

**Themed visit to hospital
units for the assessment
and treatment of people
with learning disabilities**

**The Mental Welfare
Commission for Scotland**

THEMED VISIT TO HOSPITAL UNITS FOR THE ASSESSMENT AND TREATMENT OF PEOPLE WITH LEARNING DISABILITIES

Who we are and what we do

We put individuals with mental illness, learning disability and related conditions at the heart of all we do: promoting their welfare and safeguarding their rights.

There are times when people will have restrictions placed on them to provide care and treatment. When this happens, we make sure it is legal and ethical.

We draw on our knowledge and experience as health and social care staff, service users and carers.

Our Goals

- To help individuals using mental health or learning disability services to get the best possible care and treatment
- Help people working in mental health and learning disability services to provide the best possible care and treatment for each person using those services
- To provide independent expertise in applying best ethical and legal practice in care and treatment

Our Values

Individuals with mental illness, learning disability and related conditions have the same equality and human rights as all other citizens. They have the right to

- be treated with dignity and respect
- ethical and lawful treatment and to live free from abuse, neglect or discrimination
- care and treatment that best suits their needs
- lead as fulfilling a life as possible

THE PURPOSE OF THE VISIT

There has been a transformation in service provision for people with learning disabilities over the past 30 years. In 1980 6,500 people were in hospital care. In 1998 there were still 2,450. Today, excluding forensic beds, there are fewer than 240 people in acute and longer stay assessment and treatment beds.

One of the key recommendations in the Same as You? (SAY), published by the Scottish Government in May 2000, was the closure of long stay hospitals. SAY was the first review of learning disability services for several decades. It set out a 10 year programme of change to improve services and support for people with learning disabilities, their families and carers.

The report stated that long stay hospitals were not an appropriate setting for social care or for most health care and that they should close by 2005. However it recognised that there was a need for a small number of inpatient beds for those with specialised or complex needs which could not be met in the community, as well as a small number for people whose treatment required a hospital setting for a longer period.

A SAY subgroup was set up in 2002 to monitor hospital closure and service redesign. In December of that year there were 818 hospital beds, excluding forensic services.¹ The 'Survey of Learning Disability In Patient services in Scotland' in May 2007 found there were 297 non-forensic patients. Although the 2005 target for hospital closure and redesign was not fully met by that date, we are now in a position where all health boards have redesigned their services, health care is largely delivered on a community basis and there are only 239 hospital beds for people with learning disabilities, excluding forensic beds, across Scotland.

The Commission last visited hospital services for people with learning disabilities in 2007. We were aware that there had been further redesign of services and further reduction in bed numbers since then. We were keen to see the impact of this on the care and treatment provided and to see whether some of the concerns from our previous visits had been addressed. These included delayed discharges, the physical environment, meaningful activities, physical health care, risk assessment and management plans, and service user involvement.

AREAS WE LOOKED AT

We gathered information from Clinical Service Managers and from interviews with staff, from those service users who were able to give us their views, from service users' care plans and other records and from those relatives who asked to see us. We had four general areas of enquiry.

¹ <http://www.scotland.gov.uk/Publications/2004/01/18741/31584>

- **Health needs** – including access to regular health checks and specialist support and whether issues of consent to treatment had been considered
- **Rights and restrictions** – including whether risk assessment and management plans were in place and whether any restrictions on individuals, such as restraint or seclusion, were legally sanctioned
- **Quality of Life** – including the environment, the quality of their care plans, opportunities for therapeutic, social and recreational activities, opportunities to maintain or develop daily living skills, and discharge planning
- **Participation and involvement** – including service user involvement in care planning and reviews, the support they received in communicating their views, access to advocacy and family involvement

THE UNITS WE VISITED

Between June and September 2011 we visited all 20 hospital sites - 19 NHS sites and one private hospital. We did not visit forensic units for people with learning disabilities, as these were visited recently as part our forensic visit programme.

There are 239 beds in total on these sites. This is made up of 72% (171) assessment and treatment beds and 28% (68) longer stay assessment and treatment beds. There are 25 separate units and the average number of beds per unit is ten. The accommodation ranges in size from units for four people up to one unit with 26 people. In June 2011 there was 90% occupancy (215 people). 68% of people in these units were men, 32% women. See Table 1 (Appendix).

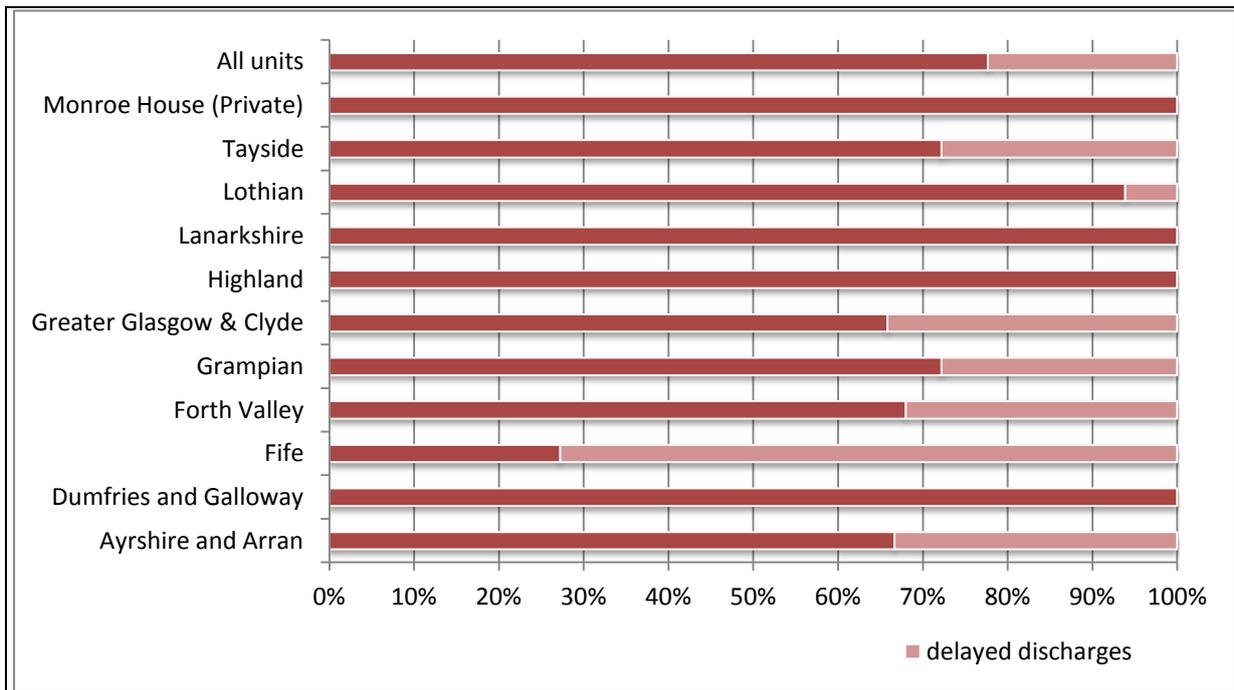
The legal status of all patients in the assessment and treatment units in June 2011 was as follows:

- 71% of people were subject to the Mental Health (Care and Treatment)(Scotland) Act 2003 (MHA)
- 2% were subject to the Criminal Procedures (Scotland) Act 1995 (CPSA)
- 27% were informal patients.

There was a considerable difference between units in the proportion of people subject to legislation. This ranged from units where 44% of people were detained to units where 100% were detained. Whilst there are some variations in the functions of the units and in the population they provide for, we believe this variation is more likely to be due to the differing practice of consultants and their interpretation of the Mental Health Act. 18% of people were on welfare guardianship orders under the Adults with Incapacity (Scotland) Act 2000 (AWIA).

We were concerned to learn that 22% of people in the units were designated as delayed discharges, as reported to the NHS Information Services Division. This included people for whom a placement had been identified but the move had not yet happened. Table 2 (Appendix) and Figure 1 below outline the situation in June 2011, as reported to us by the Clinical Service Managers in each health board.

Figure 1 Percentage of individuals subject to delayed discharge in learning disability hospital units, June 2011



Obviously numbers of delayed discharges will vary considerably over time, depending on the availability of robust resources and providers that can meet very complex needs, on funding availability from different local authorities and on the time scale for opening new facilities or acquiring suitable housing. We are aware that new resources will come on stream in Fife and Grampian in 2012.

THE PEOPLE WE VISITED

We looked at the care and treatment of 113 people, about half the hospital population at the time of the visits. As far as possible, the number of people we saw was proportionate to the size of the unit (see Table 1 Appendix). We focussed on those individuals who asked to be seen; as many of those identified as delayed discharges as possible; some people who were subject to restrictions such as restraint or seclusion; and a random sample of other people from the list supplied by each unit. Although we examined records for 113 people, not all of them were able or willing to meet us face to face. We conducted personal interviews with 70 of the 113.

21% of patients we saw were informal patients, 75% were subject to the Mental Health Act and 4% were subject to the Criminal Procedures Act. The gender and age of people we saw is shown in Table 3 (Appendix). Of the people we saw on our visits, 39% were women and 61% were men.

In almost all cases, people we visited had more than one diagnosis, as shown in Table 4 (Appendix).

We asked about people's length of stay in hospital. Women tended to have shorter admissions than men. 57% of women were in hospital for less than 3 years compared to 37% of men. 34% of people visited had been in hospital for over 6 years. Only 16% of women we saw were in hospital for over 6 years, compared with 45% of the men. The information is set out in Table 5 (Appendix). These findings on gender differences and the length of stay in hospital are similar to those found in the MWC's 2010 census of all people with learning disabilities subject to compulsory treatment in Scotland.²

NEED FOR HOSPITAL CARE

For the majority of people with a learning disability care and support can be provided by social care organisations. For the people we saw, it was clear that the complexity or severity of their presentations meant that a period of assessment and treatment in hospital was necessary and in some cases, that hospital would be the only appropriate care setting for many years. The following case vignettes provide examples of the sorts of difficulties identified in determining the need for hospital based care.

Mr K is a middle aged man with a diagnosis of mild learning disability. He has been in NHS care for many years. He was initially admitted following his conviction for a serious sexual assault on a child and has made little progress despite considerable specialist input and frequent attempts to help him understand the seriousness of his behaviour. He does not agree that he has done anything wrong or that he needs any support. He absconded from hospital in the more recent past and when he was found he was in possession of a weapon that was similar to that used in his index offence. He therefore poses a significant risk to the community.

Ms D was admitted on a short term detention certificate following her referral to services. She was abusing alcohol and drugs, relying on other addicts to inject her with heroin as she was unable to do so herself, had been seen begging and offering sexual favours in return for money and had been seriously sexually assaulted on at least one occasion. She had not eaten for several days and had several infected sores on her legs. She was unable to comprehend the risks that she was taking. Following assessment and a period of in-patient treatment she was discharged with the added protection of a guardianship order.

Mr B has a history of depression and a mild learning disability. He also picks his skin until it bleeds when he is anxious. He was admitted compulsorily to hospital following a number of episodes of attempting to kill himself, including overdose and walking onto a railway line. He was initially admitted to an adult acute ward but was subsequently moved to a specialist learning disability ward where he was better known. He has had a number of previous admissions but it has proved very difficult on this occasion to effect any

² http://reports.mwscot.org.uk/web/FILES/Visiting_Monitoring/LD_Census_2010.pdf

sustained improvement in his mental health. He continues to express suicidal ideas and also has episodes of verbal and physical aggression.

SUMMARY OF MAIN FINDINGS AND RECOMMENDATIONS

The main points from our findings are summarised in the key messages and recommendations below. This is followed by the more detailed information collected from service users, staff, relatives and records, on which we have based our recommendations. We have cited some examples mainly of good practice we noted from our visits in shaded boxes in the text. We would hope these would be shared between services.

We were pleased to find that

- Access to physical health care was good and nearly everyone we saw had had an annual health check, although this could be improved by use of a learning disability specific check.
- Risk assessments had been carried out and risk management plans were in place
- Care plans addressed physical, mental and behavioural issues
- There was good multi disciplinary working with reasonable access to specialist assessment where required
- People were engaged in meaningful activity. Services seemed to recognise how important this is for wellbeing and recovery.
- Where appropriate resources and providers were identified, the transition between hospital and community was well managed.
- People were generally involved in discussion and review of their care plan and in discharge planning
- There were a number of good examples of how users were being enabled to participate in their own care and to give their views on the service as a whole.

There were some concerns which require the attention of the services visited or the relevant health boards. The most significant are

- The number of delayed discharges in some areas
- Environmental issues such as maintenance of buildings and gardens and the availability of kitchen and laundry facilities to allow people to maintain and develop their skills
- Care plans which concentrate on health and behavioural concerns but do not adequately address the person's social needs
- The cancellation of activities due to staffing, transport and budgeting issues
- The level of participation and involvement of service users with considerable variation in accessible information, user friendly care plans, appropriate signage, and pro active user and carer feedback
- Consent to treatment documentation which does not conform to the recommendations of the Adults with Incapacity Act Part 5 Code of Practice.

Key Messages 1: Health Needs

Regular health checks were carried out, but they were often not specific to the needs of people with learning disability. Treatment was not always in line with best practice under relevant legislation

Recommendations: Health Needs

- **All assessment and treatment units should ensure people have an annual health check, preferably learning disability specific, and there should be a clear record of these.**
- **Consent to treatment documentation under the AWI Act and the Mental Health Act should be regularly audited to ensure it is legal and in line with the codes of practice.**

Key messages 2: Rights and restrictions

Restrictions, when used, appeared to be lawful and necessary. Risk assessment and management plans were good although 10% did not have a review date.

Recommendations: Rights and Restrictions

- **There should be clear dates set for review of risk assessments**

Key Messages 3: Quality of Life

The environment

Not everyone was able to be involved in activities of daily living or to access peaceful and less stimulating areas inside and outside their ward. Information for patients was often not provided in a suitable format.

Recommendations

- **Assessment and treatment units should ensure people have access to the appropriate facilities to enable them to maintain and develop their daily living skills whilst in hospital.**

- There should be a quiet area in all units
- Gardens should be safe and maintained to a reasonable standard
- Units should ensure that signage and information is provided in the most accessible format for the people using these facilities

Assessment and Treatment Plans

General assessments and, where appropriate, specialist assessments were well provided. However, in a third of cases, care plans did not provide or did not reflect a holistic approach to care.

Recommendations

- Care plans should reflect the holistic needs of the person and the input from specialist assessments

Activities

Activity plans were individualised, with a good range of opportunities but difficulties in implementation were noted in 20%. Recording of participation was poor.

Recommendations

- Services should ensure that activities are supported by adequate staffing, transport or social budgets
- There should be a clear record of participation in activities and of the reasons for cancellation of activities and these reasons should be addressed

Discharge Planning

Discharge planning and management was good. The discharge of those with complex needs who no longer require NHS care should be carefully monitored to minimise delay.

Recommendations

- NHS Boards need to work closely with local authorities and providers to re-examine how the needs of those with very complex needs who are delayed discharges can be addressed.

Key messages 4: Participation and involvement

There was good evidence of individual participation in care planning and reviews. Support with communication, whether by physical means such as Talking Mats or the use of advocacy was variable.

Recommendations: Participation and Involvement

- **Units should examine ways in which people's involvement in decisions about their own care and treatment can be increased. This should include Speech and Language Therapy input to enhance communication of options and users' choices and to maximise their understanding of the processes and policies. The involvement of advocacy is also important and should be encouraged.**
- **Units should share good practice in providing accessible information about their service and getting feedback from service users.**

HEALTH NEEDS

Key Messages 1: Health Needs

Regular health checks were carried out, but they were often not specific to the needs of people with learning disability. Treatment was not always in line with best practice under relevant legislation

Detailed Findings 1: Health Needs

People with learning disabilities have higher than average rates of particular medical conditions. 25% have epilepsy, whilst 47% and 63% have hearing and visual impairments respectively. There is a higher incidence of respiratory disease, coronary heart disease, dysphagia (swallowing problems), osteoporosis, hypothyroidism, diabetes, urinary tract infections and injuries due to falls. There is also a higher incidence of mental illness and behavioural difficulties. People with learning disabilities also have a lower life expectancy and the causes of death have a different distribution from the general population. Due to this different health profile,

strategies to improve the health of the general Scottish population are unlikely to have a significant impact on the health inequalities experienced by those with learning disabilities.³ More focussed health promotion strategies are needed to address the needs of this client group.

What we expect to find

- The person has had a health check in the last year, preferably a learning disability specific health check
- The person can access specialist input where this is required
- For anyone on medication, either the person is able to give informed consent or the treatment is legally sanctioned by the Adults with Incapacity Act or the Mental Health Act. Where medication is being given under the AWI Act, a section 47 Certificate of Incapacity and a treatment plan should be evident in the person's records. Where it is being given under the Mental Health Act, the appropriate documentation and safeguards have been observed.
- There is a policy in place with regards to the administration of covert medication.

What we found

Health Care

Twelve of the 20 units use GP services and 8 use a hospital doctor. All patients have a physical health check on admission.

All units except one carried out annual health checks, which was an improvement on our findings in 2007. Very few of these, however, were learning disability specific health checks. We were told by several services that learning disability specific health checks were more likely to be done by Community Learning Disability Nurses when individuals were in the community, rather than in hospital. Where there were any concerns picked up in hospital, the individual is referred on for specialist advice. However more specific health checks are likely to pick up on health issues which are asymptomatic and only evident from testing, such as tests for the presence of *helicobacter pylori*. We would therefore recommend learning disability specific health checks.

We saw some examples of good practice. The NHS Grampian booklet 'Annual Health Screening for Inpatients with Learning Disability' forms a very comprehensive annual health check. Monroe House used a learning disability specific health check and the Speech and Language Therapist used Talking Mats to prepare individuals for their health check.

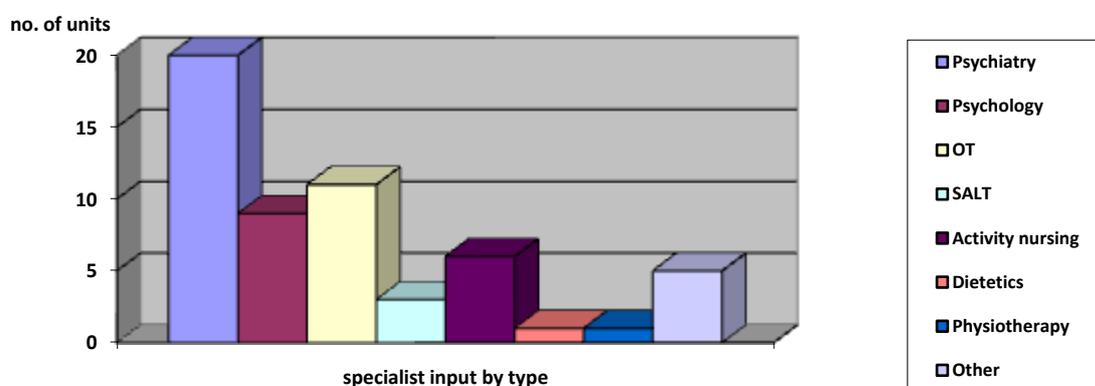
³ Emerson E., Baines S. Health Inequalities in People with Learning Disabilities in the UK:2010, Improving Health and Lives: Learning Disability Observatory, 2010

We were concerned about the lack of a system for recording annual health checks and review dates in several units.

Specialist Input

All units reported they had access to the following specialist services: psychiatry, psychology, occupational therapy (OT), speech and language therapy (SALT), physiotherapy and dietetics. Figure 2 indicates the number of units that had dedicated time from these professionals. For the remaining units, access to specialist services was by referral.

Figure 2 Incidence of dedicated specialist input in learning disability inpatient units



Services such as ophthalmology and audiology were accessed by referral in all cases. Most units used local opticians and dentistry services where possible but a number of patients required referral to specialist services.

We noted the success of the RNIB'S Bridge to Vision project based at Arrol Park Resource Centre in Ayrshire. They provide a pre-assessment visit to people with a learning disability and can accompany individuals to the optician or can arrange for the optician to come to the person. They also provide training for optometrists and dispensing opticians which includes communication with people with learning disability and alternative testing methodologies.

Very few units reported difficulties accessing specialist services. Several units in the same health board reported a variable response time from psychology and OT services across their area. They were setting up a single contact point for allied health professional referrals to monitor this, identify specific areas where there were difficulties and hopefully improve the consistency of allocation.

Consent to Treatment: Adults with Incapacity Act

Medical treatment for people who lack capacity to give informed consent is covered by the provisions of part 5 of the Adults with Incapacity Act.

Of the 89 people who had been assessed as lacking capacity to consent to their treatment 55 had a certificate with an accompanying treatment plan. This is in line with the code of practice where treatment for more than one or two problems is required.

For those individuals where there was a certificate but no accompanying treatment plan, in 31 of these cases a treatment plan may have been indicated as recommended under Part 5 of the Act. Annex 5 of the Part 5 Code of Practice gives examples of treatment plans.

Five of the people we reviewed had no section 47 certificate in place at all, even though they were unable to consent to the treatment being given. It is unlawful for staff to be administering medication without proper legal authority. Where staff are not clear about the legal authority then they should discuss this with the appropriate member of medical staff as soon as possible. Any treatment should however be continued. For example the MWC visitor to one unit commented -

We found that staff were not clear where section 47 certificates were kept, some could not be found on the day and one was out of date. In addition there was no clear record of annual health checks.

There were 24 people who did not require a S47 certificate. Where necessary, their treatment was given under the authority of the MHA or they had capacity to consent to treatment.

Consent to Treatment: Mental Health Act

73 people visited had T2/3 consent to treatment forms in place but we found in two cases that the treatment being given had not been properly authorised in the forms. There were also a number of T3 forms that were over 3 years old. The Commission recommends that, even where medication has not changed, a Designated Medical Practitioner opinion should be sought every 3 years.

Issues with consent to treatment for individuals were raised with staff on the day of the visit or fed back to the service by letter.

Covert Medication

Staff reported that four people were receiving medication covertly. In all cases this was in line with the Commissions guidance⁴.

Recommendations 1: Health Needs

- **All assessment and treatment units should ensure people have an annual health check, preferably learning disability specific, and there should be a clear record of these**
- **Consent to treatment documentation under the AWI Act and the Mental Health Act should be regularly audited to ensure it is legal and in line with the codes of practice.**

RIGHTS AND RESTRICTIONS

Key messages 2: Rights and restrictions

Restrictions, when used, appeared to be lawful and necessary. Risk assessment and management plans were good although 10% did not have a review date.

Detailed Findings 2: Rights and restrictions

What we expect to find

- Risk assessments and management plans to address these risks are in place.
- Where there are behaviour management plans, particularly those which involve restrictive measures such as physical restraint or seclusion, these are regularly audited, reviewed and are within the law.

What we found

⁴ http://www.mwcscot.org.uk/web/FILES/Publications/Covert_Medication.pdf (insert reference)

Risk Assessment and Risk Management

In 106 of 107 records examined risk assessments had been carried out and clearly recorded in case files with details of the type of risk. Dates to review the risk assessment were evident in 90% of cases.

Plans indicating how the identified risks were to be managed were evident in 103 of the 106 assessments we looked at. These were set out either in a separate risk management plan, in a behaviour management plan or in the nursing care plan. Good individualised practice examples included:

In Waterloo Close a young man was being encouraged to go out and about with his relatives and support workers. There were clear protocols in place to minimise the challenging behaviour that arose from his anxiety at transition times. This included being given information about going out shortly before this was due to happen, staff being alerted by a phone call to ensure he was ready to go with his coat on when his relative arrived and any relevant information was given to them, and there was to be a swift exit with no delays at the door as he left.

In Overtoun Court staff were working on giving Mr R responsibility for managing his aggressive outbursts. If he felt he was going to 'lose it', he would alert staff to this, go to a quiet area and, if need be, indicate to staff that he needed PRN medication.

Evidence of positive risk-taking was noted by MWC visitors in about two-thirds of the plans we saw. For instance:

One Commission visitor to Greenbank noted 'Despite the risk of absconding and falls, Mr T is encouraged to participate in activities outwith the unit. To maximise his independence he is encouraged to move on his own between the unit and the therapy department, although he can be observed by staff.'

In Blythswood most service users, even those with very challenging behaviour, were accessing community resources, such as sports centres or college courses. Staffing levels often started at 2:1, then 1:1, then escorted travel but no staff presence in the class, then in a few cases unescorted outings.

Restrictions: Specified Persons

Of 113 people, nine were designated as Specified Persons as set out in Sections 281-286 of the 2003 Act and the associated regulations. Specified Persons are detained patients who have specific restrictions imposed on them with regard to interception or withholding of mail, access to phones, searching of the individual or their visitors or other restrictions required for the safety and security of the hospital. Seven people were specified in terms of Safety and Security in Hospitals, one in terms of the Use of Telephones and one in terms of both. These measures are used

to protect others, as well as to safeguard the rights of those who have specific restrictions imposed on them.

In eight cases, the restrictions complied with the requirements of the legislation. In one case the measures were being used but the documentation had expired. This was immediately rectified when it was brought to the attention of staff.

Restrictions: Restraint

We looked at the use of restraint over the previous six months. Twenty of 113 people had required some level of physical intervention in that time. Three of these had required floor restraint, the remainder seated restraint or minimal guidance from one area to another. Six of the 20 were restrained on a regular basis (from fortnightly to daily restraint), the remainder on an occasional basis.

All staff had appropriate training. We were made aware of one incident of inappropriate restraint techniques having been used and one unit was unable to find the record of restraints for us. This will be followed up. In all other cases the appropriate records were seen.

Restrictions: Seclusion

We looked at the number of people subject to periods of seclusion in the previous six months. Of 109 cases, eight people have this as part of their management plans, and this is audited and regularly reviewed by the multi disciplinary team. Five of the people involved are in one health board and this would appear to correlate with the greater availability of designated seclusion areas in that health board. Only three of the units visited have designated seclusion rooms. Seclusion is often used in preference to restraint or “as required” medication and at times in addition to these.

Restrictions: CCTV

CCTV was being used appropriately. Eight units had CCTV for external security, three used CCTV in designated seclusion rooms for observation and one for monitoring a corridor area.

Recommendations 2: Rights and Restrictions

- **There should be clear dates set for review of risk assessments**

QUALITY OF LIFE

Key Messages 3: Quality of Life

The environment

Not everyone was able to be involved in activities of daily living or to access peaceful and less stimulating areas inside and outside their ward. Information for patients was often not provided in a suitable format.

Assessment and Treatment Plans

General assessments and, where appropriate, specialist assessments were well provided. However, in a third of cases, care plans did not provide or did not reflect a holistic approach to care.

Activities

Activity plans were individualised, with a good range of opportunities but difficulties in implementation were noted in 20%. Recording of participation was poor.

Discharge Planning

Discharge planning and management was good. The discharge of those with complex needs who no longer require NHS care should be carefully monitored to minimise delay.

Detailed Findings 3: Quality of Life

What we expect to find

For a high proportion of the people we saw, the hospital unit was their 'home' for months or years, rather than weeks. We therefore had a number of expectations for their quality of life, including:

- a clean and well maintained environment with an enclosed garden. People should have their own rooms and there should be a variety of sitting areas, including a quiet area. Facilities should enable service users to maintain their daily living skills, have space for activities and have privacy for visitors. There should be good signage to assist with orientation.
- a choice of food

- a care plan that addresses their mental and physical health needs, behavioural difficulties, communication and social needs
- a clear and accessible plan of day to day activity that reflects their choices, needs, age and abilities. This should include therapeutic, social, educational and recreational activity, as well as opportunities to maintain or develop daily living skills. People should have the opportunity of activity outwith the hospital unit, whenever possible. Transport and staffing levels are needed to support the use of community resources on a regular basis.
- full entitlement to benefits and the management of their money, including savings, in line with the principles of the Adults with Incapacity Act i.e. it is being used for the benefit of the person, in a manner that maximises their skills and in the least restrictive way
- a discharge plan

What we found

Environment

There were 29 separate units on the 20 sites we visited. Twelve of the 29 were single sex.

Three units were not clean and these were all within the same health board. In particular there were comments from our visitors and some service users about the smell of urine in all the toilets, apart from the staff toilet, in one unit; a smell of urine in the sitting room and the shabbiness of the chairs in another; and a stale smell and general lack of cleanliness in a third. These issues were followed up with the Clinical Service Manager.

Two other units were described as run down but were awaiting refurbishment

In another the MWC visitor described a number of problems.

We were informed that £50,000 was spent on the unit last year but it is still quite shabby with marks on most walls and small repairs waiting to be done. The shower/bathroom areas had unpleasant smells. The garden area was covered in cigarette ends mainly from staff who smoke. Residents informed us that they used to have individual keys to their rooms until recent renovations. Now all room locks use the same key and residents felt their rooms were not as secure. The general layout of the building gives a homely feel but it is not conducive to managing the difficult and challenging behaviour that frequently occurs.

Maintenance is crucial. There were comments on a number of units in this regard. For instance, one manager commented, 'these units are in need of decoration. Given the client group, this requires to be a fairly continual process to maintain a pleasant environment.'

Environment: Communal Areas

Nearly all the units were relatively quiet on the day of the visit, though one had a TV on when there were no service users in the building. One had given consideration to reducing noise for people who were hypersensitive to noise. In another, efforts were made to take the louder people out together to give others quiet time. Five units did not have a separate quiet area.

In half the units the kitchens are open. Service users may, if able, make their own drinks, snacks and in some cases meals. The reasons for kitchens being locked were mainly related to safety, although in one unit we were told that, even if all service users were assessed as being safe to use the kitchen, this would not be allowed 'under health and safety'. This seems an unnecessary restriction in such circumstances. Water and drinks were available in units with locked kitchens at intervals throughout the day and people could ask at other times.

In 18 units service users could do their own laundry with support. 11 units were unable to offer this. In some, even if people were able to do their laundry, we were again told that health and safety policies prevented this. We feel health and safety policies must take into account the function of a unit. In assessment and treatment units for people with learning disabilities it is important that individuals are not deskilled by their hospital admission.

Seventeen units said they had space and equipment to support activities in the unit. In many units rooms were multi-purpose and dining rooms or quiet rooms were also used for activities. 10 units reported they had no space available for activities.

Twenty one (of 29) units were locked during the day. Nearly all units had a locked door policy to support this. However some were out of date and there were very few who had accessible information to explain the policy to them.

Kylepark in Lanarkshire was a good example of a unit with user friendly information with pictures in relation to locked doors

Environment: Bedrooms

Everyone had their own bedroom with the exception of one unit which had two rooms for two people. We asked people to show us their bedrooms and all of the 53 bedrooms we saw were personalised, although a small number were sparse as the person could only tolerate the minimum of items around them.

In Lochview we noted the attention paid to ensuring each person's bedroom was personalised and reflected their individual tastes. We thought this was a good use of people's funds and some who were able to show us their rooms were obviously delighted and very proud of them.

Examples of comments we made about bedrooms

Lots of Aberdeen memorabilia and family photos - nice room.

Really nice room with his own home made furniture

A has bought storage boxes, pictures and her own bedding ... She took pride in showing her room which she keeps tidy herself.

Very few negative comments were noted about the rooms: in one unit some toilets were without lids; one bedroom had frosted glass instead of curtains for safety reasons [the staff member agreed to look into the possibility of putting up curtains using velcro as the individual was upset by his room being different].

In 8 units the bedroom doors were locked, the reasons being largely for the protection of individuals' property, though people could access their rooms on request. Of the 76 service users we were able to interview, three were not able to access their rooms at times but for specific reasons, as one person commented, '*If I go to my room I would sleep my life away.*'

Environment: Garden

All units had access to a garden, though doors to them were nearly all locked. This was sometimes due to a few individuals requiring a staff presence, if they were outside.

Several gardens were poorly maintained and equipped for the group they served and the opportunity of a valuable work and recreational resource was missed. However we saw some examples of imaginative use of the garden area.

In Netherton, for example, each person had a small area of the garden for themselves as a vegetable plot, each with a mini polytunnel. Vegetables were used in the unit's menu. Service users were involved in cooking their own meals with the support of staff, if required.

Five of the people we interviewed in person – all in different units - said that they worked in the unit garden.

Some gardens were used as smoking areas and were marred by cigarette ends. There was a smell of smoke in one unit, where in fact none of the service users smoked.

Catering

Where this was commented upon by individual service users, equal numbers praised and criticised the food provided.

Food is good here, I am slow at eating, that is ok. I like cereal, Weetabix is my favourite, "do they always have it?" Yes.

Carry out meal on a Saturday - different ones.

The food is not good. You can't choose your meals.

The food is terrible here. You don't get a three course meal anymore - I would like custard. Always sandwiches for dinner - Usually hot meal at tea is good.

Recommendations

- **Assessment and treatment units should ensure people have access to the appropriate facilities to enable them to maintain and develop their daily living skills whilst in hospital.**
- **There should be a quiet area in all units**
- **Gardens should be safe and maintained to a reasonable standard**
- **Units should ensure that signage and information is provided in the most accessible format for the people using these facilities**

Assessment and care and treatment plans

Nearly everyone had a general needs assessment completed on admission to the unit. Most used a specific assessment tool such as FACE (Core Assessment and Outcomes for Learning Disability with the Risk Assessment tool); or HoNOS-LD (Health of Nations Outcomes Scales for People with Learning Disability) for people with a learning disability and mental health needs; or their own tool. One unit only completed a risk assessment and did not have a generic assessment. There was some variability as to how fully these forms were completed.

87% had had one or more specialist assessments, such as SALT, OT or psychology. In 3 cases staff were aware that assessments had been done but these could not be found in the file. For example in one instance the SALT had assessed and drawn up communication guidelines but these could not be found

Of 100 care and treatment plans examined, three were several years old and needed updating. 38 plans covered some but not all needs. Most of these fully addressed mental and physical health needs and behavioural issues but did not address areas such as communication, social needs, relationships, family contact, skills building and aspects of emotional wellbeing such as building self confidence and self esteem.

The documentation did not always evidence the care that was being given. Looking through the records there were usually other documents, which, if read in conjunction with the care plan, outlined the care being given. These documents included Essential Lifestyle Plans, personal planning books, users' daily activity plans, specialist assessment and guidance and so on. In general staff knew service

users well and were clear on the care and treatment they were providing but this was not pulled together into one cohesive care and treatment plan.

Fifty-nine care and treatment plans out of the 100 covered all identified needs. They addressed the majority of issues above, where appropriate to that person. There were clear goals set out and the interventions to work towards these goals were specific and individualised. Specialist assessments informed the care and treatment plan as in the example below.

Sarah's care and treatment plan is very much based on positive skills building with clear objectives and interventions which support these. She is a young woman with a mild learning disability, a history of abuse and significant behavioural difficulties, including self harm and violence towards others. She had a structured behaviour management plan to encourage positive behaviours and development of her independent living skills and to minimise her inappropriate behaviours such as aggression and self injury. Her care plans included improving her self esteem, confidence and self management of her behaviour; gradually withdrawing restrictions and developing community access with 1:1 outreach support; promoting a healthier lifestyle through weight loss and activity; reintegrating her into her local area; home visits and leave to a local respite facility with an opportunity to see her family; monitoring reduction of her medication; psychological support to discuss past issues, self management of her finances.

Recommendations

- **Care plans should reflect the holistic needs of the person and the input from specialist assessments**

Activities

We were pleased to find that there were written activity plans for 87% of 105 responses. The 13% who did not have a structured timetable were engaged in activities on a more ad hoc basis, depending on their mental or physical health difficulties.

On our last themed visit to these units in 2007, although people were involved in various activities, very few had activity plans. We felt the emphasis on the value of meaningful activity had increased and was a more integral part of the therapeutic process.

There were many examples of programmes that reflected the individual's therapeutic needs as well as their interests, and offered a range of opportunities on and off site. These included a whole variety of work, educational, sensory, creative, sporting, social and recreational activities, as well as daily living activities such as laundry, cooking, and other household chores. Many offered new opportunities for people or demonstrated individualisation. For example a group at Blythswood were doing

drama sessions with Theatre Nemo, whilst an individual at Greenbank had built a greenhouse out of plastic bottles in the garden and was using it to grow tomatoes. There was a limited number of structured activities on some activity planners due to the person's mental health or behavioural difficulties but these reflected current need rather than lack of thought.

In contrast the quality of the activity plans in three of the units could have been improved. Some gave the appearance of structuring the person's week but were largely composed of unspecified activities- e.g. community activity, outing, in house activity, choice of activity and so on. 'In house activities' on either a unit timetable or an individual timetable does not enhance the engagement of people. It is much more meaningful to have the option of two or three in house activities that the individual is known to enjoy to help them make a choice. Similarly if it is on a unit timetable with no pictures or symbols, it has little value as a means of communication with service users.

The MWC visitor reported the views of one service user about the lack of individualised activities.

Ann would like to go out more and repeatedly asked myself and her advocate to take her out. She wanted to make arrangements for outings. She wanted to do more cooking and gardening. The advocate said that most activities were provided by a team who were not based in the unit. She felt they were not individualised and did not reflect that Ann is more able than others.

Thirteen (12%) people we saw were not able to have planned activities on a number of occasions because staff were not available to make it happen. In most cases this was because people required 1: 1 staffing or more (up to 4:1 in one instance). In some instances high levels of staff for one patient can lead to the cancellation of activities off-site for others. Staff in eight different units highlighted this as a problem. One unit commented that 'more able patients often had things cancelled at the last minute and were left disappointed with nothing to do.' One unit had had difficulties due to a number of staff retiring around the same time, service redesign had slowed recruitment and staff had had to be moved from other units. This impacted on people getting out, as they needed someone who knew them well. Two other units reported the difficulties posed by high rates of staff sickness.

In three cases availability of transport or drivers was a problem Responses in the staff questionnaire also identified the inconsistency in budgets for social activity. In most units staff costs in accompanying people are met. In a few units the person has to pay the first £3.50 of staff costs. In one unit we were told there is no budget, so sometimes patients pay for staff, on other occasions staff pay for patients.

Many units struggled with the best way to record participation in activities. Many record this in the chronological account of care and most allied health professionals record in these notes, as well as keeping their own records. However it can be difficult to extract the level of participation over a period of time, or identify where problems in participation lie, without trawling through copious notes. Some units have forms where participation is recorded, along with comments on the level of

engagement and reasons if a planned activity is cancelled. This gives a more immediate overview, but even these were not always consistently completed.

Recommendations

- **Assessment and treatment units should ensure that activities are supported by adequate staffing, transport or social budgets**
- **There should be a clear record of participation in activities and of the reasons for cancellation of activities and these reasons should be addressed**

Finances

The hospital managed finances for 65% of people we visited, either by DWP appointeeship Part 4 of the AWI Act or both. Families and carers managed finances in 22% of cases, 7% of people managed their own finances and 6% were managed by financial guardians or attorneys.

There were financial problems in four instances- there was difficulty accessing funds from bank accounts in two cases, a dispute over a Power of Attorney in another and one person refused to spend his money.

We heard of a number of examples of imaginative and thoughtful ways of spending people's savings to improve their quality of life.

One man for his birthday had booked a show in Edinburgh that he particularly wanted to see. He took one of his friends from the same unit and they were accompanied by two staff. They stayed overnight in a hotel.

One man who wanted to get fit used his finances to have sessions with a personal trainer

One man had a passion for a particular Celtic design and constantly carried pictures of it with him. Staff arranged for a silversmith to make a copy of this for him

We were told of someone who was terminally ill, who paid for his sister to come over from Canada. He was thrilled to see her. He also made arrangements for her to come over to plan and be at his funeral. Staff reported this made a huge difference to the remaining months of his life.

Discharge Planning: Delayed Discharges

We looked at the records of 30 of the 48 people whose discharge was delayed and interviewed 22 of them to establish the reasons for these delays.

Six of these people had placements arranged and were waiting to move or in the process of moving. A further five had an identified placement but there were administrative delays such as problems with the lease of the building. Three people had insufficient funding allocated to them for the model of care they required and this was being re-examined by the local authorities concerned.

The most significant difficulty was finding a suitable resource for people with very complex needs. Sixteen people were in this position, one of whom was also unsure about funding. This group of people had additional behavioural difficulties, including verbal and physical aggression, sexually inappropriate behaviour and sexual vulnerability. They generally required robust providers with experience of managing these issues. Robert provides an example of the level of need of many of this group.

Robert has a moderate learning disability, long standing problems of verbal and physical aggression and demanding behaviour and has in the past made unfounded allegations of assault. He is now at a point where it is unlikely that there will be much change in his presentation. He does not require a hospital setting but needs a care setting that can provide a safe environment for him and those around him. Staff will need to continue actively managing his behaviour, noting predictors and perseverating factors. Such a placement would allow him to maximise his abilities and social and recreational opportunities and minimise his periods of distress.

The situation seemed to be similar to that in 2007, when there were 68 delayed discharges of 388 patients (this included forensic patients) across Scotland. A number of units said they expected the numbers of delayed discharges to increase with the strain on local authority resources.

Discharge Planning: General

In addition to those who were designated as delayed discharges, there were a further 18 people who were actively working towards discharge to a variety of community settings. Eight had identified placements and were in the transition process. Two others had identified placements but were waiting for agreement on funding. Seven were still at the stage of looking for a suitable placement and one had just recently been referred to Social Work to begin discussion on the options.

We were generally impressed with the transition planning between health, social work and providers, where placements had been identified. All those who were moving to supported living situations had the proposed providers working with them several times in the week and were becoming familiar with the staff who would be supporting them, in some cases residents they would be sharing with and the area they were moving to. In most cases there was continuity in the multi disciplinary

team planning and supporting the person. In some cases ward staff planned to have contact for a period after discharge to support the person and their providers.

There were two individuals who were awaiting a move to alternative hospital care but beds were currently unavailable.

Recommendations

- **NHS Boards need to work closely with local authorities and providers to re-examine how the needs of those with very complex needs who are identified as delayed discharges can be addressed.**

PARTICIPATION AND INVOLVEMENT

Key messages 4: Participation and involvement

There was good evidence of individual participation in care planning and reviews. Support with communication, whether by physical means such as Talking Mats or the use of advocacy was variable.

Detailed Findings 4: Participation and involvement

What we expect to find

- Each person has an individualised care plan
- People are involved as far as possible in that plan and reviews of it and in discharge planning
- Preparation and assistance is provided to enhance the person's communication and involvement in the process
- Access to advocacy
- Information in the unit is provided in a user friendly format
- Appropriate involvement of families and carers

What we found

Care and treatment plans and reviews: supporting service users

As outlined above care plans varied in quality. Some addressed individual physical, mental health and behavioural needs but did not always incorporate the person's holistic needs and choices. Some were excellent and were very person-centred. A

number of people had Essential Lifestyle Plans or Personal Life Plans, which were reflected in the care plan. Most people, where able, attended their reviews or part of their review.

The key nurse or named nurse generally met with the person before the review of their care plan to help them express what they felt about their plan and what needed changing. Good practice examples include:

In Mayfield these 1:1 meetings between the nurse and service user are on a weekly basis, and discussion on the care plan or any other issue are clearly recorded.

In Blythswood and Netherton people have a user friendly copy of their care plan, setting out how they communicate, their self care and domestic routines, activities they are involved in, their psychological needs and so on. This is compiled with the service user and illustrated with symbols or pictures of that person doing the task or activity.

In Elmwood (Bracken ward) service users have accessible care plans that have been created with the assistance of Talking Mats. These are proving a very effective communication aid and extend user choice. In Elmwood (Fern) the specialist dietician uses pictorial aids to help people understand her recommendations regarding diet options

Similarly in Monroe House, Talking Mats are used to prepare people for Care Programme Approach meetings, health checks and other events, as well as to support behavioural change.

Care and treatment plans and reviews: Users' Views

Service users we interviewed told us a bit about how they were involved in their own care. There were 43 people who said they attended meetings about their care. They said that they were listened to, they heard about plans for their future and one person said she made suggestions about what she would like to do. Many of them mentioned who was at the meetings. A few said that their independent advocate and, in some cases, a relative went to the meetings with them. In a few cases the person said that they attended the meeting only for a short time or there was an indication that their participation was limited.

Twenty people said that they did not attend meetings about their care, mostly because they did not want to go. Thirteen of them said that others (family or an advocate) went to the meetings, and may or may not have kept them informed.

'My mum goes to meetings but I don't know what they say at the meetings. There is a meeting tomorrow that my mum will go to. I think they will talk about me living at my mum's when I go home.'

In Primrose Lodge, where most people are unable to participate in meetings, there is an initiative to look at this. There is a general service user involvement sheet to prompt thinking about ways to enhance participation by looking at barriers and ways to overcome them. In addition pre and post meeting sessions are held with the individual to try to gain views and then inform about decisions/plans.

In a few cases the person was dissatisfied with their involvement. In one case the visitor noted:

'There was a meeting last week but she wasn't given the chance to go along. Advocate meant to update her but hasn't been in touch. The person concerned said that her mother had been to some meetings in the past and she herself would like to go along to find out what was going on.'

Advocacy

All units said that they had access to advocacy services but reported different levels of involvement. Information was displayed about advocacy in only ten units. Some units, such as Elmwood, had consistent advocates for a number of people and they often attended team meetings, as well as supporting people in Mental Health Tribunal Service proceedings. In some units advocacy had involvement when discharge plans were being developed, in others it was restricted to involvement in Tribunal proceedings. Four units expressed concerns about some aspect of the advocacy service – these included difficulties with availability of the service, consistency of advocate, lack of clarity of some advocates about their role and some advocates raising unrealistic expectations. Others, such as Arrol Park, were very positive about their availability, the consistency of personnel and their contribution in supporting service users' opinions.

Provision of information about the service

We looked at the efforts units had made to inform people about their service, as well as seek their views on how this can be improved. The responses were very varied.

Some units provided a user friendly introduction to the unit. For example, Elmwood has a welcome leaflet with basic information including what to bring with you, what will happen when you come in and visiting arrangements.

Mayfield have invested a lot of effort in producing a very comprehensive induction booklet, using pictures and symbols, which includes clear information about the facilities and layout of the unit, the daily routine, the roles of people who will be helping the user, the care plan, visiting arrangements, what to bring and so on.

In some units, such as Kylepark and Elmwood, efforts have been made to make information and policies and procedures accessible. In Elmwood, Boardmaker has been used in the design of some information posters about the ward, the complaints process and the locked door policy.

User friendly signage to identify rooms was evident in 18 of the 29 buildings we visited. In some services there was little evidence of good signage, user friendly care plans, accessible policies and procedures, induction leaflets, accessible menus and so on.

We saw some good examples of units who actively seek service user feedback in a variety of ways. Service users in Netherton had helped to construct an easy read questionnaire, which is filled in annually. Blythswood use a similar questionnaire. In Elmwood advocacy support individuals, carers and families to attend forums and say what they think of the service. The Lothian Health Board units have service wide meetings supported by SALT and advocacy to get users' views. The Greater Glasgow and Clyde Health Board services are similarly setting up a service user forum across all four units facilitated by the Equality and Diversity support worker.

Contact with Family and Carers

Ninety-three of the people we saw had contact with relatives. It was clear staff were committed to supporting people in maintaining these contacts. This involved helping with phone calls, assisting with visiting arrangements, welcoming visitors with coffee or tea, keeping family, where appropriate, informed of any concerns, events or generally updating them, inviting them to social events, and keeping memory sheets for family birthdays and anniversaries.

One relative in Overtoun expressed the positive factors from a parent's point of view

As well as all the meetings, staff let us know the good things that have happened as well as the difficulties. Despite staff being on the receiving end of some of my son's very difficult behaviour, they are totally professional. The communication is very good. Staff are flexible about us visiting. There are no set times and they always make us welcome. It feels homely because we have got to know the staff and some of the other residents.

Recommendations 4: Participation and Involvement

- **Units should examine ways in which people's involvement in decisions about their own care and treatment can be increased. This should include Speech and Language Therapy input to enhance communication of options and users' choices and to maximise their understanding of the processes and policies. The involvement of advocacy is also important and should be encouraged**
- **Units should share good practice in providing accessible information about their service and getting feedback from service users.**

CONCLUSION

There were many positive findings from our visits to people with learning disabilities in hospital wards throughout Scotland. We have tried to highlight areas of best practice where we have come across them. The key messages in this report are designed to make services aware of our findings, including the concerns identified in our visits to assessment and treatment units. We hope that staff working in these areas will bear them in mind and respond effectively in providing services in their area in line with the principles of the AWI Act and the Mental Health Act.

Table 1 Units visited and people seen

NHS Board	UNIT	No. of beds	No. of patients in unit		People seen on visit			% patients seen*	Personal interviews
			Male	Female	Male	Female	All		
Ayrshire and Arran	Arrol Park	19	9	6	6	3	9	60%	6
Dumfries & Gal (HB)	Lahraig	4	1	1	1	2	3	150%	1
Fife	Mayfield	13	6	5	2	3	5	45%	4
Forth Valley	Lochview 1	8	4	4		3	3	38%	1
Forth Valley	Lochview 2	6	4	2	2	2	4	67%	3
Forth Valley	Lochview 3	6	4	1	2		2	40%	2
Forth Valley	Lochview 4	6	2	4		2	2	33%	1
Grampian	Elmwood Bracken	12	1	5		3	3	50%	2
Grampian	Elmwood Fern	12	11		7		7	64%	5
Greater Glasgow & Clyde	Blythswood	12	7	5	5	7	12	100%	9
Greater Glasgow & Clyde	Netherton	8	8		4		4	50%	3
Greater Glasgow & Clyde	Overtoun	16	12	4	5	3	8	50%	6
Greater Glasgow & Clyde	Waterloo Close Unit 2	4	2	2	2	1	3	75%	1
Greater Glasgow & Clyde	Waterloo Close 4	2	1		1		1	100%	
Highland	Willows	6	3	3	2	1	3	50%	
Lanarkshire	Kylepark	12	6	1	2		2	29%	2
Lothian	Camus Tigh	8	7		2		2	29%	2
Lothian	Carnethy	8	7		3		3	43%	
Lothian	Dunedin	5	5		3		3	60%	2
Lothian	Greenbank	12	11		6		6	55%	3
Lothian	Primrose Lodge	8		8		6	6	75%	4
Lothian	William Fraser	12	7	4	2	2	4	36%	2
Tayside	Bridgefoot	6	5	2	4	1	5	71%	3
Tayside	Carseview Learning Disability Assessment Unit	10	5	6	1	1	2	18%	2
Tayside	Monroe House	26	19	6	7	4	11	44%	6
ALL		241	147	69	69	44	113	52%	70

*Note: numbers of patients were reported to us by clinical service managers in advance of visits. In some cases, vacant beds were filled by the time of the visit. This accounts for us apparently seeing more than 100% of patients in Lahraig.

Table 2 Delayed discharges in learning disability inpatient units by Health Board, June 2011

Health Board	No. of patients	No. of delayed discharges	Delayed discharges as % of total patients
Ayrshire and Arran	15	5	33
Dumfries and Galloway	2	0	0
Fife	11	8	73
Forth Valley	25	8	32
Grampian	18	5	27
Greater Glasgow & Clyde	41	14	34
Highland	6	0	0
Lanarkshire	5	0	0
Lothian	49	3	6
Tayside	18	5	28
Monroe House (Private)	25	0	0
All units	215	48	22

Table 3 People visited by gender and age

Age group	% Female	% Male	% All	No. of people
16<25	14%	16%	15%	17
25<35	20%	23%	22%	25
35<45	16%	17%	17%	19
45<55	36%	26%	30%	34
55<65	11%	12%	12%	13
65+	14%	6%	4%	5
No. of people	44	69	113	113

Table 4 Incidence of specific diagnoses in people visited

Diagnosis	People with diagnosis	
	No.	Percent.
Mild learning disability	44	39%
Moderate learning disability	45	40%
Severe learning disability	19	17%
Autistic spectrum disorder	25	22%
Mental Illness	50	44%
Challenging Behaviour	46	41%
other	19	17%
No additional diagnosis recorded	2	2%

Note: 'other' diagnoses were personality disorder and Prader-Willi syndrome. Some people have more than one additional diagnosis

Table 5 People visited, by gender and number of years since admission at time of visit

Years since admission	Female		Male		All	
	No.	%	No.	%	No.	%
<1	12	27%	10	14%	22	19%
1<3	13	30%	16	23%	29	26%
3<6	8	18%	8	12%	16	14%
6<10	1	2%	11	16%	12	11%
10+	6	14%	20	29%	26	23%
Missing info.	4	9%	4	6%	8	7%
All	44		69		113	100%