mental welfare
commission for scotland

VISIT AND MONITORING REPORT

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February 2016

Contents

The Mental Welfare Commission for Scotland

What we do

We protect and promote the human rights of people with mental health problems, learning disabilities, dementia and related conditions.

We do this by

- Checking if individual care and treatment is lawful and in line with good practice.
- Empowering individuals and their carers through advice, guidance and information.
- Promoting best practice in applying mental health and incapacity law.
- Influencing legislation, policy and service development.

Executive Summary

We visited all 18 hospital units for people with learning disability (excluding forensic units) from August to October 2015.

We examined the records of 104 people, just over half the people in the Scottish service. We met with 46 people individually and six others gave some views through their advocate or by other means.

We were pleased to receive feedback from 47 carers of people in 14 of the 18 units we visited (two carers did not specify a unit).

We looked at delayed discharges and discharge planning, and at the legal basis for treatment and any restriction on people's freedom. In addition we consulted users of the services and their carers and looked at issues that were important to them, including maintaining skills, activities, participation and involvement and the environment in the units.

Summary of findings

1. Quality of life
The outstanding issue for individual patients, carers and the service as a whole was the number of people whose discharge was delayed. Despite evidence of some excellent discharge planning, we were very concerned that almost a third of current inpatients (32%) across Scotland were experiencing long waits for discharge. In one health board this applied to 46 percent of inpatients. The goals of many of the assessment and treatment units we visited are significantly impeded by the issue of discharge delays.

The main reasons for delays in discharge were lack of funding, accommodation, or an appropriate care provider; or a combination of these issues. The implications for those awaiting discharge, who remain in hospital sometimes for significant periods for no clinical reason, and for those urgently requiring admission to a specialist unit, cannot be underestimated.

The majority of care and treatment plans were good, with some excellent positive behaviour support plans. A quarter of plans were more deficit-based and could have included more on developing skills for daily living and social and recreational activity. There was good input from allied health professionals to care planning and reviews, though in three units disorganised patient records limited the value of this.

Most patients had a good programme and reasonable range of activities in and out of the unit. However, inconsistent recording meant that evidence of participation, and cancellation of activities and the reasons for this were difficult for managers to audit. Some units reported problems with staff cover, transport and socialisation budgets.

Patients reported positively on their interaction and support from staff, particularly if they were worried or upset. Over three quarters of carers said they were satisfied or fairly satisfied with the care and treatment of their relative or friend.

2. Environment

Twelve of the 18 units were thought to be not fully fit for purpose. Each was inadequate in some aspect such as the availability of indoor or outdoor space, adequate facilities to fulfil their assessment and treatment purpose, maintenance, decor or cleanliness. Many of these issues were identified in our report in 2011.

3. Rights and restrictions

Risk assessments had been carried out for all patients, though review dates were not evident in 16 percent of cases. Risk management plans were on the whole good and promoted positive risk taking. Where Positive Behaviour Support Plans included more restrictive measures, such as physical intervention and seclusion, there were clear protocols in nearly all instances for when such measures were required. There were a small number, however, where there were no protocols in place for physical intervention and seclusion and staff were not clear as to what constitutes seclusion.[1] This is extremely concerning in terms of human rights and patient safety. There were a small number of people subject to restrictions as Specified Persons where the legal requirements had not been met.

4. Health needs

The majority of hospital units (11 of 18) were carrying out, or were in the process of initiating, learning disability specific health checks and screening. This was an improvement since our visit in 2011 but more work needs done in this area to address health inequalities. Access to podiatry was difficult for some units and they were using private services.

The legal requirements of consent to treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act) had been carried out for the most part. We were concerned that in nine percent of cases the legal requirements of prescribing and administering treatment under the Adults with Incapacity Act (Scotland) Act 2000 (the 2000 Act) had not been fully met.

5. Participation and involvement

Overall there was good support from advocacy for attendance at Tribunals and review/discharge meetings. Most patients interviewed who wanted to attend their review meetings did so with the support of advocacy, their family or both. Some only attended part of their meeting.

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[1] http://www.mwcscot.org.uk/media/191573/final_use_of_seclusion.pdf

Most patients were unable to articulate the reasons for being in hospital but knew what care and support they were getting and if there were plans for their discharge.

The provision of user friendly information, appropriate signage and efforts to encourage user feedback on the service varied greatly with some units making much more effort to facilitate participation than others.

Carers were generally very complimentary about the services, including being made welcome, the visiting arrangements, communication with staff and involvement in reviews. Six carers did not feel involved through the review process and some had concerns about discharge planning and whether community facilities could meet their relative or friend's needs.

Only one NHS board and the private hospital had a carers' forum for the units in their area/ company. Around half the carers who contributed were not sure if there was a carers' group attached to the unit and many did not know of any alternative carer support group in the area. Only 21 percent of carers felt involved in wider service issues and some were concerned about lack of information on changes in personnel and possible closures of units.

Recommendations

1. Quality of life

- The Scottish Government, in partnership with integrated joint boards, should develop a plan to end delayed discharges, in the context of health and social care integration.
- The Scottish Government should ensure that monitoring and reporting of delayed discharge is robust.
- Unit managers should ensure that specialist assessments are easily accessible for use by staff to inform the care and treatment plan and are reflected in care plans.
- Unit managers should ensure that care plans are holistic and include opportunities to maintain and develop skills of daily living. NHS Boards should ensure that activities are supported by adequate staffing, transport and socialisation budgets.
- Unit managers should ensure that there is a clear record of participation so that there is evidence that activities are taking place and in order that cancellation and reasons for this can be audited by the service.

2. Environment

- NHS Boards should ensure through their capital planning programmes that within three years all learning disability inpatient units are fully fit for purpose. Units should provide a well-maintained environment that is clean, odour free and minimises the effects of noise. They should have adequate facilities to ensure that patients,

including those with physical disabilities, can be nursed safely and have appropriate access to facilities to develop and maintain their daily living skills. Gardens should be safe, adequately maintained and assessed for their therapeutic potential.

- The Scottish Government should make fit for purpose environments a priority in the next Keys to Life implementation framework.

3. Rights and restrictions

- Unit managers should ensure that risk assessments have a review date.
- NHS Boards should ensure that all staff are clear what constitutes seclusion and aware of the appropriate procedures[2].
- Unit managers should ensure that all restrictive measures, including physical intervention and seclusion, are part of a Positive Behaviour Support Plan with clear guidance and safeguards for their use and regular review of these towards less intrusive measures where possible.
- Unit managers should ensure that restrictions on Specified Persons under sections 281-286 of the 2003 Act comply with the requirements of the legislation.

4. Health needs

- Unit managers should ensure that all inpatients have a learning disability-specific health check annually and these should be easily accessible in the patient's records.
- Unit managers should ensure that the legal safeguards for treatment under the Adults with Incapacity Act are adhered to. A section 47 certificate must be in place, and should have an accompanying treatment plan. These should be evident in the medication prescription chart so that staff are clear about their legal authority to administer medication.

5. Participation and engagement

- Unit managers should provide user friendly information on the unit, its processes and policies and ensure signage is appropriate.
- Unit managers should have systems in place to get users views on the service on a regular basis and provide responses to the issues raised.
- Unit managers should provide introductory information for carers on the unit, how they can be involved in their relative or friend's care and treatment, processes and policies and signposting to carer advocacy and support groups.
- Unit managers should ensure there are systems in place to get carers views on the service on a regular basis and provide responses to the issues raised.
- NHS Boards should support the development of carers' forums in their areas.

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[2] See Mental Welfare Commission Good Practice Guide on Use of Seclusion
http://www.mwcscot.org.uk/media/191573/final_use_of_seclusion.pdf

PART 1 - Introduction and background

1.   Why we carried out these visits

One of the ways in which the Commission monitors individual care and treatment is through our visits programme. We visit people in a range of settings throughout Scotland: at home, in hospital or in any other setting where care and treatment is being delivered. As part of this programme we carry out national themed visits each year. National themed visits enable us to assess and compare care and treatment for particular groups of people across Scotland. Our aim is to help services learn from good practice and to respond to any issues that are identified.

Policy context

Over the past 35 years there has been a transformation in service provision for people with learning disabilities in Scotland. In 1980 there were 6,500 people in hospital care, which fell to 2,450 in 1998. In 2000 the Scottish Government published *The same as you?*[3] report. It was the first major review of learning disability services for several decades. It set out a 10 year programme of change in health and social care to improve services and support for people with learning disabilities, their families and carers. It recognised that people with learning disabilities should have the same opportunities to live independently with the same choices, control and protection as other Scottish citizens.

One of the key recommendations was the closure of long stay hospitals by 2005. However the report acknowledged that there would still be a need for a small number of inpatient beds for people with learning disabilities, for a range of specific purposes. The first was for those whose need for specialised or complex health assessment or treatment could not be met in the community (probably not more than 150 to 200 people in Scotland). The second group was people on statutory orders, some of whom may be offenders with mental health problems. The third group was a small number of people whose treatment may be lengthy or who need a more supportive setting for a long period.

Following *The same as you?* report there was a further decrease from 818 hospital beds (Dec 2002), excluding forensic services, to 297 (May 2007). By the time the Commission last carried out a national themed visit to these units in 2011 this had decreased to 239. At that time the recommended provision was four inpatient assessment and treatment beds per 100k population. A Scottish Government single occasion survey (2012) found variation between health boards. Half of Scotland's NHS Board areas appeared to have met the target but five boards had more than double the number of recommended in-patient beds.

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[3] http://www.gov.scot/resource/doc/1095/0001661.pdf

The Keys to Life (2013)[4], the Scottish Government's strategy for the next 10 years, concentrates on health needs. It makes three recommendations (Recommendations 50-52) in relation to those with complex care needs. These relate to:

- Developing joint discharge agreement protocols for people for whom there is no suitable community placement;
- Looking at how to enable people in out of area placements to be supported nearer their home and family; and
- Scoping public sector investment required for high-cost care packages and alternative models of provision.

In 2015 the Scottish Government published the Keys to Life Implementation Framework and Priorities 2015-2017[5], which is the first implementation framework for strategy delivery, and includes exploring alternative models to out of area placements for people with complex care needs. During 2015 the Scottish Government also commissioned a two-year national project to identify the types of support required for individuals who have complex care needs.

Our previous visit in 2011

In 2011 we visited hospital learning disability units (excluding forensic units) and looked at the care and treatment of around half the inpatients.[6]

The concerns arising from our visit and our recommendations related to:

- The number of delayed discharges in some health board areas. Across all the units 22 percent of patients were designated as delayed discharges. These were people with complex needs who required high-cost packages of care. Many of these people had experienced an irretrievable breakdown of their placement and required re-commissioning of their package of care and support, including identifying suitable accommodation and a robust support provider.
- Concerns about 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 concentrated on health and behavioural concerns but did 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 patients, with considerable variation in accessible information, user friendly care plans, appropriate signage, and proactive user and carer feedback.

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[4] http://keystolife.info/
[5] http://keystolife.info/wp-content/uploads/2015/06/The-Keys-to-Life-Implementation-Framework-and-Priorities.pdf
[6] http://www.mwcscot.org.uk/media/239699/learning%20disability%20themed%20visit%20report%202012.pdf

- Consent to treatment documentation which did not conform to the recommendations of the Adults with Incapacity Act Part 5 Code of Practice.

2. Planning and consultation for this themed visit

On this visit, which took place from August to October 2015, we particularly wanted to look at delayed discharges and discharge planning. It is a focus for recommendations in the Keys to Life and on our 2011 themed visit, delayed discharge was a major issue for inpatient services. We also looked at the legal basis for treatment and any restriction on people's freedom.

In addition we wanted to ensure that we were focusing on the issues that were most important to the users of the services and to their carers. We held four consultation sessions, two in Edinburgh and two in Glasgow. We are grateful to the services for hosting these visits. We invited all inpatients in the Lothian service and in the Greater Glasgow and Clyde service to attend with their advocates or supporters. In separate sessions we invited views from relatives, friends or carers of people who were currently in hospital in these two health board areas. We were pleased that 20 patients and 11 carers attended or contacted us to give us their views of what was important for them. In addition we consulted our Advisory Committee, and a number of user and carer groups. These were People First[7], Scottish Consortium for Learning Disability[8], and PAMIS[9] We also sought views from the Learning Disability Nurse Forum.

Patients felt it was important for us to ask questions about:

- **Discharge planning** – getting information and being kept informed, involvement in decision-making about where and with whom they live, lack of appropriate resources, access to a social worker.
- **Maintaining skills** – opportunities for cooking, shopping and other activities of daily living, access to occupational therapy (OT) services.
- **Activities** – involvement in planning these in and out of unit, access to college, training etc, restrictions due to staff shortages and transport.
- **Opportunities to talk to staff** – accessing key worker, doctor and 1:1 time with staff.
- **Contact with friends and family** – access to phones, mobiles, privacy to meet visitors, understanding why there may be restrictions on contact.
- **Participation** – in care planning and reviews, preparation, participation and feedback from meetings, access to advocacy, access to a patients' forum to raise issues.

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[7] http://peoplefirstscotland.org/
[8] Now Scottish Commission for Learning Disability, www.scld.org.uk
[9] http://www.pamis.org.uk/

Relatives, friends and carers felt the following were important:

- **Discharge planning** – lack of appropriate community resources, delays, deskilling whilst in hospital, effects of short stay facilities and resources being used for both longer stay and short stay patients with different needs.
- **Involvement of relatives, friends and carers** – importance of family involvement, communication between staff and family, coordinating the whole of the person's care, consultation and information sharing when there are planned changes in the service such as the closure of units.
- **Maintaining life skills** – resourcing and staffing for this.
- **Activities and approaches to care** – opportunities and choices for activities within the unit and out of the unit, risk management and whether it promotes positive risk-taking.
- **Participation** – person's involvement in decision-making.
- **Staffing** – availability including evenings and weekends, training in autistic spectrum disorder (ASD).
- **Money** – use of person's money for their benefit and accessing it timeously.
- **Environmental issues** – size and location of unit, outside space, safety of belongings, visiting facilities, purchase and ownership of specialist equipment.

The issues raised by patients and carers helped to inform the questions asked in this themed visit. We constructed a series of questionnaires, and we piloted these on a visit to Camus Tigh in August. We are grateful to Camus Tigh for participating in the pilot visits.

We gathered information by the following methods:

- We issued a preliminary questionnaire to clinical service managers a week before each visit. This collected information on current numbers of patients in the unit; their status under the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act); any delayed discharges; management of patients' finances; the availability of professional input such as psychology and speech and language therapy; and staff training.
- On the day of the visit we completed a questionnaire with nursing staff. This obtained a ward level picture of activities, any restrictions on patients, patient participation, involvement and communication, carer involvement, health needs, finances, delayed discharges and staff training.
- We completed a questionnaire to assess the suitability of the environment for this group of patients.
- We spoke to nursing staff about individual patients and consulted their records. We asked about risk assessment and management, care planning and reviews, discharge planning and finances.

- We spoke to as many individual patients as possible and asked their views of on activities, the care and treatment they were receiving and their participation in decision-making.
- We invited input from carers and families by a range of means. We asked nursing staff to circulate a questionnaire to carers prior to our visit. Carers had the option of completing and sending this to us, meeting with us on the day of our visit or phoning us and giving us their views. We use the term 'carers' in this report to include relatives and friends who are actively involved in the person's care, but not staff in a caring role.

3.   General information on the service across Scotland

The information from clinical service managers gave us an overall picture of the service across Scotland.

There were 198 assessment and treatment beds, excluding forensic beds, in 18 locations across Scotland. Thirty seven of these beds were identified by the managers as longer term treatment beds. Eighteen beds were unoccupied during the period of our visits; this included five beds in one unit which were unavailable due to the needs of one patient and six beds which were unoccupied in a private hospital. Sixty nine percent (125) of patients were male and 31 percent (55) female.

Seventy six percent of all 180 patients (136) were detained under the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act) or the Criminal Procedures (Scotland) Act 1995 (4).

Thirty eight percent (69) of patients were on welfare guardianship orders under the Adults with Incapacity (Scotland) Act 2000 (Act 2000). Thirty percent of all patients (54) were both detained and on welfare guardianship.

Overall, clinical service managers told us that 32 percent (58) of patients were formally notified as delayed discharges. This was a particular problem in the units in NHS Lothian where 46 percent (17 of 37) patients were delayed discharges, followed by NHS Greater Glasgow and Clyde with 37 percent (15 of 41) and NHS Forth Valley with 33 percent (8 of 24). The reasons for the delays included lack of identified funding for community placements (41%), lack of an identified or appropriate support provider (62%), lack of identified housing or accommodation (74%), other reasons (24%) or a combination of these (60%).

We are concerned about delayed discharge, both because of the impact on patients awaiting discharge and their families, and because it affects the ability of the service to respond to those requiring admission. There were nine people on waiting lists for admission, eight of whom were in the NHS Greater Glasgow and Clyde and NHS Lothian

areas. Of the nine, four people were at home, three were in acute psychiatric or Intensive Psychiatric Treatment Unit (IPCU) beds and two were in out of area placements.

4.   The units we visited

We visited all 18 hospital sites, 17 NHS hospitals and one private hospital, between August 2015 and October 2015. We did not visit forensic units for people with learning disabilities, as these are normally visited as part of the Commission's forensic visit programme. In 2016-17 we will be carrying out a themed visit to low and medium secure forensic services. We examined the records of 104 people, just over half the people in the Scottish service.[10] Thirty eight percent of people whose records we saw were diagnosed with a mild learning disability, 41 percent with a moderate learning disability and 21 percent with a severe learning disability. All had additional diagnoses and/or had behavioural issues: 49 percent had a mental illness; 40 percent had Autistic Spectrum Disorder; 59 percent had behavioural issues; and 17 percent had other issues such as personality disorder, dementia, physical or sensory disabilities, Acquired Brain Injury (ABI) or alcohol problems.

Seventy seven percent (80) of the people we saw were detained under the 2003 Act. Almost half of all patients had been in hospital for over three years and just over 20 percent had been in hospital for over 10 years.

Table 1: Length of stay in hospital

Length of stay in hospital	Number of patients	Percentage of patients
Up to 1 year	32	31%
1 to 2 years	21	20%
3 to 5 years	20	19%
6 to 9 years	10	10%
10 to 19 years	12	12%
20 years and over	9	9%
Grand Total	**104**	**100%**

We met with 46 people individually and six others gave some views through their advocate or by other means. Some people did not wish to be interviewed and others were not able to give us their views.

We found that 87 percent of people had involvement with their families. We were pleased to receive feedback from 47 carers of people in 14 of the 18 units we visited (two carers did not specify a unit). The patients they were supporting or caring for broadly reflected the range of patients in the units in terms of gender and age.

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[10] We also saw one person recently discharged who wanted to give us his views. We did not look at his records.

PART 2 - Detailed findings

Where we had concerns about the care and treatment of individuals, we took these up with the service on the day or following the visit. We advised hospital staff in 17 instances and raised 11 issues with ward managers. We also gave advice to six patients and carers. We are following up further issues relating to nine patients. Where there were more general areas needing improvement, we wrote to the service and these may be followed up on our subsequent visits. We also gave written feedback to the service on any good practice we saw on our visits.

1.   Quality of life

What we expect to find

We expect to find appropriate assessments and care plans for each patient in the unit, which draw on specialist input where necessary. Specifically, we expect:

- Care plans individual to each patient, that address their mental and physical health needs, behavioural difficulties, communication and social needs.
- A clear and accessible plan of day-to-day activity that reflects each patient's choices, needs, age and abilities. This should include therapeutic, social, educational and recreational activity on and off site, as well as opportunities to maintain or develop daily living skills. Transport and staffing levels should be sufficient to support the use of community resources on a regular basis.
- A discharge plan.

What we found

Assessment and care and treatment plans

The model of professional input to units varied. Some units had dedicated time from psychology (7 units); speech and language therapy (SALT) (7); occupational therapy (OT) (9); physiotherapy (5); dietetics (3); and these disciplines regularly attended multidisciplinary meetings. Others, particularly those with longer term patients, operated on a referral system. None reported difficulties in accessing allied health professionals.

Eighty eight percent (91 of 104) of people had had at least one specialist assessment in the past year. These included psychology (50%), occupational therapy (56%), speech and language therapy (50%), dietetics (29%), and physiotherapy (13%). Only 12 percent of people had not had a specialist assessment of some sort in the past year but in most cases previous assessments were still relevant. We felt two of the people we saw would benefit from referral for a psychological assessment and this was raised with the staff on the day. In the majority of cases the assessments were easily accessed and clearly addressed in the care and treatment plan. For example, in Netherton (NHS Greater Glasgow and Clyde)

we saw good nursing and allied health professional assessments incorporated in person-centred plans, which largely focussed on people's strengths. The assessments were filed with the relevant section of the care plan, ensuring they were addressed in the appropriate care plan and were immediately accessible to staff.

Similarly in Kylepark (NHS Lanarkshire) the Commission visitor commented on the allied health professional (AHP) contribution to the care plan:

> *'Psychology assessments are central to risk management and care planning. This was produced in a multi-disciplinary way and recognises and addresses specific areas of risk. The ASD specialist has also contributed to the risk assessment framework document. The speech and language therapist is directly contributing to Easy Read versions of documents, or to convey information in clear and consistent manner. Dietician assessment has provided a care plan on a healthier diet for him. The physiotherapist has provided exercises to address diagnosed osteopaenia.'*

There were three units where the standard of documentation was poor. The assessment and input of allied professionals was referenced within correspondence and within nursing notes but we did not see sufficient evidence of how their assessments contributed to care planning and risk management due to problems in locating the relevant documents and excessive amounts of documentation. The full value of the assessments is diminished by disorganised patient records; they are less likely to inform the care and treatment plan; and it increases the likelihood of inconsistent management of issues by staff.

In 73 percent (76) of cases Commission visitors felt that all needs were clearly addressed in the care and treatment plan. For example, one Commission visitor noted:

> *'There are a number of care plans aimed at positive skill building, in addition to problem focussed care plans. For example, she has a care plan aimed at improving her understanding of her CTO[11] and general treatment using various communication strategies. Use of more adaptive/helpful behaviours when in distress is being encouraged through care planning and appear to have been of benefit. There are care plans aimed at supporting her reporting and discussing grievances with staff. The psychology formulation is very helpful and has been used in care/treatment planning. There are scripts in her case notes which help her discuss difficult issues with staff. There is also a care plan aimed at improving budgeting skills and expanding social and recreational activities. There were a number of care plans aimed at minimising the risk of her sexual and financial vulnerability.'*

Similarly the following relates to a young man who has severely challenging behaviour when anxious and upset. He can be very impulsive and volatile with aggressive outbursts

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[11] Compulsory Treatment Order under the Mental Health (Care and Treatment) (Scotland) Act 2003

towards himself and others that have led to assault charges. He can be sexually inappropriate.

'Strengths/needs lists inform care plans which are person-centred and outcome focused, taking into account those things that he can do independently or with minimal assistance, so that these areas can continue to be promoted. Developing Activity of Daily Living (ADL) skills by helping with supper preparation and organising his laundry. As noted above, his inclusion in his work placement and development of skills and opportunity to access the garden is building on positive aspects of his life.'

Twenty seven percent (28 of 104) of care and treatment plans were judged as meeting some but not all of the patient's needs. These were generally more deficit-based and could have included more on skill building and social and recreational activity.

Meaningful activity

As well as more problem-focussed treatment in relation to mental health, physical health and challenging behaviour in the person's care plan, we looked at the opportunities for therapeutic, social and recreational activity. This included the maintenance and development of daily living skills.

We asked Commission visitors to consider the appropriateness and availability of activities. For 34 percent (35 of 104) of the people who we saw or whose records we examined, our visitors were very satisfied with the person's access to activities and 59 percent (61) were fairly satisfied. For instance the Commission visitor's comments on Kylepark (NHS Lanarkshire) were:

'Very impressive activity options - high quality activity rooms, sensory room, garden project, STAR group for dealing with stress, local walks, gym with physio or nurse assistance, therapet visits, coping skills group, outings to library & local shops, training kitchen, various meal groups, art groups, music activities, and skills group for independent living.'

The examples below illustrate the range of activities and evidence of the person's participation:

'He had a good activities timetable with appropriate activities and these are being provided. Good documentation of involvement in activities - over the previous week documented activities had included go karting, bowling, walking group, going out to play pool, snooker, out twice locally with staff, fishing, cooking, walks with staff. His mother also visits once per week.'

'*He was very keen to show me the garden, including the shed, where he was picking tomatoes to be brought into the unit kitchen and used towards meals or snacks; he was keen to show his high-vis vest which he put on prior to going to his work placement.'*

There was concern in seven percent (8) of cases about the opportunities on offer. Comments included:

'Activities are limited to those provided mainly by OTs'.

'He does not seem to be doing much. He has very complex needs and is subject to restrictions due to his challenging behaviour. Very limited in activities in house that he can engage in but he likes to observe others. His care plan in the last unit indicated he had time out for walks. This has not happened since he moved here some months ago. The manager also talked about him enjoying water based activities but has not done anything as yet to pursue this - we talked about accessing the school pool out of hours or other water-based activities but none of this had been taken forward. I felt the staff could be more proactive in following up the few areas where he might potentially engage.'

There were very few units where staff regularly kept a record of what activities the patient had done and their level of participation. This needs to be addressed. For most patients, it was necessary to read through the chronological notes to establish this. This makes it hard to get a picture of the patient's week. It is also difficult for managers to audit whether and how often activities are cancelled and for what reasons. In 15 percent (16) of cases we noted there was sometimes difficulty in adhering to people's timetables. For nine people this was due to staff issues and in three instances there were transport problems.

Staff in 12 of the 18 units told us that activities were sometimes cancelled when there was insufficient staffing to cover both clinical needs and off-ward activities. This can be due to the need for increased observation levels for patients, staff sickness or bank/supernumerary staff on shift who are not fully trained to be able to work 2:1 with individuals. Thirty three patients spoke to us about their activities. Fourteen of those told us activities were sometimes cancelled, mainly due to other patients requiring increased staff time because of behavioural issues. Most said that staff then tried to rearrange the activity or offer an alternative on site. This was not reported as a regular occurrence by any of those who raised it but it does reinforce the need for accurate recording.

Most units had their own transport to support activities, though two units only used public transport or the patient's own transport. Three units reported some difficulties with transport: one reported difficulties with frequent repairs to the minibus and the lack of a necessary adaptation for one particular patient to the replacement bus; one unit felt they needed a second minibus; and one was restricted at times by the lack of a driver on shift. Socialisation budgets were very variable. Whilst patients generally paid for the costs of their own activities, there was usually some money from the budget to supplement those and to cover staff costs. However three units reported they had no budget to meet staff costs which made it difficult if they were, for example, taking a patient out for a meal. In one of these units the patient/s would cover the staff costs, where the outing was seen as part of their community involvement programme. Otherwise the staff member either bought their own meal or bought a coffee whilst the person they were accompanying ate their meal.

Patient satisfaction with care and treatment

Forty five people met with us to give us their views and six others gave some views through their advocate or by other means.

Nearly everyone was positive about their ability to talk to staff. When asked who they would talk to if they were worried or sad about something, they said it would be members of staff, as well as their family or advocates. Comments included:

'All the staff are brilliant and deserve a bonus!'

'I can talk to just about anyone. The staff listen'

A few were unhappy with staff. One patient had a particular concern about one particular member of the nursing staff and this was raised by the Commission visitor on the day. Another commented *'Some are crabbit, some are nice'*. Two others were very unhappy with being in hospital. One said *'I hate it here'* and the other felt *'I shouldn't be here. It's because of the lying ... and the ...doctor'*

We found that people found it hard to articulate why they were in hospital. This may have been that it was a difficult area to discuss with someone unfamiliar or that more work needs to be done in helping people understand why they are in hospital. People were, however, able to tell us who else was involved in their care along with nursing staff and what help they were getting. For example:

'I see the OT for cooking and kitchen skills, the psychologist for anger management and anxiety and they give me strategies for dealing with my feelings.'

Carer satisfaction with care and treatment

Fifty three percent (25) of the 47 carers and family members who gave us their input were very satisfied, and a further 23 percent (11) fairly satisfied with the care and treatment on the ward. Three people did not know or did not answer this question. Comments included:

'The house staff respond actively to any issues raised, are very attentive to [him] and are always willing to 'go the extra mile' to improve his care and treatment. They truly put 'partnership with parents' into action.'

'They have totally transformed his challenging behaviour. Staffing level has been reduced. Has been taken off medication, virtually drug free.'

Fifteen percent (7) were slightly dissatisfied but no-one was very dissatisfied.

'Feel he is isolated from others, doesn't seem involved in activities and doesn't appear to be making much progress.'

'Staff are kind and supportive. Mainly dissatisfied regarding behavioural management - he has passport not being used. [He] wasn't as safe as he could be from other patients - better supervision needed.'

Finances

There were minor financial issues for a few patients but this related to the accumulation of money for some people and difficulty in spending their income and savings. We were pleased to see that in most cases people's money was being spent by the hospital on items or activities to enhance the person's life.

There were 13 people whose money was managed by the hospital who had over £10,000, including a few with substantially more. Meetings were held six monthly with patient funds managers to make spending plans which would benefit patients. In one instance there was a report of a delay in accessing money for large items of furniture where the hospital was managing the person's money. In a few cases relatives would have liked the person to go on holiday but staffing and paying for staff costs were a barrier to this. In other units staff were able to facilitate holidays. For example one woman had been to a log cabin with a hot tub for four nights with two staff. This was a very positive experience for the patient. It allowed her a short break from the hospital and contributed significantly to her wellbeing.

Commission visitors commented on the need for more creative use of funds in a few cases but, for the most part, efforts were made to ensure people benefited from their income and savings. One man bought in extra support to enable to increase his community-based activities. The examples below illustrate the more creative ways in which people's funds were spent.

'Items for his room - decor, furnishings, bathroom and personal belongings - have been chosen by him. Funeral plan arranged with sister's input, using his money. Purchased items for garden, including furnishings, as he likes to sit outside or near the garden window. Enjoys sitting in summer house so this was furnished for him. Leased a car to promote activity access. Has purchased sensory items specifically for his use.'

'Enjoys shopping and is given a budget to spend on items he selects. Very creative use of his finances to pay for him and a carer to go to his voluntary work placement. This contributes to development of self-esteem and he looks forward to contributing to the work twice a week. Contributes to transport, which he is able to access regularly for outings off the ward.'

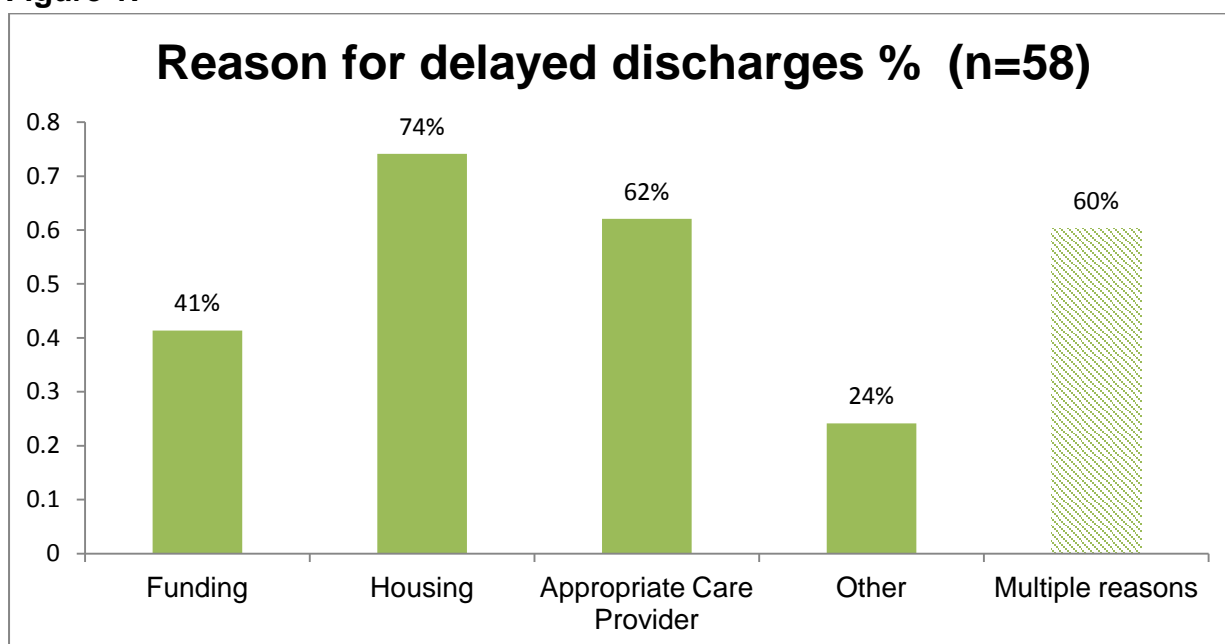## Discharge planning and delayed discharges

Prior to our visits we asked for information from clinical service managers on the numbers of formally notified delayed discharges on their ward. Delayed discharges should be

recorded on Edison.[12] Edison is a real-time national information system that records and shares information on patients delayed, the care setting in which they are delayed and the main reason for the delay. The information we received raised serious concerns about the deprivation of liberty of a considerable number of people detained in hospital, often for considerable periods of time. They could be living in less restrictive community settings if appropriate accommodation and funding were available.

There were 180 inpatients in total at the time of our visits. Of these, clinical service managers told us that 32 percent (58) were delayed discharges.

We found that there were inconsistencies in the interpretation of codes used on Edison. Some clinical service managers included as delayed discharges they reported to us people who were coded as 'code 100'[13], but some did not include this group. People with this code are acknowledged as 'ready for discharge', but are not included in national delayed discharge statistics. However, we regard them as being kept in hospital when this is recognised as no longer the best place for them to be living. Some people given this code have been 'ready for discharge' for a number of years. The inconsistency in how this coding is interpreted may mean that the figure above is an underestimate of the number of people actually waiting for a long time in hospital when it has been recognised that they could be discharged.

Figure 1:

Reason for delayed discharges % (n=58)

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[12] Edison is the national coding and reporting system for delayed discharge. http://www.jitscotland.org.uk/resource/edison/

[13] 'Ready for discharge' (code 100) is defined in the guidance Delayed Discharges Definitions and Data Recording Manual (NHS National Services Scotland, 2012, http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/Guidelines/) as long-term hospital inpatients whose medical status has changed such that they can be considered for accommodation in non-hospital settings, who might be going through lengthy discharge planning after a prolonged period of treatment, or patients awaiting relocation to another NHS or social care facility as part of a 'reprovisioning' programme.

The situation was worst in the health boards with the largest number of beds – in NHS Lothian 46 percent (17 of 37) patients were delayed discharges, in NHS Greater Glasgow and Clyde 37 percent (15 of 41) and in NHS Forth Valley 33 percent (8 of 24). (See Table 2 in Appendix) The reasons given by the clinical service managers are set out above but for the majority of people there was a combination of reasons, including funding, an appropriate provider and appropriate housing/accommodation. This group of people are remaining in hospital not for clinical reasons, but because of issues of funding, accommodation and service availability. The impact of this level of delayed discharges cannot be underestimated for the people waiting to move out, many of whom are detained (48 of 58); for the people who are urgently requiring a bed in a learning disability unit and are in general psychiatric wards, Intensive Psychiatric Care Units (IPCUs), out of area placements or at home; and for health and social work staff who are dealing on a daily basis with patients', carers' and each others' frustrations.

We looked at 104 patients' records on our visits. Discharge planning was underway to varying degrees for 46 of them. Twenty one of these 46 people were notified as delayed discharges on Edison. The issues contributing to those delays were also evident for many people in the discharge planning process who were not yet designated as delayed discharges.

Causes of delayed discharges and challenges in discharge planning included:

- No suitable accommodation and support currently for the complex needs of many of these patients. Many required a specially commissioned service and approval of the funding that entailed. They needed 24 hour, seven day care and support with 1:1, or sometimes 2:1, staffing.
- Identified placements which were no longer suitable due to issues such as adult support and protection concerns in the identified unit; deterioration in the person's mental or physical health; the staff team in the identified unit feeling they could not manage the person's support needs; and potential incompatibility with other residents they were to share with.
- Coordination of the availability of funding from the local authority with the availability of appropriate accommodation and a robust service provider.
- The impact of the constraints of local authority budgets. On some occasions placements were lost because of delays in securing funding.
- Delays in adaptations to properties.
- Delays in allocating a social worker to complete the assessment along with insufficient involvement of the social worker in regular planning meetings. Two of these had led to formal complaints by carers.
- Delays in recruitment and training of support staff, particularly in less urban areas. The turnover of support staff also impacted on getting a trained team in place.
- Delays in progressing guardianship applications where it was evident at an early stage that this would be needed.

In three cases the length of delay and lack of progress had led to the Tribunal making a Recorded Matter for the local authority to identify supported accommodation and progress discharge. It was hard to judge the effectiveness of this. For example a Recorded Matter about 'identifying accommodation and support' in six months was made for one woman in September 2014 and was not met; it was varied in May 2015 to' identify accommodation and have a staged discharge plan in place' again in six months (November 2015) and it still remains unmet.

These challenges have led in some cases to difficulties in managing the expectations and involvement of patients in the process. For some the long-drawn-out process was detrimental to their mental health and motivation. The multi-disciplinary team (MDT) and families had to give careful consideration as to when and how to involve the patient and balance the benefits of involvement against risks to their mental well-being.

Despite the difficulties above we noted a lot of good practice in discharge planning. This included:

- Good social work involvement in MDT, Care Programme Approach (CPA)[14] and discharge planning meetings, and social workers very actively pursuing placements, funding and linking with providers to plan transition.
- Service providers and hospital staff working closely together in the training and induction of support staff with the individual and making the transition.
- Thoughtful consideration of how and when to involve the patient. We saw good support from named nurses, consultation with families, and input from SALT e.g. in preparing 'scripts', social stories and using other communication aids. We saw a good example of staff taking a patient to see an old house being demolished where his new flat will be built, to help him understand that plans were progressing.
- The involvement of advocacy to ensure the patient's views on future placements were taken into account, both in planning meetings and at Tribunals.

In contrast we saw examples of poor practice, some of which have already been mentioned: problems with allocation of social workers; no copies of single shared assessments/community care assessments in ward records; poor communication between health and social work staff; lack of clarity on funding; delays in guardianship applications; and delays in adaptations.

Staff outlined the implications for the service. They were concerned about patients with learning disabilities who are acutely unwell and on the waiting list for admission being placed in acute general adult psychiatric wards and the pressure on the service to provide input and support to these people. There were challenges in managing the mix of patients in the unit when there are patients whose discharge is delayed and who are living there for

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[14] The Care Programme Approach (CPA) is a way that services are assessed, planned, co-ordinated and reviewed for someone with mental health problems or a range of related complex needs.

some considerable time together with patients who are acutely unwell. Some nurses felt they were providing care to people who do not need nursing care whilst there are others in '*dire need of being admitted to a specialist service'*. There are also delays in closures of units where NHS boards are planning to reduce longer-term bed numbers.

Staff also detailed the difficulties for some of the people concerned and their comments reflect the frustration and unhappiness of some patients.

'It causes him increased anxiety. He fixes dates in his mind, then fixates on this and becomes highly agitated.'

'People are frustrated and confused in relation to the timescale for moving on and mistrust services.'

'It has a huge impact. The restricted environment limits his freedom and engagement.'

'He is so depressed and upset and desperate to move out.'

'The frustration has led to deterioration in his mental health.'

Some carers also expressed frustration at delays in discharging their relatives.

'Slightly dissatisfied - care good but very unhappy with delayed discharge which has undone a lot of good work.'

'Delayed discharge since 2014 due to lack of suitable resources. [Social work] have tried, but there has been nothing to meet her needs. Now have [provider]. Very much admire what [the unit] do, they have been great. Frustration re delayed discharge was shared by [the unit]. Not a reflection on them. Very grateful and impressed by NHS service. [The unit] has done a lot of good things for [her].'

Summary of findings
The outstanding issue for individual patients, carers and the service as a whole was the number of people whose discharge was delayed. Despite evidence of some excellent discharge planning, we were very concerned that almost a third of current inpatients (32%) across Scotland were experiencing long waits for discharge. In one health board this applied to 46 percent of inpatients. The goals of many of the assessment and treatment units we visited are significantly impeded by the issue of discharge delays.

The main reasons for delays in discharge were lack of funding, accommodation, or an appropriate care provider; or a combination of these issues. The implications for those awaiting discharge, who remain in hospital sometimes for significant periods for no clinical reason, and for those urgently requiring admission to a specialist unit, cannot be underestimated.

The issues relating to delayed discharge were identified in our 2011 learning disability themed visit report. They were recognised in the Scottish Government's learning disability strategy Keys to Life (2013) and were the subject of its recommendations 50-52. These relate to the development of joint discharge agreement protocols for people for whom there is no suitable community placement; how people in out of area placements are to be supported nearer their home and family; and scoping the public sector investment required for high-cost care packages and identifying where these funds will come from; as well as looking at alternative models of provision. The Keys to Life Implementation Framework and Priorities 2015-2017[15] includes exploring alternative models to out of area placements for people with complex care needs, and in 2015 the Scottish Government commissioned a two-year national project to identify the types of support required for individuals who have complex care needs.

The majority of care and treatment plans were good with some excellent positive behaviour support plans. A quarter of plans were more deficit-based and could have included more on developing skills for daily living and social and recreational activity. There was good input from allied health professionals to care planning and reviews, though in three units disorganised patient records limited the value of this.

Most patients had a good programme and reasonable range of activities in and out of the unit. However, inconsistent recording meant that evidence of participation, cancellation of activities and the reasons for this were difficult for managers to audit. Some units reported problems with staff cover, transport and socialisation budgets.

Patients reported positively on their interaction and support from staff, particularly if they were worried or upset. Over three quarters of carers said they were satisfied or fairly satisfied with the care and treatment of their friend or relative.

Recommendations

- The Scottish Government, in partnership with integrated joint boards, should develop a plan to end delayed discharges, in the context of health and social care integration.
- The Scottish Government should ensure that monitoring and reporting of delayed discharge is robust.
- Unit managers should ensure that specialist assessments are easily accessible for use by staff to inform the care and treatment plan and are reflected in care plans.
- Unit managers should ensure that care plans are holistic and include opportunities to maintain and develop skills of daily living. NHS Boards should ensure that activities are supported by adequate staffing, transport and socialisation budgets.

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[15] http://keystolife.info/wp-content/uploads/2015/06/The-Keys-to-Life-Implementation-Framework-and-Priorities.pdf

- Unit managers should ensure that there is a clear record of participation so that there is evidence that activities are taking place and in order that cancellation and reasons for this can be audited by the service.

2.   Environment

What we expect to find

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

- A clean and well maintained environment with an enclosed garden.
- Patients having their own bedroom and access to a variety of sitting areas, including a quiet area.
- Facilities that enable patients to maintain their daily living skills, space for activities, good signage to assist with orientation, and privacy for visitors where appropriate.

What we found

There was considerable variation in the quality of the unit environments visited. Some units were modern, well-designed spaces that offered good facilities for therapeutic activity and the development and maintenance of daily living skills. Others did not. This was especially disappointing given that 69 percent of the inpatient population had been in hospital for over a year.

Configuration of wards
All patients had single bedrooms. Ten units had all en suite rooms; five had some en suite rooms; and three had only shared toilet and bathing facilities.

Maintenance and cleanliness
Most were clean, but two of the 18 units were noted to be unclean or have unpleasant odours, including a smell of urine. One of these and two other units were identified as being 'not well maintained,' while a further four were noted to require some element of refurbishment or renovation. Therefore we considered that eight of the 18 units did not reflect the standard of environment we would expect for these inpatient services. The majority of these were in one health board area. Comments from our visitors included:

'Bathrooms need to be upgraded.'

'Decor is grubby and tired . . . and areas are very tired and shabby.'

In contrast, Lochview (NHS Forth Valley) provided a good example of a well-maintained unit:

'*Patients individual bedrooms are personalised and very clearly tailored to their individual needs. The bedrooms, corridors, and communal spaces have a homely feeling and patients have been significantly involved in choice of furniture and decoration.*'

Noise

The noise level was acceptable during all our visits. However, staff or patients interviewed in six units commented that it could be noisy at times. Increased noise levels were most frequently attributed to particular patients. In one unit, bedrooms were in close proximity and managing noise was difficult because of this.

Two of these six units advised that access to a separate sitting room or having a more spacious environment assisted in the management of a noisy ward and reduced the noise impact on patients. Some patients, especially those with autistic spectrum disorder (ASD), can be particularly sensitive to noise levels and many units reported that caring for patients with autism in a noisy ward environment can be difficult to manage.

Heating and ventilation

Three of the 18 units were noted to have unsatisfactory heating and ventilation on the day of the visit, with a further fourth ward advising that some rooms can be *'overly warm,' 'with little scope for ventilation.'* One particularly unsatisfactory ward advised that patient areas *'can get quite cold'* and additional electric radiators had been required. We were advised that a draught comes through the garden door, along with snow at times. On the day of the visit there was a rolled up blanket at the bottom of the door.

Signage and communication

Communication is crucial to ensure that people can express themselves and make sense of the world around them. Within inpatient units for people with learning disabilities we would expect to see the use of visual aids to assist with communication, making use of easy read strategies to promote better understanding for patients of the world around them. This could include pictorial signs; symbols; large fonts; and simple language. We found that 15 of the units had some degree of easy read signage, though this was often limited to basic signs for the toilet and bathroom.

Kylepark (NHS Lanarkshire) promoted their patients awareness and understanding of timetables and ward rules by prominently displaying this information in an easy read format; this was reinforced by easy read versions of individual timetables held in the individual's bedroom, when this was appropriate.

In relation to our expectation of easy read and adapted communication, we asked about how patients make their meal choices known, and how far in advance this was done prior to a meal. We were advised that all the units offered some form of choice: six wards chose

their meals the day before; three on the day; and nine more than a day in advance. In fact we found that in two of the units patients were given no choice. Only one of 18 units specifically commented on the use of a meal planner that included photographs or pictures. This was disappointing given that many patients may have the ability to make a supported decision regarding meal preference if offered the right assistance.

Adaptations

The units we visited potentially have to admit patients who have a physical disability in addition to learning disability. Eight wards had at least one adapted bedroom available, some of which were en suite. Six wards had an adapted bathroom on the ward, which was shared by all residents. Five units had both adapted bedrooms and bathrooms, whereas four units had no adapted spaces to facilitate access for wheelchair users or patients with mobility problems. At the time of our visit one ward, with an adapted bathroom, was struggling to access particular hoisting equipment for use in the patient's bedroom, though progress was being made to address this.

It was noted in another ward that, while there were adapted en suite bedrooms, there were no doors on the toilets in these rooms. This was highlighted by the Commission as requiring urgent attention to ensure the privacy and dignity of patients.

Environmental restrictions

All wards that we visited have the main door locked. However, 23 percent (24) of the patients we visited were informal at the time of our visit. The situation for informal patients within a locked ward varied across the units. Four units commented that, when able, informal patients may ask to leave the ward and staff may facilitate this. It was unclear from the data we gathered whether or not all of these informal patients understood that they could ask to leave, despite the door being locked. Guidance on locked doors can be found in Rights, Risks and Limits to Freedom.[16]

Seclusion rooms

There is only one health board with dedicated seclusion rooms. In a few other boards seclusion was taking place in bedrooms. In a hospital setting it would be best practice for seclusion to take place in a dedicated area suited for this purpose and not in bedrooms, wherever possible. We discuss the approaches to seclusion we found further in the section on Rights and Restrictions.

Environmental contribution to therapeutic activity

Nine units had a designated activity room within the unit. Nine did not. Where there was no activity room, activities tended to occur in the dining room, when available; sitting rooms were also used as alternative activity spaces. This suggested that on-site activity was more difficult to arrange than if a separate activity room was available. One unit accessed some activities in other units in the health board area.

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[16] http://www.mwcscot.org.uk/media/125247/rights_risks_2013_edition_web_version.pdf

Five units had a designated sensory room; 13 did not.

Eleven of the units we visited had access to an Activities of Daily Living (ADL) kitchen.[17] ADL kitchens were either contained within the unit or were nearby on the hospital campus. Seven units had no access to an ADL kitchen, though one of these had a large well-equipped kitchen (but not ADL compliant). ADL kitchens provide an important resource in which people can practice functional tasks related to meal preparation and cooking. For the patient in hospital, this can be an opportunity to learn new skills and/or maintain existing skills.

One unit without an ADL kitchen noted:

> *'Without access to a training kitchen or facilities for patients to do their own laundry, those patients who are more able on admission lose skills while they're in hospital.'*

The staff of several units that did not have an ADL kitchen specifically commented that this would be a desirable resource; they felt that development opportunities for their patients were being missed. One unit supported their patients to practice cold food preparation in the dining room.

Outside space

All 18 units visited reported that they had outdoor space for patients to access. However, four units reported that these outdoor spaces were restricted to certain patients, based on risk assessment. Two units were noted to have insufficient safety and security within their garden space and in some cases maintenance was poor. One unit advised that patients must request access to the garden because the door was generally kept locked; this was observed to be the case in many units.

> *'The garden space is not safe.'*

> *'Outside space is only accessible for some residents.'*

> *'One patient's garden has inadequate screening . . . There are privacy and dignity issues posed by this. The garden gate is not sufficiently secure.'*

We did find some examples of excellent garden facilities, in which patients contributed to the design of the garden, participated in its upkeep and engaged in groups and activities outdoors.

For example, in Lochview (NHS Forth Valley) significant financial investment had been made into the outdoor spaces, as well as significant input of the time and energy of staff and patients. There was a summer house with inside and outside seating; a growing shed;

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[17] A kitchen for use by patients to maintain and develop skills

fruit and vegetable patches; and many pots of plants and flowers. Nearly all patients were reported to spend meaningful time here and patients were able to use the produce grown to prepare meals or snacks. Staff here anticipated that gardening skills learned while in hospital could be transferred into patients' discharge plans. Longer stay patients had been supported to spend their money on gardening items big and small, which can be taken with them at the point of discharge from hospital. Patients interviewed spoke very favourably about growing vegetables to use in their own food preparation.

Kylepark (NHS Lanarkshire) and Claythorn House (NHS Greater Glasgow and Clyde) had developed activity plans for patients that were inclusive, when appropriate, of structured, supported activity time in the garden.

Visitor space

We expect suitable, comfortable facilities for patients to spend time with visitors in private. Fourteen of the 18 units (78%) reported that they had private spaces in which patients can meet with their visitors. In most units visits typically occurred in either a patient's own bedroom or flat in the unit; or in the dining room. Only two units had a designated Visitors' Room; six others had a quiet lounge or smaller meeting room that could be used by patients and their visitors.

Almost all the carers we heard from (43 of the 46 people who answered the question) said they could visit their relative or friend in private. Usually this was in their bedroom or in a quiet room or visitor's room, or they went out.

Some carers mentioned that for safety reasons staff were present or observing nearby during visits.

Fit for purpose

In 12 of the 18 units we visited, the opinion of the Commission visitor and of at least one staff member from the unit was that the environment should be improved. The majority of concerns were in relation to lack of space, with staff from several units emphasising that their ward was cramped, lacked adequate storage and lacked appropriate facilities for their patient group such as ADL kitchens as mentioned above. Where space was considered too confined, staff often also commented that the ward can be noisy. Maintenance and decor were also mentioned.

'The building needs an upgrade; it's now quite tired.' 'Bedrooms are on first entry to the ward, which affects patient privacy. The building is tired.'

'There is no separate room for staff to meet with visitors or have clinical review meetings . . . This has led to more staff discussions with relatives taking place over the phone than might be the case otherwise.'

'Mealtimes are difficult because there is not enough space, but many clients need their own space.'

'There should be more facilities to improve and maintain life skills, such as laundry facilities for patients.'

'Long corridor makes observation intrusive.'

'All bedrooms have a window in the door that can be easily looked into.' (It was discussed with the ward manager on the day of the visit that the bedroom windows needed to be addressed as a matter of urgency, due to the significant intrusion into patients' privacy and dignity that these windows posed).

The majority of those considered fully fit for purpose – those affording sufficient space, patient privacy, adequate lighting, and a layout conducive to provision of care and treatment for all patients, even when experiencing stressed or distressed behaviour – were units that were opened within the past ten years. These units tended to have single, en suite bedrooms; spacious corridors and bedrooms that provided ample space for observation and intervention; and had resources on site, including ADL kitchens and private visiting spaces.

Summary of findings

Twelve of the 18 units were thought to be not fully fit for purpose. Each was inadequate in some aspect such as the availability of indoor or outdoor space, adequate facilities to fulfil their assessment and treatment purpose, maintenance, decor or cleanliness. Many of these issues were identified in our report in 2011.

Recommendations

- NHS Boards should ensure through their capital planning programmes that within three years all learning disability inpatient units are fully fit for purpose. Units should provide a well-maintained environment that is clean, odour free and minimises the effects of noise. They should have adequate facilities to ensure that patients, including those with physical disabilities, can be nursed safely and have appropriate access to facilities to develop and maintain their daily living skills. Gardens should be safe, adequately maintained and assessed for their therapeutic potential.
- The Scottish Government should make fit for purpose environments a priority in the next Keys to Life implementation framework.

3.   Rights and restrictions

What we expect to find

We expect that patients' rights are fully respected, and that where their rights are restricted, this is in line with the law and with good practice. In particular, we expect that:

- Risk assessments and management plans to address these risks are in place.
- Risk management plans promote positive risk taking as appropriate for each individual.
- Where there are positive behaviour support plans, particularly those which involve restrictive measures such as physical intervention and or seclusion, these are regularly audited, reviewed and are within the law.

What we found

Risk assessments had been carried out and the details of the types of risk recorded in all but two of 104 patients' records examined. There was no risk assessment or management plan for one patient, where there was clear evidence in his medical file that he presented a significant risk to females. The other patient without a risk assessment had just been admitted.

Dates to review the risk assessment were evident in 84 percent (87) of records. Sixteen percent did not have recorded review dates and these were concentrated in four units. In five instances risk management was felt to be unsatisfactory, generally due to lack of individualisation and detail to address specific risks. For example, risk assessments were vague and provided insufficient detail on proactive strategies for minimising risk for one young woman with fluctuating mental health issues and behavioural issues. For another young man there was an identified risk with regard to his nutrition, but the management plan by the dietician was neither specific nor individualised. It stated *'he will comply with guidelines outlined within his current detention'*. This was also outdated information as he was an informal patient.

Overall, however, risk management plans were good. We were impressed with the quality, detail and clarity of the majority of Positive Behaviour Support Plans as well as the input from psychology, SALT, OT and nursing in drawing up guidelines to deal with these and other behavioural issues.

Commission staff assessed that risk management plans promoted positive risk taking in 88 percent of cases (42% fully and 49% partially). Good examples included:

'[He] can be very volatile, if not getting what he wants, leading to him put staff and others, including himself, at risk. However there are clear guidelines for managing this,

which are followed. Despite the risks which can occur in the community, these are actively managed and [he] is supported to participate in local community events and various events with his peer group.'

'The psychologist has drawn up an excellent Positive Behaviour Support Plan with input from OT, SALT and nursing staff. Improved communication and an increase in diversionary strategies have meant that observation levels have been reduced. [He] is going out regularly on a 2:1 basis when out of the hospital grounds and staff are encouraging his access to the wider community in order to help him develop and maintain skills. There is a very clear care plan supporting him in a most empowering way during transitions, so that he is encouraged to make choices himself and utilise coping strategies more independently.'

Specified persons

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 for the safety and security of the hospital. Six people were specified in terms of safety and security, three people in terms of phones, three in terms of safety and security and phones and one in terms of safety and security, phones and mail.

These measures are used to protect others as well as to safeguard the rights of those who have specific restrictions imposed on them. There were issues in three of the 13 cases which did not comply with the requirements of the legislation. These were taken up by the Commission and have been rectified.

Physical intervention

There were a number of patients where positive engagement and de-escalation strategies are at times unsuccessful and whose behaviour management plans include more restrictive measures, including physical intervention and seclusion.

Twenty people had been subject to physical intervention, using techniques such as seated restraint and floor restraint, in the six months prior to our visit, due to aggression or self injurious behaviour. In six of these cases physical intervention had been occasional (less than once in a month) rather than on a regular basis.

All staff involved had been appropriately trained. Protocols for when restraint was necessary were in place in all but one case. This case was taken up by the Commission. Of those patients who had been restrained, six were detained in one health board area and three in another. We were unable on a single visit to identify reasons for the higher numbers in these two boards - it may reflect a particular group of inpatients, established patterns in the management of aggression, constraints of the environment or a variety of other factors. Health boards do audit such incidents and management strategies so they can minimise physical intervention.

Seclusion

We looked at the number of people who were subject to seclusion. Locking someone in a room alone, because of their behaviour, is usually referred to as seclusion. The use of seclusion can cause distress and psychological harm and can increase the potential risk of self-harm, but it may be used as an alternative to sedative medication or restraint, for managing extremely difficult situations.

The Commission's view of seclusion is that it is "the restriction of a person's freedom of association, without his or her consent, by locking him or her in a room. Seclusion can only be justified on the basis of a clearly identified and significant risk of serious harm to others that cannot be managed with greater safety by any other means." (MWC, 2014)

Although this definition of seclusion does not include situations where someone prevents a person from leaving a room, for example, by physically blocking the exit, the same principles should still apply in such a situation.

Seclusion can be seen as a form of deprivation of liberty, albeit of relatively short duration. From this perspective, it may be useful to look at ways in which benefit, least restriction and best interests can be considered alongside an apparent infringement of a basic human right. Seclusion may reduce the need for prolonged restraint or the use of 'as required' medication. We would expect that proactive behaviour support plans would largely negate the need for such restrictive measures.

Seclusion can be in a room specifically designated for the purpose or could be in the person's bedroom or other safe place. It should always be for the shortest time necessary.

Thirteen of the 18 units reported that they did not use seclusion. One unit was discussing the possible reintroduction of seclusion due to high levels of violence and aggression.

Of the 104 patients we met or whose records we examined, ten were subject to seclusion. One person had seclusion in his care plan but it had never been used. Seven of those subject to seclusion were also restrained at times. Seclusion for the other three was seen as an alternative to physical intervention.

We found that there was no protocol in place for one person who was being secluded. It was clear that this patient was being placed in his room and staff were holding the door closed and jamming it with a towel to prevent him getting out. In addition the room was not suitable for this purpose as, when he needed seclusion, items had to be removed from his room which might present a risk to him. Staff told us others had been treated in a similar way. We have asked the senior management in this unit to consider what needs to be in place to ensure that, if seclusion is necessary, it is being used safely and appropriately, and documentation is in place to support this. In a hospital setting it would be best practice for seclusion to take place in a dedicated area suited for this purpose and not in bedrooms, wherever possible.

Staff need to be absolutely clear that, if they redirect someone to a quiet space, the person is free to go elsewhere if they wish. Where they are prevented from leaving the room, this should be treated as seclusion with the appropriate safeguards.

There is only one health board with dedicated seclusion rooms. Six of the ten people subject to seclusion were in this health board area.

A number of people subject to seclusion are nursed in single person suites with locked doors due to the risk to other patients and staff – these may open onto their own garden space. These people have a programme where they have scheduled time on their own but are for the most part with nursing staff. If they want staff when they are on their own, staff should be on hand to respond to them. We do not consider that, where the patient can have the door unlocked and staff can enter at the patient's request, they are secluded. However, if, due to the person's behaviour, staff have to leave them alone and the door remains locked for a period of time whilst they calm down, we would consider the person is secluded and appropriate protocols should be in place.

One health board has three individual suites in a specialist unit. For two individuals, the door is kept locked. The development of this facility has enabled these two individuals to return to their home area from highly specialist hospital placements in England. The Clinical Director discussed with the Commission visitor why it is felt that the model of care in this unit has been very successful. It has enabled individuals to be managed with a much reduced need for physical interventions and "as required" medication than when they were in shared patient environments in the past. There is a strong emphasis on provision of individual activities within and outwith the unit.

The Scottish Patient Safety Programme – Mental Health currently has a workstream on restraint and seclusion. This is being implemented through supporting frontline staff to test, gather real-time data and reliably implement interventions, before spreading these across their NHS board area. The work is being delivered through a four year programme, running from September 2012 to September 2016. The programme is looking at how improvement in outcomes for patients can be made through introduction of training, early intervention and systems of monitoring, debrief and review of practice. This will enable closer scrutiny by hospital managers, Health Improvement Scotland and the Mental Welfare Commission. Although this is a mental health programme, the learning from this work will inform learning disability services.

Other restrictions

There were a further 13 people who use their bedrooms or other quiet spaces and were redirected there when they were becoming upset. We were told that none of these people were confined to their rooms and they could leave if they wish. This was part of their Positive Behaviour Support Plan or care plan.

Adult support and protection

Where there are concerns that an adult may be at risk of harm because of their disability and inability to protect their own rights, the local authority has a duty to investigate this. All public bodies such as health boards have a duty to cooperate with the local authority.

Of the 104 records we examined, 11 people had been referred since their admission to the local authority under adult support and protection (ASP) legislation as potentially at risk. Of these eight were assaults or alleged assaults of one patient on another, resulting in minor or no injuries. One person had a more serious injury which remained unexplained after an extensive ASP investigation by the local authority. Two patients were referred because of sexual allegations, one by a relative when the patient was out of the ward and one in the ward by another patient. There was no concentration of referrals in one unit.

Summary of findings

Risk assessments had been carried out for all patients, though review dates were not evident in 16 percent of cases. Risk management plans were on the whole good and promoted positive risk taking. Where Positive Behaviour Support Plans included more restrictive measures, such as physical intervention and seclusion, there were clear protocols in nearly all instances for when such measures were required. There were a small number, however, where there were no protocols in place for physical intervention and seclusion and staff were not clear as to what constitutes seclusion[18]. This is extremely concerning in terms of human rights and patient safety. There were a small number of people subject to restrictions as Specified Persons where the legal requirements had not been met.

Recommendations

- Unit managers should ensure that risk assessments have a review date.
- NHS Boards should ensure that all staff are clear what constitutes seclusion and aware of the appropriate procedures.
- Unit managers should ensure that all restrictive measures, including physical intervention and seclusion, are part of a Positive Behaviour Support Plan with clear guidance and safeguards for their use and regular review of these towards less intrusive measures where possible.
- Unit managers should ensure that restrictions on Specified Persons under sections 281-286 of the 2003 Act comply with the requirements of the legislation.

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[18] http://www.mwcscot.org.uk/media/191573/final_use_of_seclusion.pdf

4. Health needs

What we expect to find

We expect to find that the physical health of patients in learning disability units is looked after proactively, and that all care and treatment is lawfully provided. Specifically, we expect that:

- Each patient has an annual health check, preferably a learning disability-specific health check, and has access to targeted health screening, where relevant, in line with the Keys to Life recommendation 17[19].
- The patient 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 authorised by the Adults with Incapacity (Scotland) Act 2000 or the Mental Health (Care and Treatment) (Scotland) Act 2003. Where medication is being given under the 2000 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 2003 Act, the appropriate documentation and safeguards have been observed.

What we found

Annual health checks

People with learning disabilities have higher than average rates of particular medical conditions. Twenty five percent of people with learning disabilities have epilepsy, whilst 47 percent and 63 percent have hearing and visual impairments respectively. There is a higher incidence of respiratory disease, coronary heart disease, swallowing problems, poor oral health, osteoporosis, hypothyroidism, diabetes, urinary tract infections and injuries due to falls. There is also a higher incidence of mental illness, dementia and behavioural difficulties[20]. In addition people with learning disabilities are less likely to exercise and eat healthily and may not always have the knowledge or ability to make healthy choices or understand the purpose of screening for health problems.

The Scottish Learning Disabilities Observatory[21] has been funded by the Scottish Government to look at providing information on the health of people with learning disabilities to improve policy and provision, taking into account user and carer views. They will develop a process of annual reporting of trends in the management of long term conditions and a better understanding of the causes of unnecessary deaths of people with learning disabilities.

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[19] http://www.gov.scot/resource/0042/00424389.pdf

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

[21] http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/sldo/

People with learning disabilities have a lower life expectancy and the causes of death have a different distribution from the general population. Due to this 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. An annual learning disability-specific health check therefore should be the norm.

We found clear evidence that 71 percent (74) of the 104 patients whose records we saw had had an annual health check, 18 percent (19) had not and the remainder were unclear. Of the 18 percent who had not had an annual health check, 14 people had been in the unit less than a year but five had been there over a year and should have had an annual check. In addition there were difficulties in accessing some records as several units did not have a proper system for filing these or a copy in the ward file. There were also forms that were incomplete. This is not acceptable, particularly in a health setting.

We were pleased to see that 11 units were using a learning disability-specific health check or were in the process of rolling this out. In most cases this was the Health Equalities Framework or a locally devised tool. This is a great improvement since our last themed visit to these units in 2011-12, when only a few units were completing learning disability specific health checks.

We saw some examples of good practice, such as the use of Talking Mats, to prepare individuals for their health check.

Screening

All units told us that general population screening, such as cervical or bowel screening, took place for those in the relevant age groups.

In one unit an admission checklist on screening needs was being developed. Others said screening was monitored through the annual physical health monitoring. This is particularly important considering the low take up of screening by people with learning disabilities. A recent research study (Monteith 2015), produced as part of the PROP2 (Practitioner Research: Outcomes and Partnership) programme, notes the problems with take up of cervical screening and explores the barriers for women attending checks and what could be done to encourage them to attend.[22]

It is essential to have a system which monitors screening. Where medical services are not provided by the GP, patients will not receive appointments and reminders about screening. Similarly where patients are in hospital on a short term basis, screening appointments may be going to their home address and be easily missed. An example of good practice is Rannochmor (NHS Lothian):

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[22] http://lx.iriss.org.uk/content/what-helps-women-who-have-learning-disabilities-get-checked-cervical-cancer

'When screening is required e.g. cervical smears, it is arranged for the individual to attend a clinic to have this as there is no GP service. Part of the annual health monitoring undertaken in the ward includes completing a monitoring form which records screening/need for this. Medical and nursing staff organise this as appropriate.'

Access to other health care services

Overall access to other health care services was good.

No problems were noted in the provision of optometrist/ optician services. Units generally used local services. A small number of patients required a specialist optometrist. RNIB would attend the unit for more complex cases or people were referred to hospital. We noted good practice at Arrol Park (NHS Ayrshire and Arran) where the RNIB's Bridge to Vision provides a service and some staff have attended vision related training.

No issues were noted in accessing specialist ENT and audiology services.

The majority of units had access to specialist on-site/hospital dental services. Alternatively patients could attend the dentist they normally saw at home or a local dentist by referral. We noted good practice at Lynebank (NHS Fife) where the hygienist provided sessions to promote good oral hygiene.

There were positive comments from staff where there were on-site/hospital podiatry services, though the regularity varied from six weeks in five units to three months in two units. Other issues related to podiatry included lack of regular input; long delays following initial referral; and having to pay for a private service (five units), where the NHS only provided checkups, unless the person had a specific health need such as diabetes. We noted good practice again at Arrol Park (NHS Ayrshire and Arran) where nursing assistants had been trained in basic foot care.

We asked staff about weight management in relation to all the patients in their units. Four percent (8 of 180) of patients were underweight and this was being addressed by regular (weekly) dietetic input and supplements. Thirty four percent (61 of 180) were overweight. This was being addressed in a number of ways including reviews of medication; healthy eating advice from the dietician and nursing staff promoting healthy choices when shopping or at mealtimes; health promotion care plans, diet and exercise plans; healthy eating groups; walking and other activities such as Zumba, swimming and trampolining; and Active Champions encouraging people to be more active.

Consent to treatment: Mental Health Act

We were pleased to see that nearly all consent to treatment documentation (T2/T3 forms) for those who required it was in place (68 people). However there were two that did not cover the medication being given and 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. These instances were addressed at the time with staff.

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. Seventy five percent (78) of people were assessed as lacking capacity to consent to their treatment.

Nine percent (7) did not have a valid section 47 certificate of incapacity as required by the Act. It is unlawful for staff to administer medication without proper legal authority. Where staff are not clear about the legal authority, they should discuss this with the appropriate member of medical staff as soon as possible. Any treatment should, however, be continued meantime.

Twenty two percent (17) did not have an accompanying treatment plan which is recommended as good practice under part 5 of the Act. These basic requirements should be picked up through regular audit of legal paperwork and through reviews of individual's care and treatment.

We discussed these issues with staff during our visits.

Summary of findings

The majority of hospital units (11 of 18) were carrying out, or were in the process of initiating, learning disability specific health checks and screening. This was an improvement since our visit in 2011 but more work needs done in this area to address health inequalities. Access to podiatry was difficult for some units and they were using private services.

The legal requirements of consent to treatment under the Mental Health Act had been carried out for the most part. We were concerned that in nine percent of cases the legal requirements of prescribing and administering treatment under the Adults with Incapacity Act had not been fully met.

Recommendations

- Unit managers should ensure that all inpatients have a learning disability-specific health check annually and these should be easily accessible in the patient's records.
- Unit managers should ensure that the legal safeguards for treatment under the Adults with Incapacity Act are adhered to. A section 47 certificate must be in place, and should have an accompanying treatment plan. These should be evident in the medication prescription chart so that staff are clear about their legal authority to administer medication.

5. Participation and engagement

What we expect to find

We expect that people with learning disabilities being treated in inpatient units are supported to be as engaged as possible with their care and treatment. In particular, we expect that:

- Patients are involved as far as possible in their care and treatment plans and are supported to attend review meetings.
- Patients are involved in discharge planning.
- Every effort is made to enhance the person's communication and involvement.
- Patients have access to advocacy.
- There is good communication with and appropriate involvement of families and carers.

What we found

Patient involvement

Forty five people met with us to give us their views and six others gave some views through their advocate or by other means.

All units had access to advocacy services. Of the 51 people whose views we heard, 38 told us they had or had had an advocate. Advocates generally supported people at Tribunals, at their review/discharge planning meetings or with regard to individual issues such as smoking.

With regard to support at review meetings, 27 of 38 people who responded had an advocate who attended their review, 18 had a family member who supported them and of these 12 had both an advocate and family who attended. One person told us that advocacy was only available for tribunals. However the following was more typical of advocacy involvement: *'I go out for coffee before any meetings to talk about what I want and meet up after.' 'The advocate goes to Tribunals but he also comes in every two weeks.'*

Of 45 people we met, 32 said they attended their own review meetings, though some only came in for part of the meeting. Eight people did not attend and this appeared to be by choice. Five were unsure if they attended or not. Most people said they felt listened to at meetings. A few did not. For example:

'*I want to talk about passes and I feel decisions about my passes are made before the meeting*' and '*I don't like the day centre but staff say I have to go, as part of treatment. I told them at several meetings - they don't listen.*'

The Association for Real Change has a National Involvement Network of people with learning disabilities who have produced a Charter for Involvement[23]. The Charter sets out how people with learning disabilities want to be involved and how they believe organisations can improve involvement. Although the Charter is mainly aimed at social care services, the principles and ideas will also be helpful to inpatient services.

We asked people their views on their discharge plan. Of the 41 people who answered, 24 said there was a plan, though the stage of discharge plans varied. Nine of these people voiced concerns about their plans which reflected the delays in discharge discussed above. For instance:

'The plan is to go back and live in the community. I am still waiting to find out where this will be but could take a while to sort out.'

'Yes, but I'm unhappy that there has been a delay.'

'I should have been out in March. I am scared about the area I am being sent to but I need to give it a go as I want to get out.'

'Takes ages - I have been waiting years for the right house and support.'

For others it was more positive.

'Going back to my house in [town].'

'I am leaving in a couple of weeks. I've been to my flat twice and staff have been here. The care manager, psychiatrist and the community nurse are involved and come to meetings.'

Information and patient feedback on the service

There were strengths and weaknesses across the services in how they provided information and sought feedback. Some health boards had given much more thought to this than others. We felt there could be more sharing across services to enhance good practice.

Some services had pictorial signage to assist navigation around the unit, three services did not. Some had user-friendly introductory information and others did not, although some were planning to provide this. Some had policies and complaint procedures, information on mental illness, medication and medical procedures all in easy read formats. Some used

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[23] http://arcuk.org.uk/scotland/charter-for-involvement/

visual planners for informing users of planned activities in the unit, as well as for individual timetables.

We saw a range of methods for getting feedback on the service. Eight units told us they had user-friendly questionnaires which were completed with patients three-monthly or less frequently and had a system for auditing these. In Monroe House (Danshell) Talking Mats were used to assist people to complete their satisfaction questionnaires. In Arrol Park (NHS Ayrshire and Arran) we saw clear feedback on the 'You Said, We Did' board.

All the NHS Greater Glasgow and Clyde units had suggestion boxes for patients, as well as staff and carers, again with a system for audit and feedback. Ten units said they had patient meetings or forums to discuss present and previous issues. Some of these were weekly or fortnightly meetings for patients to plan activities and raise issues. Others were held less frequently. Some of these were chaired by advocacy, most by staff. Some of these, as in NHS Greater Glasgow and Clyde, were open to people in their four units. Some, such as the meetings in Monroe House (Danshell), took issues forward to their regional and national forums.

Some units relied solely on individuals raising issues with staff or in 1:1 meetings with their keyworker and these were then discussed at the MDT meeting. However, we thought that gathering the views of the whole patient group in these units would enhance user participation in service issues and highlight what was important for users. There is an opportunity here to learn from practice in other units.

Involvement of families and carers

It is important that carers are involved from the point of admission onwards in both the formal processes of decision-making and informally.

Introduction to ward

Of the 40 people who gave us their views on the admission of a relative or friend, 25 had had a verbal introduction and been shown around, with nine also receiving written information. Two received written information only. Six people had had no introduction to the ward and a further seven gave other responses. Most were happy with their introduction but a few were unhappy about the experience at admission. One person had made a complaint about the transition into the ward.

'*Complaint is in relation to how his transition occurred; didn't feel [he] was treated like an individual. Felt his transition into hospital was not appropriate and upset that he was not allowed to see his parents for nine days. Parents were told to leave quickly on arrival. Didn't get to say goodbye.*'

Welcome and communication

Eighty seven percent (39) always or often felt welcome when they visit; there were many positive comments about how friendly and helpful they found staff; and there were few issues with visiting times or arrangements. Comments such as *'Great staff, give updates, offer tea/coffee etc'* and *'Incredibly warm and welcoming staff. I can tell they really care.'* were typical.

In Kylepark (NHS Lanarkshire) there was good communication with family and formal and informal carers. They told us:

> *'A carers' support worker is identified daily, like the identification of senior charge nurse etc. This person links with formal and informal carers on their arrival to provide update on the patient and provide anything necessary for an outing or visit. There is a 'carer note' template for feedback from paid carers and they get verbal feedback from family members.'*

Visiting

Three people, in two units, said their visiting was limited. They did not have a clear understanding of the rationale for this. A further three people said they rarely felt welcome when they visited. One person described concerns about the safety of her family while visiting because of the behaviour of other patients. The unit has addressed this by developing a waiting room for families by the door.

Twenty nine carers said they were able to take the person out of the ward, although for some this could depend on the person's mood and behaviour. For those who did not or could not take the person out, this was sometimes through choice, or because of the person's behaviour and their support needs. However, three said that outings were not possible because staff would need to provide escorts, and two said they had not known that going out could be an option; for one of these patients we discussed with staff the potential for outings and this is now being done.

Role of guardian

Sixty percent (28) of carers who gave their views were welfare guardian and 82 percent (23) of those felt that staff recognised and respected their role. However, two people felt that this was not the case, and two of those who felt their role was generally respected had not always been consulted or kept informed. It is important to establish and record on admission what the guardian's powers are and how they wish to exercise or delegate these.

Involvement in reviews and discharge planning

Sixty six percent (31) felt involved in the person's care and a further 15 percent (7) felt this was sometimes the case. Thirteen percent (6) did not feel involved. Nearly every carer (91% (43)) was invited to attend review meetings. There were a variety of reasons given by the small number who did not attend, including the timing of meetings, a disagreement and not feeling listened to. Most people described being kept up-to-date by staff via phone calls

and during visits as well as at reviews. Two said they were not kept up-to-date and three felt that they were not given enough information.

Forty seven percent (22) carers said they were involved with discharge plans. Thirty percent (14) said there were no current discharge plans and 23 percent (11) people said they would like to be involved, or to be more involved. Some people were not happy, either with the plans being made or with the lack of availability of appropriate services. Comments included:

'No: Aware that son is on "delayed discharge" for last 10 months - no specific accommodation available and no plans for provision that we are aware of.'

'Yes, but limited specialist services available and unable to move at present.'

'My son is being assessed for discharge soon and they are looking to put him very far away which is upsetting me. I do not drive, I do not work and my life is seeing my son four times a week as he comes home for a visit on a Monday. I am angry that they are looking so far away and no one is listening to me.'

Carer involvement in service issues
We were pleased to hear that a carers' forum for the four units in NHS Greater Glasgow and Clyde had been re-established in May 2015 and was supported by a nurse responsible for the engagement and participation of users and carers. The group were looking at providing an 'engagement pack' for carers. The company who own Monroe House had a national family forum which met in the north of England. Other units told us that they were able to signpost carers to other carer groups in the locality.

Only 8 percent (4) of carers said they attended a support group attached to the service. Thirty four percent (16) said there was not a group, although three of these were attending groups elsewhere. Some said that they feel sufficiently supported by staff. Only one indicated that they would like to be able to attend a group. Forty six percent (23) of carers were not sure if there was a carers' group.

Other carer groups
Carers also reported a lack of carer support groups elsewhere that they could attend. Ten percent (5) attend support groups elsewhere and another five were unable to attend. Forty two percent (21) said there was no group and a further 24 percent (12) were not sure.

In terms of wider issues affecting the ward, such as changes to services, only 21 percent (10) carers felt they were included in discussions about these. Particular concerns raised were lack of information, staff changes and the continuously changing dates for the closure of two of the units.

Other feedback mechanisms

Five units used questionnaires to get feedback on the service from carers. Four units had a suggestions box, as mentioned above. Other means for collecting carer feedback included informal ongoing chats or phone calls with staff on the ward and regular inclusion in MDT, CPA, and review meetings.

Other issues raised by carers

We asked carers if there was anything else they wanted to tell us. Many were very complementary towards the care and treatment their relative was receiving and the staff. One had nominated the ward for an award. Comments included:

'My wife and I feel that [he] could not be in better hands for care, commitment, or treatment. The leadership and staff of [the unit] are truly committed to the principle of 'personalisation' where patients and carers are concerned.'

'[His] placement in the community was at breaking point. They could not provide enough staff. He was in a council property which was in a poor state of repair. [The Council] could not provide another service. On moving to [hospital], [he] changed, his health improved. They reduced and removed the use of drugs like diazepam, lorazepam etc. His behaviour pattern has changed from nearly an incident every two days to only two incidents in year and a half he has been there. They offer him a safe, structured, proactive, friendly, respectful environment. He is always out and about - example rebound, art gallery, museum, beach walks, cafes, cinema. They also arrange activities - example; baking, arts and crafts, music, gardening. Everybody has been supportive, respectful and friendly to us as his carers fully taking on board what we say. Could not ask for a better service but he needs to move to a more residential support unit to develop further.'

Some expressed a lack of confidence in whether there were community facilities which could meet their relatives' needs:

'Due to lack of appropriate community services, the Mental Health Act is used. In this situation no treatment as such - better community alternatives required.'

'Need to be staff with expertise, who can pick up cues. Could be too big a leap from the boundaries and structure here to community placement.'

Some outlined what could be done to improve things or expressed their dissatisfaction. These included:

- Three carers who felt their relative could have more and a greater variety of activity in their day and get out more. One felt that his relative spent too much time in the ward and that he was being denied opportunities due to a risk averse approach by staff.

- One who had concerns that new staff were not as aware of their relative's physical health needs, whilst another had concerns about a decline in health due to a change in medication.
- One who felt social work were doing nothing to help their relative move on and as a result their relative was 'incarcerated in hospital.'
- One who felt staff needed more training in autism. (The majority of units said staff had had specific training in ASD.)
- One who expressed concerns about the cost of visiting where relatives were placed at some considerable distance from family.

Involvement of others

Ninety seven of 105 people had family involvement (in three instances this was only by phone). Where people had no family involvement we saw some examples of good practice. For example, referrals had been made to befriending services, though there tended to be long waiting lists for these services. In Netherton two people who had no family contact had citizen advocates who were able to spend regular periods of time with the patient. They were recruited and supervised by the local advocacy service.

We asked about contact with friends in the community. Staff were aware that 23 people had friends before their admission, 13 of whom were in contact or visiting the person in hospital.

Summary of findings

Overall there was good support from advocacy for attendance at Tribunals and review/discharge meetings. Most patients interviewed who wanted to attend their review meetings did so with the support of advocacy, their family or both. Some only attended part of their meeting.

Most patients were unable to articulate the reasons for being in hospital but knew what care and support they were getting and if there were plans for their discharge.

The provision of user friendly information, appropriate signage and efforts to encourage user feedback on the service varied greatly with some units making much more effort to engage users than others.

Carers were generally positive very complimentary about the services, including being welcome, the visiting arrangements, communication with staff and involvement in reviews. Six carers did not feel involved in the review process and some had concerns about discharge planning and whether community facilities could meet their relative or friend's needs.

Only one NHS board and the private hospital had a carers' forum for the units in their area or company. Around half the carers who contributed were not sure if there was a carers'

group attached to the unit and many did not know of any alternative carer support group in the area. Only 21 percent of carers felt involved in wider service issues and some were concerned about lack of information on changes in personnel and possible closures of units.

Recommendations

- Unit managers should provide user friendly information on the unit, its processes and policies and ensure signage is appropriate.
- Unit managers should have systems in place to get users' views on the service on a regular basis and provide responses to the issues raised.
- Unit managers should provide introductory information for carers on the unit, how they can be involved in their relative or friend's care and treatment, processes and policies and signposting to carer advocacy and support groups.
- Unit managers should ensure there are systems in place to get carers' views on the service on a regular basis and provide responses to the issues raised.
- NHS Boards should support the development of carers' forums in their areas.

Conclusion

There were many positive findings from our visits to people with learning disabilities in hospital units throughout Scotland this year. In comparison with our themed visit in 2011, there are now fewer patients in these units. We found that overall, both patients and their carers were in the main positive about their experiences, and we heard positive feedback about involvement.

We are pleased to see that there has been improvement in some of the areas we had concerns about in 2011. Three quarters of the care plans we saw had all needs clearly addressed, and there was good access to and use of specialist assessment. Access to activities appeared to have improved, and we found only a few issues with regard to people's legal rights being respected.

However, we are concerned that the problem of delayed discharge, well-recognised as a strategic issue, remains. The proportion of patients who are experiencing delays in their discharge was 22 percent when we visited in 2010 and on this visit was 32 percent. This has serious implications for the people who remain in hospital when this is no longer the best place for them, and for those who in consequence may be unable to be admitted when they need to be, and is a human rights issue. The reasons underlying the delays are complex but this issue needs to be further addressed and acted upon. We would expect the new integrated partnerships to address in their strategic planning their responsibility to ensure sufficient and appropriate services in the community which are able to meet complex needs.

We are also concerned that we found that aspects of the environment in 12 of the 18 units were not fit for purpose, despite similar findings in 2011.

Within the units we found much good practice, which we have highlighted in this report. However, there are other areas where there is scope for improvement in terms of practice and record-keeping, which we hope NHS boards, private providers and staff will consider in relation to their own service.

Table 1 Units visited and people seen

Units	No. of beds	No. of patients in the unit			Records examined				Personal interviews	Views via other
		Male	Female	Total	Male	Female	Total	% examined		
Arrol Park	16	9	2	11	4	1	5	45%	3	
Mayfield	13	6	5	11	3	3	6	55%	4	
Lochview	26	16	8	24	4	4	8	33%	2	
Elmwood (Bracken)	8	2	4	6	2	4	6	100%	1	
Strathmartine BSI Unit	8	4	4	8	3	2	5	63%		
Blythswood House	16	10	6	16	4	3	7	44%	4	1
Claythorn House	12	6	5	11	6	1	7	64%	4	
Netherton A & B	8	8		8	7		7	88%	6	
Waterloo Close	6	6		6	5		5	83%	2	1
Willows	6	3	3	6	2	3	5	83%	3	
Kylepark	12	7	5	12	2	1	3	25%		3
Camus Tigh	8	7		7	6		6	86%		
Primrose Lodge	8		8	8		3	3	38%	1	
Dunedin	5	5		5	5		5	100%	5	
Islay Centre	11	12		12	7		7	58%	2	1
William Fraser Centre	5	5		5	5		5	100%	3	
Carseview Learning Disability Assessment Unit	10	7	3	10	5	1	6	60%	2	
Monroe House	20	12	2	14	4	4	8	57%	4	
ALL	**198**	**125**	**55**	**180**	**74**	**30**	**104**	**58%**	**46**	**6**

Table 2 Delayed discharges in learning disability inpatient units by Health Board, visited Aug-Oct 2015, from clinical service managers on date of visit

Health Board	Number of patients	Number of delayed discharges formally notified	Delayed discharges as % of total patients
Ayrshire & Arran	11	3	27%
Fife	11	3	27%
Forth Valley	24	8	33%
GG&C	41	15	37%
Grampian	6	2	33%
Highland	6		0%
Lanarkshire	12	2	17%
Lothian	37	17	46%
Tayside	18	7	39%
Monroe House (Private)	14	1	7%
Total	**180**	**58**	**32%**

Table 3 People visited by gender and age

	Female		Male		All	
	No.	%	No.	%	No.	%
16-17		0%	2	3%	2	2%
18-24	4	13%	10	14%	14	13%
25-44	14	47%	34	46%	48	46%
45-64	9	30%	26	35%	35	34%
65-84	2	7%	2	3%	4	4%
85+	1	3%		0%	1	1%
Grand Total	**30**	**100%**	**74**	**100%**	**104**	**100%**

Table 4 People visited, by gender and number of years since admission at time of visit

	Female		Male		All	
	No.	%	No.	%	No.	%
up to 1 year	11	37%	21	28%	32	31%
1 to 2 years	8	27%	13	18%	21	20%
3 to 5 years	6	20%	14	19%	20	19%
6 to 9 years	2	7%	8	11%	10	10%
10 to 19 years	1	3%	11	15%	12	12%
20 years and over	2	7%	7	9%	9	9%
Grand Total	**30**	**100%**	**74**	**100%**	**104**	**100%**

national
preventive
mechanism

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mental welfare
commission for scotland

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