “There could be opportunities for staff to be more active in identifying people and trying to find housing etc for them when they leave...It’s when people go out and there is nothing on the outside that the problems start...doesn’t matter if someone is an adult or under 21, there is nothing out there to help them, so they come back in on a revolving door.”
Formal mechanisms for throughcare and after care planning

8.13 While ‘informal’ planning approaches to throughcare and after care planning tend to be uni-disciplinary, the ‘formal’ and statutory are multi-disciplinary.

8.14 These ‘formal’ mechanisms are of 2 kinds: the criminal justice social work led process for people being released on statutory licence or supervision orders; and the health care led Care Programme Approach (CPA). Two prisons referred to the use of CPA. In one case it was in relation to someone with mental health problems, but in a second case a prison based RMHN was involved in implementing CPA for someone with learning disabilities. Although perhaps limited as evidence, these examples do illustrate the potential use of CPA as a mechanism for ensuring continuity of care for people with learning disabilities across and within institutions and agencies.

8.15 More frequently reference was made to the formal process of release planning for people leaving under licence. This involves multi-disciplinary case conferences, led by criminal justice social work, and involving different disciplines from within the prison and external agencies with responsibility for providing support on liberation. These may include specialists in learning disabilities. For one person in the sample, a Schedule 1 sex offender, this process was in the early stages at the time of the site visit, but was set in the context of what were described as “grave concerns”:

“Social work now in charge. Going to convene a case conference. Talking about an intensive care package because of the risks he poses both to himself and to others.”

8.16 Criminal justice social workers in 3 teams included in the study made the point that in developing release plans for individuals with learning disabilities an added concern was the degree to which people retained or understood information about their responsibilities and the requirements being placed upon them. One team for example commented:

“How can one say what the individual understands or retains – but this is important in terms of safety in the community.”

8.17 Two of these criminal justice teams, one prison based and one community based, made the point that without being able to understand what information the individual could retain and comprehend the risk for someone with learning disabilities was that they were effectively being “set up to fail”. One prison social work department described how, in relation to an individual who had committed a serious offence, the fact that they had a learning disability was highlighted in the course of release planning specifically because of the implications for how the person would respond to information. Efforts were made to ensure that the individual understood what was required of them. This included identifying a local agency to provide a ‘befriending’ service to work through with the individual and spell out what was expected of them under certain circumstances and the consequences if they failed to do this.
8.18 On the basis of the responses from the prisons current after care arrangements may mean that people committing less serious offences or on short sentences are at risk of returning due to lack of support outwith the prison. On the other hand, those going out on licence or under supervision may be at risk of returning to prison because they breach an order they do not fully comprehend.

8.19 In order to strengthen and extend current arrangements the report of the Tripartite Group (Scottish Executive, 2003) made a number of recommendations including: extending present arrangements for prisoners on Extended Sentences to all prisoners subject to statutory throughcare; prioritising voluntary after care for 3 groups including Schedule 1 offenders and sex offenders, young offenders and prisoners who have shown a commitment to addressing their offending; and formalising liaison arrangements between the Scottish Prison Service and local authority criminal justice social work services. When implemented these arrangements may indirectly benefit people identified as having learning disabilities and /or ASD: both as people subject to statutory licence, or because they come within one of the proposed priority groups for voluntary aftercare.

**Forward planning in secure accommodation for children**

*Forward planning*

8.20 Under Section 17 of the Children (Scotland) Act 1995 local authorities have a duty to provide advice and assistance to help prepare a child when he or she is no longer looked after by a local authority. Section 29 sets out the responsibilities of local authorities toward young people who leave care after school leaving age.

8.21 Of the 3 young people in secure accommodation for whom case recording forms were completed 2 had a discharge plan. A third young person had been assessed for transfer to another type of unit.

*Joint working in forward planning*

8.22 The data from the study suggest that the secure accommodation units are forward focused and proactive in terms of throughcare and after care planning. Further, that these processes are multi-disciplinary and multi-agency, including both unit and community-based professionals and providers. One unit, for example, described the regular review meetings, involving outside agencies and professionals, as a forum for putting together a throughcare plan.

8.23 The proactive role of the secure accommodation units in throughcare and after care planning, together with the emphasis on multi-disciplinary working emerges from the example given of one young person with learning disabilities on a probation order. An initial plan for 24-hour monitoring until the end of the probation period was felt to be inappropriate by the unit which drew attention to the young person’s therapeutic and long term needs. Working with the individual’s criminal justice social worker and adult social work department, staff were
successful in getting the person placed in supported accommodation. One practitioner involved in planning described how:

"Initially the only option proposed was a package focused on the sexual risk he posed….But the school and the criminal justice social worker argued up through social work management that he should go to [Supported Housing project] on the basis that his needs related to his severe learning disability – not the risk of offending. [Supported Housing project] would not only be able to manage the risk, but would also be able to support the development of his independent living skills. The school and criminal justice social worker were successful in getting the person placed in [Supported Housing project]."

8.24 What this example also illustrates is how the tension between the risk/offending behaviour and the vulnerabilities which stem from having a learning disability and/or ASD, identified in chapter 5 surface and continue into throughcare and after care planning.

**Discharge planning in the State Hospital and other health care settings**

*Discharge planning*

8.25 Of the State Hospital sample 9 out of 11 for whom case recording forms were completed had a discharge plan. Discussions had also taken place in respect of the remaining 2 people.

8.26 On units outwith the State Hospital discharge plans were “being developed” for 2 out of the 20 people in learning disability units, although some discussion seems to have taken place in relation to a further 5 people. The small numbers of people for whom some discharge planning had taken place may reflect the inclusion of assessment and continuing care wards: for the former it may be too early to consider plans for discharge; the latter, by their nature, may not anticipate people moving on, especially those who have already recently moved from another hospital.

8.27 Discharge plans were in place for 2 out of 6 people in psychiatric units.

*Joint working in discharge planning*

8.28 Within the State Hospital the decision to discharge is made by the State Hospital team, following which Consultant Psychiatrist to Consultant Psychiatrist negotiations begin with the relevant local area. Although multi-disciplinary, the majority of those involved in discharge planning for patients on the State Hospital site were professionals based within the hospital, although Community Learning Disability Teams were involved in 2 cases. The Scottish Executive also requires to be involved in relation to people on restriction orders.

8.29 A ‘Managed Forensic Mental Health/Learning Disabilities and Social Care Network’ was being piloted between the State Hospital and 3 health boards. This sets out the roles and responsibilities of different agencies at each stage of the patient’s journey, pre, during and on
transfer from the State Hospital. This may open up the possibility of greater involvement of external agencies in the process of discharge decision-making and planning.

8.30 In learning disability and psychiatric units outwith the State Hospital there appears to be a greater involvement by community based health, social work and housing agencies in the discharge planning process.

Mechanisms for discharge planning

8.31 For the majority of people in the State Hospital sample the discharge plan involved moving to another in-patient unit of lesser security, rather than direct to the community. One respondent remarked that “Moving straight from maximum security to community is a major challenge [it] requires a lot of work and huge packages of care”.

8.32 A number of mechanisms were in place or being developed to ensure continuity and joint working for people moving on from the State Hospital. CPA was increasingly being used, including for people with learning disabilities. In one case a local secure unit operated CPA as part of a process of admitting someone with Asperger’s syndrome from the State Hospital. To ensure that services would also be available once the person was ready to move on from the local unit the receiving Consultant Psychiatrist also involved the joint commissioners for the local service.

RESOURCES FOR AFTER CARE

Gaps in resources

8.33 As already outlined in chapter 7, across settings the key issue for respondents was the perceived availability of appropriate resources to support people once they were ready to move on from the secure environment.

8.34 The perceived ‘gaps’ include the lack of different types of resources, for example 24-hour supported accommodation, places in healthcare units with lower levels of security and adolescent psychiatry units.

8.35 What was also felt to be lacking was sufficient support to continue therapeutic work already started with an individual in the secure setting, and/or a structure of support to prevent people returning to the secure setting. As described in chapter 7 people in the State Hospital, in the secure accommodation units and even the prisons were felt to be able to access a level of therapeutic and other supports that would not be available to them outwith the secure setting.

8.36 For example, in relation to one person with learning disabilities coming up for parole, prison health care staff expressed concerns about how the person would be maintained safely in the community:
“[He] is known to the A & E department of his local hospital because of the number of threats of overdosing. But he is also dangerous. Almost needs 24-hour care to protect himself. [Prison] performs a role, but he won’t get that level of supervision when he is out. Whatever it is it won’t be adequate – he won’t cope with someone with him 24/7 and he could become aggressive and cause injury. There will be conflicts and the package will fall apart unless he is in a secure setting.”

8.37 For people leaving prison who are not under licence or a statutory supervision order, prison health centre or social work staff can make contacts with relevant agencies outwith the prison but it may be some time before a community-based service makes contact with the person. Although not specific to people with learning disabilities and/or ASD the comment was made by one prison health care team that:

“The prison contacts people to say person is being released, but it’s not picked up because of the waiting lists across the board. A few weeks later the person is back in prison not having been picked up.”

8.38 One prison social work department also referred to the variability between local authorities in the extent to which they would provide voluntary after care.

8.39 One of the greatest obstacles is the perceived reluctance of other services to take referrals from people in secure settings. This includes both social care and health care services. For example, one prison healthcare centre, trying to find supported accommodation for a young offender described how “no-one would have him because his behaviour is so appalling”.

8.40 Health care settings may reject someone on the grounds that they are too capable:

“With somewhere like [local unit] the concern is that the people from the State Hospital are more able than other patients and this raises the risk of predation on the more disabled patients.”(Ward Manager)

8.41 There may also be debates with local health services over the primary diagnosis and whether the person has a learning disability or a personality disorder. If interpreted as a personality disorder they will not be accepted by some units.

8.42 The person may be viewed as engaging in the ‘wrong’ sort of offending: some health care units, for example, will not take sex offenders.

8.43 ‘Local’ secure units may not take people from prison because they come from the ‘wrong’ catchment area.

8.44 In one case someone in prison was assessed for transfer to the State Hospital, but turned down. Within the prison one interpretation was that the Hospital felt there was nothing they could do for the person: “the State Hospital felt that [his] problems were contained at [prison], in
a context in which the State Hospital is trying to get people out”. The prison had also contacted an in-patient unit with a secure facility “but they felt he was too high risk for them”.

8.45 It is the capacity for local units to cope with the risks posed which is perhaps the crux of the problem. One State Hospital respondent summarised what they perceived to be the difficulties for local units:

“Have had statements that someone was ‘too tall’ for the service i.e. for the ceiling tiles. But the problem behind this is that they don’t have sufficient experience or knowledge to take people on. They don’t have the skills for this unique, special group. They don’t have the confidence in their ability to do the job.”

8.46 For one person in the sample funding for additional staff had been agreed to enable them to move from the State Hospital to a local secure unit. The move though was being delayed because of the receiving unit’s concerns about being able to manage the person. As a result of the delay staff felt the person was “stagnating”.

8.47 For people in the State Hospital the stigma that attaches to the place and the “myths” which develop around individuals’ past histories may also make local areas resistant to taking people back. As such these people are truly ‘entrapped’.

8.48 The only option in relation to some people may be to seek funding for placements in privately run units, usually located in England. The need to negotiate funding can further delay an individual’s discharge from the State Hospital.

8.49 The lack of integrated care networks, clarity of agency responsibilities, and a lack of appropriate resources, including expertise and experience, has major implications for people in secure settings. Not only may their discharge be delayed, literally by years in some cases, but, when they do move it may be to units in England. This may compound their social exclusion, moving them away from any remaining family or social contacts. For people moving out of prison the lack of timely and appropriate support may increase the risk of recidivism. For people in the community with inadequate support or staff with sufficient experience and confidence it may mean a break down in community placements and admission or re-admission to the State Hospital.

**Care packages**

8.50 Despite all the difficulties, examples were described of care packages that had enabled people to move on. For example the package of support for one young person leaving secure accommodation described above. One psychiatric in-patient unit also described putting together a joint care package, co-ordinated by a care manager and involving health input, including specialists in learning disabilities, social work, social care, housing and voluntary agency contributions. The value of joint working was underlined in each of these cases. The comment was, however, made in one case, that this was almost in spite, rather than because, of the available structures to support partnership working:
“No system in place to co-ordinate multi-agency approach. Dependent on enthusiasm of care manager and Team’s personal knowledge of local resources.”

(Comment on case recording form)

8.51 People with learning disabilities have also been transferred from the State Hospital to a local secure unit. The process was felt to have been facilitated not just by the dual role of the Consultant Psychiatrist as RMO for both the State Hospital specialist unit and the local unit, but also the close working between the different professions on the 2 sites.

MANAGING TRANSITIONS

8.52 Although in each of the secure settings discharge planning involves linking in with other agencies, whether through ‘informal’ contacts, or formal mechanisms such as pre-release meetings or CPA, the process of transition may take different forms.

8.53 One of the secure accommodation units described a number of ways in which they sought to smooth transitions. Where, for example, a young person was moving from the unit to less secure care, the unit staff would be involved in preparation for the move including taking the young person on escorted visits. The view was that these visits also helped to allay security concerns on the part of the receiving unit. Work would also be undertaken with families when planning for discharge with the aim of giving them “an individual strategy for managing the young person’s risk”.

8.54 For people moving from the State Hospital to a local secure unit, respondents described how they were able to implement a ‘model process’:

“Got the staff from outside to work with the key worker and the patients so they got the real picture, both positive and negative. The OT and psychologist from the receiving unit worked with the Ward OT and psychologist and looked at ways of replicating the groups the patients were attending in the State Hospital. So that when people moved the change wouldn’t be so extreme.”

8.55 Patients were also able to spend time in the new unit prior to leaving.

8.56 The resource implications in terms of ensuring staff cover in both units meant, however, that the ‘model’ could not always be implemented. For people moving out to units in England, for example, the number of pre-transfer visits may be circumscribed by the need for the person to be accompanied by 3 staff who have to stay overnight.

8.57 For people in prison not going out on licence transitions can be comparatively abrupt. There is no further input from prison health care or social work staff. People going out on licence will have had contact with their criminal justice social work supervisor prior to discharge.
HIGH HOPES AND LET DOWNS: USERS VIEWS ON MOVING ON

8.58 In interviews people with learning disabilities and/or ASD in the prisons, the State Hospital and secure accommodation expressed their hopes and aspirations for the future: to get a job or go to college and get a place of their own. People were also aware of the obstacles in their way. One of the barriers was the feeling that they lacked the skills to realise their hopes. One person described their ambitions:

“I’d like to get a job that people with learning disabilities do. Working in Tesco’s stacking baskets or shelves, but I maybe couldn’t stack shelves as it would need to be in alphabetical order and I don’t know how to do that.”

8.59 But a major barrier, particularly for people in hospital was not being able to move on because places were not available for them in other units. There is an almost overwhelming sense of hope that the new placements will be the stepping stone to achieving the things they want from life. One person for example, felt that by moving to a local unit they would “feel a bit more stability” and the unit would give him advice on the best routes for getting a house and a job.

8.60 At the same time there is a mixture of resignation and frustration as people wait for the promised placements to materialise. For one person interviewed in hospital the opportunity to move on was also a chance to “make up for lost time”:

“I want to move on and make up for lost time....I’ll go to the local hospital. I’ve talked to the staff and the doctor. I’m waiting on feedback from [local hospital]. It could happen within the next 2 or 3 months. I just have to wait.”

8.61 For this person the worst thing about being on the unit was “wanting to move on”. Unfortunately the anticipated place was no longer available.

8.62 Another person was prepared to be transferred to a unit some distance away from his family in order to move on, but was aware that although funds had been made available, there was no place for him yet. The waiting, he said, was making him nervous and edgy.

8.63 People were also sensitive to having been rejected. One person had hoped to go to a local unit near his family, but was told there were no beds available, but believed that “15-16 beds are empty”. Another describing the reasons for the delays commented that “It seems only [local unit] will accept me. Other hospitals have turned me down”.

8.64 Echoing the views of service providers, a number of people felt there should be more places available so that when they were “clear for discharge” they could move.

“I am leaving here but there’s not enough hospitals provided for people with learning disabilities. Lennox Castle has shut down. It was for people like me...There needs to be more facilities for people with learning disabilities.”(Hospital in-patient)
EXAMPLES OF PRACTICE

8.65 Despite the obstacles and frustrations described by staff and experienced by people with learning disabilities and/or ASD, examples of ways in which these barriers were surmounted were also described in each of the different settings.

- The use of CPA to ensure continuity of care for one person with ASD moving from the State Hospital to a local unit. In this case local service joint commissioners were also involved to ensure a further smooth transition from the local unit to appropriate community services
- The graduated transitions for people moving from the State Hospital to a local secure unit
- The joint work between one secure accommodation unit, a young person’s criminal justice social worker and the local social work department to provide a care package that met the needs arising not just from the young person’s offending behaviour but from their learning disability
- The joint work between a psychiatric in-patient unit and social work to provide a package of care involving statutory and voluntary agencies able to meet the needs of an individual with ASD
- The provision of a ‘befriender’ for one person with a learning disability leaving prison under licence to help them to understand, in their own terms, what was required of them and the consequences if they breached the order

DISCUSSION

8.66 Accounts of throughcare and after care underline the need for mechanisms to be flexible enough to meet the specific needs arising from the offence related risks individuals may pose and the vulnerabilities that may arise from the learning disability and/or ASD.

8.67 At present, outwith specialist health care settings, arrangements are not specific to people with learning disabilities and/or ASD. For people in prison, or admitted to secure accommodation via the criminal justice system the mechanisms are informed by criminal justice requirements and are largely aimed at preventing re-offending. For people being liberated under licence the formal process provides a forum for multi-agency and multi-disciplinary planning and for continuity beyond secure care. But there is the risk that, unless the impact of the learning disability and/or ASD is recognised, in terms of capacity to retain information, comprehension or other behaviours, the person is being “set up to fail”.

8.68 For people in prison who fall outwith this formal framework there is a reliance on ‘informal’ arrangements. Prison health care and social work staff will make links or liaise with relevant agencies outside on behalf of the person with a learning disability and/or ASD. But there is a risk of arrangements failing if resources outside are unwilling, unable or do not exist to meet the person’s specific needs. People may also not follow through the arrangements made on their behalf. As a result transition for some people can mean leaving the comparative stability of the prison environment to chaotic unsupported lives outside and a consequent risk of returning to
In health care settings, transitions may be planned, but people may again face the obstacle of what is or is not available outside the secure setting.

There is no doubt that the examples cited where planning and transitions were felt to work well were those where there was collaborative working between and across units, agencies and professionals. Where barriers were encountered these were due not only to the lack of resources but also to a perceived reluctance on the part of agencies outwith the secure setting to take on responsibility for individuals. As a result people with learning disabilities and/or ASD can experience the rejection described by a number of those interviewed.

A number of policy developments not specific to people with learning disabilities and/or ASD have the potential to smooth the pathways for this group of people. Although the Joint Future policy, in general, and single shared assessment in particular do not appear yet to be a feature of the language of these secure environments (see chapter 6), it may open up further opportunities for partnership working as it is rolled out across community care groups,

The progress being made to set up a national forensic managed care network may also enhance opportunities for greater continuity of care. Similarly, the implementation of the Tripartite Group’s recommendations for throughcare and aftercare for people leaving prison may have a beneficial impact for people with learning disabilities and/or ASD.

The success of these different initiatives to enhance throughcare and aftercare will, though, hinge on the extent to which agencies and services accept responsibility for people with learning disability and/or ASD. They are also dependent upon the capacities and confidence of ‘mainstream’ services to respond to the combined risks and vulnerabilities of this “unique” group of people.

**KEY POINTS**

- For people in prison arrangements for throughcare and after care are contingent on whether they are on remand or sentenced, and, if sentenced, the length of sentence and/or whether they will be going out on licence or under a supervision order

- For people on remand and those eligible for voluntary after care, arranging support on release will be a largely informal process involving prison healthcare or social work staff making contact with outside agencies on behalf of the person

- ‘Formal’ mechanisms for throughcare and after care planning include the criminal justice social work led process for people going out on licence and the health care led Care Programme Approach
• The formality of the process for people going out on licence may ensure continuity of care, but may place requirements on an individual that they are unable to fulfil. The informal approach for people who are not under licence may mean they do not receive follow up or support in the community, potentially increasing the likelihood of re-offending.

• The secure accommodation units for children appear to be forward focused and proactive in planning for throughcare and aftercare. There is also an emphasis on multi-disciplinary and multi-agency working involving unit based and external professions and agencies.

• Discharge planning for people on the State Hospital site was multi-disciplinary but primarily involved professionals from within the hospital.

• In the few cases where discharge planning was in progress for people on in-patient units outwith the State Hospital there appeared to be greater involvement by external agencies and services.

• Respondents felt that one of the fundamental barriers faced by people ready to move on from healthcare settings was the lack of appropriate resources beyond the secure setting, including a range of types of accommodation and activities and interventions.

• Community-based health and social care resources may also be reluctant to take on responsibility for people, particularly those moving from the State Hospital. State Hospital staff suggested that local units may feel they do not have the capacity to cope with the risks someone poses.

• Interviews with people with learning disabilities and/or ASD revealed their hopes and aspirations but also their frustrations as they wait for appropriate places to become available so they can move on.

• The lack of integrated care networks, clarity of agency responsibilities and a perceived lack of appropriate resources can have a number of implications for people with learning disabilities and/or ASD. Some people may have to wait a number of years before they are able to move; some may have to move to units even further away from their family and friends; the risk of recidivism may increase when people move out of prison without timely and appropriate support. For people in the community inadequate or inexperienced support may mean admission or re-admission to the State Hospital.

• A number of recent policy initiatives may assist to break down some of the barriers encountered by people in secure settings. This however hinges on the preparedness of ‘external’ agencies to accept responsibility for these individuals, and the capacities and confidence of mainstream services to respond to their complex needs.
CHAPTER NINE  DISCUSSION

INTRODUCTION

9.1 Before drawing together the emerging themes it is necessary first to reiterate the boundaries of the research. First, the study was neither an evaluation nor an inspection, it was a scoping exercise, mapping out at one point in time how many people with learning disabilities and/or ASD were in different types of secure setting in Scotland, their characteristics, their needs and the ways in which these needs were met.

9.2 Second, the focus across the different settings: the prisons, secure accommodation for children, the State Hospital and secure in-patient units, was primarily on one point along the service pathway - the secure setting itself. It touches upon, but does not explore in depth the decisions and processes which propel a person to a secure environment and the outcomes for individuals, their families and the communities of which they are a part.

9.3 Further, in a context in which the identification of people was one of the research questions, the approach adopted to estimate the numbers of people in these settings both exposes the difficulties and demonstrates the implications. The perception expressed by respondents was that the low numbers identified across the prisons and in secure accommodation may be just a proportion of a larger number of children, young people and adults with learning disabilities and/or ASD in these environments.

9.4 Within these boundaries of scope and method the study has nonetheless raised a number of significant policy and practice issues and questions with implications for people with learning disabilities and/or ASD in these settings and for the services which seek to be responsive to their needs.

ON THE BORDERLINE?

9.5 The metaphor of people on the borderline was used in chapter 7 to describe where people fit in terms of these different environments. The sense of this group of people being on the edge, or periphery, or of not quite belonging recurs again and again.

9.6 A number of different policy streams will impact upon the experiences of this group of people. Some policies will affect this group because they are looked after children, others because they have a learning disability, or because they have ASD, others because they are adults with a learning disability and/or ASD who engage in offending behaviour. In effect, children, young people and adults with learning disabilities and/or ASD who require security to keep them, and/or others, safe do not exist as a specific policy group. This may mean that policies specifically targeted at people with learning disabilities and/or ASD are not consistently applied across secure settings. This is not because these policies are not relevant but because they do not extend to, or are not adapted for, the different environments within which people find themselves. The recommendations within The same as you? (Scottish Executive, 2000), for
example, may just not have common currency within the prisons or secure accommodation units for children.

9.7 Reflecting this parallel, rather than cross-cutting policy framework, is the sense that people within this group fall between different service stools: between health, social care and criminal justice pathways; between mental health and learning disability services; between ‘mainstream’ and ‘forensic’ services.

9.8 Falling between service and agency responsibilities, contingent upon age, or type of behaviours, or diagnosis may result in some individuals being cared for at levels of security higher than required, or not having the opportunity to access relevant specialist services, or being released from prison without appropriate support available in the community.

9.9 Along the dimension of capacities and abilities this group of people present distinctive management, treatment and therapeutic needs. For those with mild or borderline learning disabilities it may mean the needs stemming from their disability are not identified and they are labelled as a ‘difficult prisoner’ instead. But, even when identified their level of disability is such that they may still not be able to participate in mainstream or generic programmes or group interventions designed for a non-learning disabled majority.

9.10 At the same time a number of people combine behaviours which make them both a high risk to others as well as being ‘at risk’, either from self-harm or from abuse by others within the secure setting.

9.11 As a result, in a number of ways, people with learning disabilities and/or ASD are perceived as not fitting in with the core business of the secure environments within which they are placed: in non-healthcare settings, for example, where core functions such as providing custody, addressing offending behaviour or providing a secondary education are designed around the needs of the majority population who do not have a learning disability and/or ASD; or in healthcare settings in which the prime focus is on mental health; or people with ASD in in-patient units for people with learning disabilities. Particular groups: women with learning disabilities and/or ASD across all the secure settings for adults; and children, young people and adults with ASD across all settings, may carry the additional burden of being a minority within a minority.

**PROCESSES AND OUTCOMES**

9.12 To begin to think what this means for people with learning disabilities and/or ASD in these environments figure 9.1 summarises the range of different approaches to identification, assessment and care planning, service provision and after care planning within and across the different secure settings.
### Figure 9.1 Summary of approaches to identification, assessment and care planning, service provision and after care planning within and across different types of secure setting

<table>
<thead>
<tr>
<th>Process</th>
<th>Implementation</th>
</tr>
</thead>
</table>
| Identification               | • Pre-admission identification  
                              | • Identification at admission  
                              | • Identification post admission  
                              | • Responsive identification  
                              | • Not identified             |
| Assessment and care planning | • Specialist assessment for people with learning disabilities and/or ASD  
                              | • Additional assessments of abilities, capacities, needs  
                              | • No assessment              
                              | • Single shared assessment  
                              | • Independent assessment, but collated to inform care planning  
                              | • Independent assessment, uncoordinated, number of different care plans put in place by different professions |
| Service response              | • Mainstream generic resources  
                              | • Adapted generic resources  
                              | • Specialist resources       |
| Throughcare and aftercare planning | • ‘Formal’ arrangements for throughcare/after care planning  
                              | • ‘Informal’ arrangements for throughcare/after care planning  
                              | • No arrangements            
                              | • Multi-disciplinary and multi-agency throughcare/after care planning (including external agencies)  
                              | • Multi-disciplinary and multi-agency throughcare/after care planning (in-house professions/agencies only)  
                              | • Uni-disciplinary           |

9.13 Individual factors relating to level and type of risks posed, routes to secure care and the statutory context will be influential on where, and why people enter any particular secure setting, and the planning processes in place for when they are ready for release or discharge. Once in the setting, however, service-specific processes, and the extent to which they can be responsive to the specific needs and capacities of people with learning disabilities and/or ASD will impact upon: whether and at what stage a person is identified as having a learning disability and/or ASD; whether or not they have access to appropriate specialist expertise to assess their needs and capacities; whether and to what extent resources can be tailor-made to respond to meet their identified needs and capacities; and, for those who are not under a statutory order on
release/discharge, whether or not prior to leaving a secure setting plans are put in place to ensure that when they do move on they have access to appropriate support.

9.14 Although not a study of outcomes the comments made by respondents, particularly in the context of throughcare and after care planning, suggest that the experiences of individuals beyond the secure setting may be as variable as those relating to the process elements. Drawing on these comments Figure 9.2 illustrates some of the possible ‘outcomes’ for people moving on from a secure environment. Again these reflect both individual and service or resource related factors.

**Figure 9.2 Possible after care ‘outcomes’**

- Person is enabled to move on to an environment of lesser security or with appropriate support in the community
- Person is unable to move on/be transferred because resources outwith the secure setting are unable, unavailable or unwilling to accept them
- On discharge/release person leaves secure setting with insufficient support
- On discharge/release person leaves secure setting unsupported
- On discharge/release person chooses not to take up the service/comply with statutory requirements

9.15 In an attempt to bring together the process elements and after care outcomes figure 9.3 describes a number of scenarios. These scenarios are not mutually exclusive, nor are they intended to cover all possible permutations, including those relating to statutory requirements. Further, no assumptions are made in terms of the clinical needs, assessed risks or qualitative outcomes for individuals. Rather the figure attempts to do 3 things.

9.16 First, the scenarios illustrate some of the different approaches to identification, assessment and care planning, service delivery and after care. Scenario 1 describes an environment where an individual is identified, is involved in, and experiences a co-ordinated needs assessment, in response to which they have access to a range of appropriate services and resources. Throughcare and after care planning are similarly co-ordinated, and include internal and external agencies and professionals, as well as the individual, their advocate and their family, as appropriate. In scenarios 2 and 3, following identification, an individual experiences a co-ordinated assessment. Generic or mainstream resources are adapted to meet their needs. Different professions within the setting might take on responsibility for contacting resources outwith the secure setting to arrange support preparatory to the person moving on. In scenario 3, however, the individual chooses not to take up the after care options, or, if released under an order is unable to comply with statutory requirements. Scenario 4 represents a situation where assessments are uncoordinated and mainstream resources cannot be adapted to meet the needs of the individual. Scenario 5 represents a situation where an individual is not identified and is unable to participate or make use of mainstream resources: the immediate and longer-term needs relating to their learning disability and/or ASD are neither assessed nor addressed.

9.17 Second, the figure aims to underline how each of the different elements from identification through to after care need to be available, appropriate and *in balance*, within and beyond the secure settings. In effect, although fundamental as a starting point, no matter how joined up or co-ordinated processes of identification, assessment and planning are they may have
limited impact on the individual if the appropriate resources to meet assessed needs are not available or accessible while the person is in a secure environment or when they move on. Without this balance between the elements there is a risk of people falling through, or between, service responsibilities.

9.18 If scenarios 1, 2 and 3 are less than optimum in terms of either process and/or outcome, then 4 and 5 come close to being the worst case scenarios along both dimensions. People who, in reality, fall within these latter groups, as study respondents suggest some do, are among the most vulnerable, either because they are unidentified and their needs not addressed, or because they do not ‘fit’ and are unable to be appropriately supported within secure or community settings. As a result they may find they are caught up on a ‘revolving door’ between the community and a custodial environment.

9.19 Finally, the figure begins to suggest how, for people with learning disabilities and/or ASD in secure settings, the combination of complex individual need and lack of clear service responsibility or policy focus across settings, may conspire together to exacerbate the exclusion of a group of people already on society’s margins.

Figure 9.3 Illustrative scenarios

<table>
<thead>
<tr>
<th>Scenarios</th>
<th>Processes</th>
<th>After care outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 1</td>
<td>Person is identified, experiences a co-ordinated assessment, a package of interventions or programmes is put in place and implemented. Throughcare and after care plans are developed, jointly involving the secure setting and external agencies and professions, the individual and their advocate, their family as appropriate.</td>
<td>The person is unable to move on/be transferred because resources outwith the secure setting are unable, unavailable or unwilling to accept them</td>
</tr>
<tr>
<td>Scenario 2</td>
<td>Person is identified, person experiences a co-ordinated assessment, generic resources are adapted to assist the individual. Prior to discharge health, social work, or education professionals make contact with providers/agencies outwith the secure setting.</td>
<td>The person subsequently moves on to an environment of lesser security or with appropriate support in the community</td>
</tr>
<tr>
<td>Scenario 3</td>
<td>As scenario 2</td>
<td>Person chooses not to take up the service/is unable to comply with statutory requirements</td>
</tr>
<tr>
<td>Scenario 4</td>
<td>Person is identified and assessed by a number of different professions. Resources cannot be adapted to meet the individual’s needs. Prior to discharge health, social work, or education professionals make contact with providers/agencies outwith the secure setting.</td>
<td>Person is discharged/released but resources outwith secure setting are unable to provide sufficient support for the person</td>
</tr>
<tr>
<td>Scenario 5</td>
<td>Person is not identified as having a learning disability and/or ASD. While in the secure setting they are unable to participate in programmes or activities.</td>
<td>On release person leaves secure setting unsupported</td>
</tr>
</tbody>
</table>
KEY POINTS

• The evidence from the study suggests that children, young people and adults with learning disabilities and/or ASD could find themselves on the ‘borderline’ not just in terms of the ways in which their capacities and abilities are defined, but in policy and service terms. As a result they may be perceived as not fitting in with what providers see as the core business of the different secure environments. Some people, particularly women and people with ASD may be doubly on the margins

• To begin to understand the implications for people with learning disabilities and/or ASD the different approaches to identification, assessment and care planning, service provision and after care planning are summarised. Drawing on the comments of respondents a range of possible outcomes for people beyond secure care are described. A number of illustrative scenarios are presented to suggest that unless the different elements of the process are in place, appropriate and in balance, some people may become ‘entrapped’ within a secure environment while others may find themselves on a revolving door between community and custody
CHAPTER TEN  CONCLUSIONS

INTRODUCTION

10.1 The different secure environments included in the study have different objectives, or at least a different balance of objectives. They also differ in terms of: the age profiles of the people referred; the nature of the impairment; and the resources or interventions to which they have access. In a number of other ways the approaches these environments adopt to support people, and the problems they face in doing so are not dissimilar.

10.2 Across the different settings, services clearly strive to meet the needs of this group of people: adapting and tailoring services as far as possible. There is evidence of joint working across disciplines at the point of assessment, in service provision and planning for the future. In secure settings for adults, however, this may be limited to those disciplines and agencies ‘on site’. Outwith the specialist in-patient units for people with learning disabilities, the involvement of specialists in learning disabilities was the exception rather than the rule, and across all types of unit the involvement of people with expertise in ASD was even rarer.

10.3 The common problems experienced relate to: levels of awareness of learning disabilities and ASD in non healthcare settings; information sharing; of having the resources, such as time, to provide the level of intensive input that some individuals are felt to require; the limits of adaptability in relation to programmes and other interventions; and the limited resources to enable individuals to move on, or to move on with the appropriate level of on-going support. The different environments, including the health care settings, were also aware of the vulnerability of some of this group of people and would seek to protect people who were at risk of being bullied, made fun of, exploited or manipulated or of being abused.

10.4 Although, for illustrative purposes only, chapter 9 sets out a number of notional outcomes, what the study is unable to determine are the actual outcomes for individuals of being identified, or not, as having a learning disability and/or ASD. Certain questions are raised in terms of equity, efficiency and effectiveness. For example, do people with learning disabilities and/or ASD in different types of secure setting have the same opportunities to access specialist resources? Do they have the same opportunities to access these resources as people in the community? Are adapted services as effective for individuals as those that are specifically designed to meet their needs? A more detailed understanding of non-financial (and financial) costs, benefits and outcomes for individuals and for services would be required before these questions can be answered. Nonetheless, the study does suggest action that can be considered at a number of levels.
BRINGING PEOPLE IN FROM THE BORDERLINE

Implications for policy

10.5 There are a number of different policy domains that can touch upon the lives of this group of people to a greater or lesser extent. These include not just health, community care, children’s services and education, but also the criminal justice system, in particular SPS, and also other services such as housing. To encourage coherence and consistency of service response there may be scope for greater integration between the different policy initiatives as they affect people with learning disabilities and/or ASD in secure settings. The purpose would not be to create a new or overarching policy, but to make more explicit and clarify the roles and responsibilities of different agencies at national, regional and local levels towards this group of people.

10.6 This enhanced policy coherence and consistency of application across different secure settings may help to further ensure that this group of children, young people and adults, who come within the ambit of The same as you? (Scottish Executive, 2000), also benefit from the principles and processes that the policy sets out. This may also serve to raise awareness, and give a ‘name’ or identity, to this group of people across the different secure environments. Raising the profile (in a positive sense) may yield dividends in terms of identification at the level of practice.

Service planning issues

10.7 Although the study was charged with enumerating the numbers of people in secure settings, the method specified was more successful in illustrating the problems of identification than in estimating prevalence. It is suggested that there is a need to consider systematic assessments of a sample population using validated methods. This has particular applicability for people with learning disabilities in the context of prisons and secure accommodation, but applies across the board in relation to people with ASD.

10.8 The current study focused on just one point in the pathway, but secure settings are part of a larger system. Although outwith the scope of this study, the findings do raise issues relating to early identification, pre-secure care, including, for example, the role of SERs. This is not just about awareness raising, but also about considering the availability of appropriate alternative, non-custodial disposals. Further consideration could be given to the role and availability of diversion schemes for people with learning disabilities and/or ASD who come into contact with the criminal justice system.

10.9 The Care Pathways Framework (NHS HDL (2001) 9) requires local areas to indicate progress in meeting the policy for mentally disordered offenders. Although planning and service development issues are also beyond the remit of the study, the findings, both in terms of the numbers of people, and the complexity of needs they present, may suggest that some services require to be planned and commissioned on a regional or even a national basis. Planning and commissioning would also need to be tied in to the proposed national forensic managed care
network. As part of ensuring on-going responsibility for this group of people there may also be a value in encouraging secure settings to link in to other appropriate planning networks at local level including, for example, partnership in practice agreements.

10.10 At service level, the data suggest that secure settings are not necessarily linked into other networks which could help improve awareness and encourage greater service integration. For people with Autistic Spectrum Disorders, for example, secure settings could consider linking in with initiatives such as the Scottish Service Network for Autistic Spectrum Disorders.

10.11 From the evidence of the study it does not appear that the responsibilities of local area co-ordinators, whose role in managing and co-ordinating the care of people with a learning disability and/or ASD is described in The same as you? (Scottish Executive, 2000) extend to people in secure settings. If their role were to encompass this group of people this might enhance the scope for on-going responsibility and support beyond the secure environment.

**Practice issues for secure environments**

10.12 A key practice issue is awareness raising among health care, social work, education, social care and security staff, of the possibility of learning disability and/or ASD as an explanation for possible behaviours. This does not imply that everyone becomes an expert in learning disabilities and/or ASD, but that before labelling someone as a “difficult prisoner” or as having “challenging behaviour” they are sensitised to considering other options and routes for referring people on.

10.13 There are currently no routine screening systems for beginning the process of identification, particularly in non-health care settings. Clearly routine screening carries its own risks of false positives and false negatives. There are also ethical dimensions to consider, together with the short term and life-long implications of informing someone in prison, for example, that they may have a learning disability or ASD. There may, however, be scope for more selective screening, where an individual’s behaviour is raising concerns. Consideration could be given to the development of simple screening tools for use by non-specialists, such as that developed and described by Hayes (2002). This tool is not intended to diagnose the presence of a learning disability but to identify people who may require further diagnostic assessment.

10.14 There may be greater scope for using existing routes, for example Learning Centres in prisons already screen for adult basic education needs. Teaching staff also have an expertise which could inform early identification. This, however, requires a way of linking the different professions so that education, social work, health centre staff and security staff can co-ordinate and feed in their concerns. Within the secure accommodation units and the State Hospital this is already happening, and not just for people with a learning disability and/or ASD. In the prisons this happens in relation to people who are at risk of suicide or self-harm, or have a mental health problem. While the potentially small number involved does not necessitate replicating, for example, the prison mental health teams, there may be an argument for formalising the role of these teams as a point of co-ordination for this group of people.
10.15 There are also issues around ensuring that any information that suggests the individual does have a learning disability and/or ASD, is appropriately shared with the relevant professionals within the secure setting. Existing models for information sharing, for example those being developed in the context of the Joint Future policy (Scottish Executive, 2000), may help to establish protocols for sharing confidential information.

10.16 Systems of screening need to be supported by access to specialist resources, including speech and language therapy, to assist to identify, assess or diagnose people as well as provide or advise on treatment and support. At present, outwith the healthcare units, few secure environments have routes to learning disabilities services. Although again recommended in the Care Pathways Framework, there may still be scope for clarifying the local care pathways to these services. Specifically in relation to speech and language therapy, the recommendations of the Scottish Executive Review of Speech and Language Therapy (Scottish Executive, 2003) may provide an opportunity for NHS Boards to explore access arrangements to these services by people with learning disabilities and/or ASD in secure settings.

10.17 Single shared assessment as a concept is only beginning to infiltrate some of the health care settings, and is not part of the language of the other secure environments. If, as a model, it is felt to be a more efficient and effective way of working, then there may be scope for considering its applicability and feasibility across the range of secure settings. Nationally this would need to be addressed with SPS, local authorities and the Charitable Trusts responsible for some of the secure accommodation for children.

10.18 There are clearly perceived resource issues relating to service provision both within and outwith the secure environments. These are described in chapter 7. Although not resolving difficulties which need to be addressed on a system wide level, at the level of individual units there may be scope for considering greater input by specialists in learning disabilities, not just as providers but as a resource to advise staff within the secure units. Prisons are familiar with using external agencies to provide services to people within prison. One of the secure accommodation units also described a mental health awareness project that was being provided by an external voluntary agency. It is therefore not such a novel idea to make similar arrangements, where practicable, for people with learning disabilities and/or ASD. This could include not just health care providers, but voluntary organisations that have a specialist knowledge and expertise of working with people with ASD and learning disabilities.

10.19 The availability of resources was also raised as an issue in the context of throughcare and after care planning. Greater involvement by services from outwith the secure environment, although not the whole answer may help to link individuals into networks that will assist throughcare and after care planning and implementation.

10.20 *The same as you?* (Scottish Executive, 2000) recommends that everyone who has a learning disability should have a Personal Life Plan if they want one. If ‘everyone’ includes people in a secure setting who have been identified as having a learning disability and/or ASD, then consideration may need to be given to how this can be adapted and implemented.
10.21 The evidence from the study suggests that, within the individual prisons and secure accommodation units, no one post or professional is identified as having responsibility for issues relating to learning disabilities and/or ASD. To help to increase awareness and improve early identification and service response consideration could be given to identifying a key professional at unit level to champion the interests of people with learning disabilities and/or ASD, analogous to the role of the teacher designated to champion the interests of Looked After Children (Scottish Executive, 2001). This was already under consideration in one prison which was planning to use one of its RMHN’s as a ‘key nurse’ in this area. This person could function as a resource within the prison.

Areas for further research

10.22 In addition to a more accurate assessment of the numbers of people with learning disabilities and/or ASD in secure settings, the literature review, described in Chapter 1, and the quantitative and qualitative data collected in the course of the study have highlighted 7 areas where further research may help to inform future service development.

- The literature review found little evidence relating to the numbers and needs of children, young people and adults with ASD who offend or engage in offending behaviour. The difficulties experienced across all settings in the study, both in identifying and meeting the needs of people with ASD suggests scope for further research. This could address not just the numbers of people with ASD in secure settings, but also their routes into these environments, the nature of their offending behaviour, early identification and the specific support needs of this group of people.

- Although the study was only able to identify a small number of children and young people with learning disabilities and/or ASD in secure accommodation, the high proportion of the sample of adults who had been looked after children suggests an area that needs further investigation. Retrospective or longitudinal research could be undertaken to track the pathways of looked after children and young people with learning disabilities and/or ASD to identify the key factors influential on admission to secure settings.

- The literature review found little material comparing the experiences of men and women in secure settings with learning disabilities and/or ASD. The research sample comprised too few women in each of the settings to enable meaningful comparisons. To inform appropriate and gender sensitive service development it is suggested that further evidence is collected comparing the experiences of, and the routes to secure care for men and for women with learning disabilities and/or ASD.

- Neither the literature reviewed, nor the research sample generated evidence to illustrate the experiences of people with learning disabilities and/or ASD from minority ethnic communities who offend or engage in offending behaviour. Exploratory research may be considered to identify issues relating to, for example, early identification, assessment of need, and culturally competent service responses.
• The literature review suggests that the responses to people with learning disabilities and/or ASD who engage in offending behaviours will depend on the context in which the behaviour occurs and whether or not they are known to services. As a result some people will be processed through a criminal justice route, others will be admitted under mental health legislation. Further, people with learning disabilities and/or ASD in secure health care settings will include both offenders (i.e. people who have been charged and sentenced for an offence) and non-offenders. The study suggests there is scope for further in-depth research to obtain a better understanding of the different factors that influence the routes to different secure settings and the subsequent outcomes for people with learning disabilities and/or ASD.

• The focus for the study was largely on issues of process. The research sample however reveals that some people have long histories of institutional care. This suggests that, to break the ‘cycles of security’ into which some people become fixed, more evidence is needed on the longer term outcomes for people with learning disabilities and/or ASD in secure settings. In addition more needs to be known about the outcomes for the families and informal carers of this group of people.

• Many of the studies reviewed were largely quantitative in approach: the voices of people with learning disabilities and/or ASD and the people who care for and about them are rarely heard. To address the research questions raised by the study there is scope to use more qualitative methodologies – approaches which draw on the experiences and perceptions of people with learning disabilities and/or ASD in secure settings, and that of their families or informal carers.

10.23 The aims of the study were to establish the prevalence of people with learning disabilities and/or ASD in secure settings, the means by which they are identified and their needs assessed and met. The approach adopted for assessing prevalence illustrated the difficulties of identifying people with learning disabilities and/or ASD in these settings, but also meant that it was not possible to accurately assess the numbers in each type of environment. What the study has however yielded is evidence of the complex nature of the needs of this group of people, and the challenges they pose for policy implementation, planning, service delivery and practice.

KEY POINTS

Policy implications

• At policy level it is suggested that there is scope for linking the different policy initiatives as they impact upon people with learning disabilities and/or ASD in secure settings

Planning implications

• In service planning terms secure environments could be linked in to appropriate planning and development networks for people with learning disabilities and/or ASD
• Local area co-ordinators may also have a role in managing and co-ordinating the care of people with learning disabilities and/or ASD in secure environments

Practice implications

• In practice terms there is scope for raising awareness about people with learning disabilities and/or ASD across the different disciplines in non-healthcare settings, including health, social work, social care, education and security staff

• Consideration could be given to the development of a screening tool for use in non-healthcare settings

• There is scope for greater co-ordination of information and assessment, particularly within prison environments. Consideration could be given to introducing a single shared assessment model within secure settings

• Perceived resource constraints were described. These related to the capacity to provide appropriate services within secure environments and to the resources available outwith these settings to provide after care

• There may be scope for greater involvement of, and integration with, specialists in learning disabilities and ASD – statutory and voluntary/independent - not just as service providers, but in an advisory capacity. This includes access to Speech and Language Therapists

• The feasibility of people with learning disability and/or ASD in secure environments having the opportunity to have a personal life plan could be considered

• Within each unit there may be a value in identifying a key person with responsibility for issues relating to learning disability and/or ASD. This could, for example, be a RMHN in a prison, or a designated teacher in a secure accommodation unit

• A number of areas for further research are identified which could assist policy, service and practice development
REFERENCES


Clare, I and Murphy, G (1998) Working with Offenders or Alleged Offenders with Learning disabilities, in, E. Emerson, C. Hatton, J. Bromley and A. Caine, *Clinical Psychology and People with Intellectual Disabilities*, Chichester: John Wiley and Sons Ltd


Foundation for People with Learning Disabilities, [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)


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NHS HDL (2001) 9 Services, Care, Support and Accommodation for Mentally Disordered Offenders in Scotland: Care Pathway Document


Scottish Executive (2001b) *Learning with Care: The education of children looked after away from home by local authorities*, Edinburgh: Scottish Executive


Scottish Executive (2002b) *National Standards for Scotland’s Youth Justice Services*, A Report by the Improving the Effectiveness of the Youth Justice System Working Group, Edinburgh: Scottish Executive

Scottish Executive (2002c) *Promoting Health, Supporting Inclusion. The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities*, Edinburgh: Scottish Executive


Scottish Executive (2003b) *Scottish Executive Review of Speech and Language Therapy, Physiotherapy and Occupational Therapy for Children, and Speech and Language Therapy for Adults with Learning Disabilities and Autistic Spectrum Disorder*, Edinburgh: Scottish Executive


Smith, A and O’Brien, G (Unpublished paper) *Developmentally Disabled Offenders with Dual Diagnosis*


ANNEX ONE

PEOPLE WITH LEARNING DISABILITIES AND/OR AUTISTIC SPECTRUM DISORDERS IN SECURE, FORENSIC AND OTHER SPECIALIST SETTINGS

Additional information on learning disabilities and Autistic Spectrum Disorder

People with learning disabilities and/or Autistic Spectrum Disorders (ASD) will vary widely in terms of the nature and degree of disability they experience. It is also possible for someone to have both a learning disability and ASD. The following just provides some additional background information to help you think about the adults and children who should be included in the study.

People with learning disabilities

People with learning disabilities have a significant, life-long condition that started before adulthood, that affected their development and which means they need help to:

Understand information;
Learn skills; and
Cope independently.

(From: *The same as you? A review of services for people with learning disabilities*, Scottish Executive, 2000)

Some characteristics associated with people with learning disabilities include:

Significantly impaired intellectual ability
Significantly impaired social functioning
The disability has been present from birth (i.e. not acquired in later life for example through a head injury or as a result of substance misuse) (Holland et al, 2002)

<table>
<thead>
<tr>
<th>People with Autistic Spectrum Disorders (including Asperger’s syndrome)</th>
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</thead>
<tbody>
<tr>
<td>People with Autistic Spectrum Disorders are often described as having a ‘triad’ of impairments (Wing, 1996). These include:</td>
</tr>
<tr>
<td>Difficulty understanding verbal and non-verbal communication</td>
</tr>
<tr>
<td>Difficulties with social relationships and understanding social behaviour. As an adult they may be seen as a loner</td>
</tr>
<tr>
<td>Ritualistic behaviour or obsessional interests. These may be unusual and the person may want to talk about them a lot. People may also find it difficult to cope with change.</td>
</tr>
</tbody>
</table>

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On the Borderline? People with Learning Disabilities and/or Autistic Spectrum Disorders in Secure, Forensic and Other Specialist Settings