mental welfare
commission for scotland

A HOME OF MY OWN

Report from our visits to people with learning disabilities who are living in care homes which are registered with the Care Commission as having more than 20 places
June to September 2010

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Introduction

Who we are and what we do

The Mental Welfare Commission is an independent organisation working to safeguard the rights and welfare of everyone with a mental illness, learning disability or other mental disorder. Our duties are set out in mental health and incapacity law.

We are made up of people who have understanding and experience of mental illness and learning disability. Some of us have worked in healthcare, social care or the law. Some of us are carers or have used mental health and learning disability services ourselves.

We believe that everyone with a mental illness, learning disability or other mental disorder should:

- Be treated with dignity and respect.
- Have the right to treatment that is allowed by law and fully meets professional standards.
- Have the right to live free from abuse, neglect or discrimination.
- Get the care and treatment that best suits his or her needs.
- Be enabled to lead as fulfilling a life as possible.

Our work

- We find out whether individual treatment is in line with the law and practices that we know work well.
- We challenge those who provide services for people with a mental illness or learning disability, to make sure they provide the highest standards of care.
- We provide advice, information and guidance to people who use or provide services.
- We have a strong and influential voice in how services and policies are developed.
- We gather information about how mental health and adults with incapacity law are being applied. We use that information to promote good use of these laws across Scotland.

Our visits

One of the ways in which we monitor 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.

This report reflects our findings from a programme of national themed visits to people with learning disabilities who are living in the larger residential care homes. “Larger” is defined for the purposes of this report as a residential care home which is registered with the Care Commission as having more than 20 places. The aim of national themed visits is to 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. This report provides an overview of our findings from a series of visits we undertook across Scotland between June and September 2010.

Why we visited

The Same As You? (SAY) review of services for people with learning disabilities[1] was published by the Scottish Government in 2000. It set out a 10 year programme of change that would support children and adults with learning disabilities and Autistic Spectrum Disorder to lead full lives, giving them choice about where they live and what they do.

The review is based on 7 principles, that people with learning disabilities should:

- Be valued
- Be treated as individuals
- Be asked about what they need and involved in making choices
- Be given help and support to do everything they are able to
- Be able to use local services, wherever possible
- Benefit from specialist social, health and educational services if needed
- Receive services which take account of their age, abilities and other needs

Opportunities for those with learning disabilities should mirror the expectations of the general population; for example, a home, relationships, meaningful activity, employment, lifelong learning, and access to appropriate health care.

Similarly, in 2006, a survey of service users' views by the Scottish Consortium for Learning Disability (SCLD) stated:

"What matters most to people with a learning disability is getting their own home, having friends and being able to go out more. They also want to make sure that they stay in contact with their family, and they keep the support that is essential to their independence. They enjoy socialising more than anything else, next to that sport. They hope for new experiences."[2]

Ten years on from the SAY review we decided to visit people who were living in the larger residential care homes, that is those registered with the Care Commission as having more than 20 places. We wanted to see how far some of the changes recommended in the SAY report and the aspirations of those in SCLD's survey were affecting people's day to day lives.

Background information

The 2009 SCLD eSAY statistics revealed that 61% of 27,671 adults with learning disabilities known to the 32 local authorities in Scotland were living in mainstream accommodation, 24% in supported accommodation and 5% in other

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[1] http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp

[2] http://www.scld.org.uk/library-publications/how-it-going-a-survey-what-matters-most-people-with-learning-disabilities-scotl

accommodation.[3] Eleven per cent (2,364) were living in registered adult care homes. Roughly a quarter of these were living in homes registered for 20 or more people.

Where we include percentages in this report, these are based on information about individuals obtained from staff and case notes.

The practice examples in the report are based on real situations but some of the details have been changed to protect individual privacy.

Where issues have arisen in the course of our visits with the care, support or treatment of individuals or the legislative framework, these have been followed up by the Commission.

We would like to thank the managers and staff in all the units who were very helpful in facilitating our visits.

Areas we looked at and why

We gathered information from interviews with staff, from those service users who were able to talk to us and give us their views, and from examination of service users' care plans and other records. We had 4 areas of enquiry. These were:

- **Rights and restrictions** - including whether risk assessments and management plans were in place and whether any restrictions on the person, such as restraint, were legally sanctioned.

- **Health needs** - including access to regular health checks and specialist support and whether issues of consent had been considered.

- **Participation** - including whether the person was involved in making and reviewing their care plan, what support they received to communicate their wishes and the involvement of the placing local authority in reviews.

- **Quality of Life -** including the homeliness of the environment and the choices it afforded the person, what the person did on a day to day basis in terms of work, social, recreational and educational activities and their opportunities to maintain or develop their independent living skills, and how they were supported to maintain relationships with friends and family.

The units we visited

Between June and September 2010 we visited all the units for people with a learning disability in Scotland registered at that time for 20 or more residents. The Care Commission supplied a list of these places. The current number of residents in some cases varied considerably from the number of registered places. Five units had over 30 residents at the time of our visit, 5 had 26-30 residents, 5 had 20-25 residents and 7 had fewer than 20 residents.

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[3] http://www.scld.org.uk/sites/default/files/2009%20eSAY%20Statistics%20Release.pdf

There were 22 units in total (we considered one home as two separate units due to their very different functions and organisation). Of the 22 units, 12 were in very rural settings. There were no units in the two main centres of population in the Greater Glasgow area or the Edinburgh and Lothians area, as they provided care in much smaller units.

The model of care varied greatly between the 22 units. We found it useful to group units as follows:

‘Dispersed’ units were those where people were living in accommodation with 7 residents or fewer. These included, for example, a service where each person had their own house on a campus; one unit which had both a number of individual bedsits and a larger unit; and a number of units which had separate houses or flats with between 4 and 7 residents in each.

‘Communal’ units were those where people were living with more than 7 residents. These included, for example, units that had been divided within the one building with 11-13 residents in each subunit, and units which were not subdivided and had between 21 and 32 residents.

On this basis there were 10 ‘dispersed’ units and 12 ‘communal’ units. Four units said they provided a service for people with mild-moderate learning disabilities, 2 said they provided a specialist service (one for people with autistic spectrum disorder (ASD) and one for people with challenging behaviour), and the remaining 16 said they provided a service for people with a wide range of disability.

People we visited

We looked at the care and treatment of 151 people out of a possible 516 residents in the 22 units. As far as possible, the number of individuals we saw was proportionate to the size of the unit. We met with those individuals who asked to be seen, some of the people who were subject to extra restrictions (e.g. required restraint or 1:1 staffing), and we selected a random sample of other people from the total list of residents supplied by each unit.

Table 1, showing the age and gender of individuals we saw, can be viewed in the appendix. Forty-three percent were female and 57% were male. This corresponds with the gender balance of people with a learning disability across Scotland as collated in the eSAY statistical release.[4] Six of the units had a younger age group, largely 18-35 years of age, all of which were ‘dispersed’ units. Seven units had an older population, 35+ years of age, of which 3 were dispersed units and 4 were communal units. Nine units had a spread of ages and all but one of these units were communal units.

Of the people we saw, 39% had a diagnosis of a moderate learning disability, compared with 23% in each of the mild and severe categories. Seventeen percent had a dual diagnosis of learning disability and mental illness, and 17% had significant behavioural difficulties. Prior to the visit, we thought that people with a

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[4] http://www.scld.org.uk/sites/default/files/2009%20eSAY%20Statistics%20Release.pdf

dual diagnosis, challenging behaviour or perhaps more severe disabilities might be placed in the units where there was a dispersed model of care. Our findings did not bear this out, however. Table 2 in the appendix shows there was little difference between the 2 types of unit in terms of diagnosis of those seen.

Our findings

Summary of main findings

We were pleased to see some good quality care and support in many units:

- Personal space – overall, people had pleasant homely bedrooms where they could spend time with their personal belongings, music, TV etc and had some choice in the décor or furnishings.
- We found good access to primary health care services and Community Learning Disability Teams in nearly all units
- Staff helped people stay in contact with friends and family. They understood how important this was.

When we asked service users what they valued most about where they lived, their responses included - the staff, the company and friendships, having their own bedrooms, the work or activities they did and going out for meals or drinks. More detailed information from service users is incorporated in the general findings.

We were concerned about the considerable variation between units when we looked at a range of issues, including:

- The model of care (ranging from person centred care to more institutional care arrangements).
- Access to homely sitting and dining areas and use of kitchen facilities.
- Day to day activity programmes that reflected individual choice and interests.
- The degree of focus in maintaining or developing daily living skills.
- Attitudes of staff to resident participation in day to day decision-making.
- Access to transport and community facilities.
- Charges for certain services paid from the person’s benefits, such as mileage costs.
- The quality of care plans and reviews, including the participation of the person and the involvement of the local authority social work service.
- Knowledge and understanding of the legislative framework for medical and welfare decision-making.

In general, we found that communal units were less homely. People in dispersed units were helped to be more independent. They were more likely to make their own drinks and snacks, to help prepare meals and do their own laundry and cleaning. People in communal units were, generally, a bit older and the size and design of the unit made it difficult to involve people as much in their own care. We were pleased to see that staff and managers in some communal units did a lot to help people be more independent despite these problems. Their attitudes to providing individualised care, their enthusiasm and their creative use of space minimised the drawbacks of a communal unit.

When we asked service users what they liked least about the place they lived, responses included the noise, boredom, not getting out enough and the food. Others did not like the number of people they had to live with or particular individuals that they clashed with; some felt they were too far away from their relatives.

We have identified 4 key messages arising out of these visits. These are set out immediately below, and discussed in greater detail later in this report:

Summary of key messages

1: Rights and restrictions

Risk assessment and risk management plans/care plans:
These need to be audited and reviewed regularly. Assessed risk was not adequately addressed in 7% of the plans we examined.

Behaviour management plans:
There needs to be appropriate professional input, regular audit and review and clarity about the legal basis of the intervention, particularly where plans restrict individual freedom.

Legislative framework:
Staff need to have a clear understanding of the legal context for decision-making where a person lacks capacity to make welfare decisions and of the roles and powers of any welfare guardians or attorneys appointed under the Adults with Incapacity Act. The relevant documentation should be available in the person's file.

2: Health

Overall, there was good access to primary health care services and input from Community Learning Disability Teams.

There was poor compliance with the legislative requirements of Part 5 (section 47) of the Adults with Incapacity (Scotland) Act 2000, where a person lacks capacity to give informed consent to medical treatment. GPs and service providers should ensure a certificate of incapacity and a treatment plan are completed and copies of these documents are available in the person's file.

3: Participation in care planning and review

Service providers need to maximise the person's participation in this process. This includes preparation and assistance to enhance the person's communication and involvement and better access to independent advocacy, particularly where the person has no friends or relatives.

Local authority social work services should be involved in reviews, at a minimum, on an annual basis or, where the person is on welfare guardianship, at no more than six monthly intervals. Local authorities need to ensure that the quality of care, the care plan and placement are meeting the person’s needs and wishes and that, where there is a welfare guardianship order, the powers are being used appropriately.

4: Quality of Life

Living arrangements:
This is the person’s home. Living arrangements should be as homely as possible and the person should be given the opportunity to participate in all aspects of normal day to day home life. Staff should think carefully about how to minimise the institutional aspects of their unit; for example, through the creative use of space or improvement in the physical environment, consideration of noise levels or the necessity for staff uniforms.

Staff attitudes to involving people in day to day tasks and the ethos of the unit are also important in shaping living arrangements. Ways of increasing residents’ involvement in the day to day running of their home and training for staff in person-centred approaches to care should be considered.

Day to day activity:
Being active and involved is important to everyone. An individual should have a plan of day to day activities that reflects their choices, needs, age and abilities. This should include opportunities for educational, social, recreational and work activity, as appropriate, alongside opportunities to maintain or develop skills of daily living. While we found some excellent examples of this, there were some units where such opportunities were very limited and improvement was needed.

Transport:
Availability of appropriate transport is fundamental to arranging regular access to community resources, particularly in rural areas. We found that a minority of people were not able to leave the unit regularly due to transport difficulties. Staffing levels and lack of local community facilities also limited some units. Service providers should ensure staff and transport are available to enable people to use community resources on a regular basis.

Relationships:
We found staff were helpful in supporting relationships with relatives. More emphasis on developing friendships outwith the unit would enhance people’s quality of life, especially where they have no family contact. Relatively few residents had friends from other areas of their life who visited them at home.

Staff need to have greater awareness of the rights and issues of consent in sexual relationships. The Commission has recently produced some guidance on these issues in ‘Consenting Adults?’, which is available on our website.

Key messages

Key message 1: Rights and Restrictions

Risk assessment and risk management plans/care plans:
These need to be audited and reviewed regularly. Assessed risk was not adequately addressed in 7% of the plans we examined.

Behaviour management plans:
There needs to be appropriate professional input, regular audit and review and clarity about the legal basis of the intervention, particularly where plans restrict individual freedom.

Legislative framework:
Staff need to have a clear understanding of the legal context for decision-making where a person lacks capacity to make welfare decisions and of the roles and powers of any welfare guardians or attorneys under the Adults with Incapacity Act. The relevant documentation should be available in the person's file.

Detailed findings

What we expect to find

- That risk assessments, and care plans addressing these risks, are in place.
- That where there are behaviour management plans, particularly those which involve restrictive measures such as physical restraint, these are regularly audited, reviewed and are within the law.
- That where there is a welfare guardianship order, staff are aware of the powers granted and of the roles of the guardian and guardianship supervisor, they consult appropriately and are aware if any powers are being delegated to them. A copy of the certificate of guardianship and the interlocutor stating the powers granted should be in the file.

What we found

Risk assessments:
126 (83%) of the people we saw had risk assessments in place. These covered choking, falls, nutrition, moving and handling, road safety, epilepsy, showering, activities/outings and behavioural issues such as sexualised behaviour, verbal and physical aggression and self harm. For 5 people (4%), there were no documented risk assessments. We were not able to obtain information about risk assessment and care planning in 20 cases (13%).

The quality of risk assessments and care plans to meet the identified risk varied. In some cases every potential risk of daily living was identified, the paperwork was excessive and there was then a problem accessing the important information from this. For one person, there were risk assessments in place for activities such as baking and swimming but there was no risk assessment in place for her contact with her father, who was a convicted sex offender. Although we were told that all staff were aware that visits from the father had to be supervised by staff or a relative, our view was that there should be a documented risk management plan for this. Some care plans had a strong nursing bias and covered falls, nutrition and moving and handling risks, but did not address other aspects of the person's life or reflect a social model of care.

For 10 (7%) of the 126 people with written risk assessments, Commission visitors considered that the care plan either did not address the identified risks or did not address them in sufficient detail, or the risk was no longer current. For the 5 people without written risk assessments, we considered that their care plans addressed the issues.

Restrictive measures/restraint:

Across the 22 units staff informed us there were 13 people who were subject to restraint on a regular basis (9 in relation to significant behavioural difficulties, 3 in order to attend to their personal care and one in relation to both). Some individuals were subject to other types of restriction. There were several individuals whose contact with some family members was restricted or supervised and these were authorised by guardianship powers. One man with sexually predatory behaviour, who was on 1:1 observation 10 hours per day, was not subject to guardianship. The Commission consider there should be a legal basis for such intrusive measures.

We enquired about the legal status of those people being regularly restrained. The Commission is of the opinion that the power to restrain should be made explicit in any guardianship application under the Adults with Incapacity Act, so the matter can be examined fully by the Sheriff. He/she will consider this in light of the principles of the Act, particularly whether it is of benefit to the adult and the least restrictive option. In one unit, where 4 people were regularly being restrained, only 2 were subject to guardianship, though applications were in process for the other 2. In another unit, the person who was being most regularly restrained was not subject to guardianship. In a third unit, welfare guardianship was in place but staff were unsure of the powers and whether they covered their intervention.

In most cases there were good behaviour management plans in place to minimise use of restraint, which were audited and reviewed regularly by staff and the CLDT. However, several people had behaviour management plans which would have benefited from the specialist input of a clinical psychologist or a behaviour specialist nurse. This was not happening. Some also lacked detail or direction, or they were not being recorded or reviewed adequately.

Guardianship:

Thirty-six of the 151 people we saw were subject to welfare guardianship with a range of powers. Only 59% had clear documentation of the powers of the guardianship, and the contact details and appropriate involvement of the guardian by the unit. Where there is inadequate documentation or no documentation, or no discussion on how the guardian wished to operate the powers, staff cannot be sure they are acting legally.

Staff in 9 units had received training on the Adults with Incapacity Act and on issues of capacity and consent. In the other 13 units, many staff demonstrated very limited understanding of the requirements of the Act. All but 3 units had received input on the Adult Support and Protection (Scotland) Act 2007.

Key message 2: Health

Overall, there was good access to primary health care services and input from Community Learning Disability Teams.

There was poor compliance with the legislative requirements of Part 5 (section 47) of the Adults with Incapacity (Scotland) Act 2000, where a person lacks capacity to give informed consent to medical treatment. GPs and service providers should ensure a certificate of incapacity and a treatment plan are completed and copies of these documents are available in the person's file.

Detailed findings

People with a learning disability have higher than average rates of a range of medical conditions. Twenty-five percent have epilepsy, whilst 47% and 63% have hearing and visual impairments respectively. There is a higher incidence of respiratory disease, coronary heart disease, dysphagia (swallowing problems), osteoporosis, hypothyroidism, diabetes, urinary tract infections and injuries due to falls. There is also a higher incidence of mental illness and behavioural difficulties. People with a learning disability also have a lower life expectancy and the causes of death differ from the general population. Due to this different health profile, strategies to improve the health of the general Scottish population are unlikely to have a significant impact on the health inequalities experienced by those with a learning disability.[5] More focussed health promotion strategies are needed to address the needs of this client group. Access to specialist learning disability services, as well as good primary care services, are therefore extremely important.

What we expect to find

- The person has had a health check in the last year.
- The person can access specialist input where this is required.
- Staff are promoting healthy lifestyles for residents.
- For anyone on medication, either the person is able to give informed consent or there is a legal basis under the Adults with Incapacity Act (AWI Act) or the Mental Health Act. Where medication is being given under the AWI Act, a section 47 Certificate of Incapacity and a treatment plan completed by the GP should be evident in the person's records.
- There is a policy in place covering the administration of covert medication.

What we found

GP services:
All units seemed to have good links with their GP and many commented on the responsiveness of the service. Of the 98 people who responded, 88% said that they had had an annual health check in the last year, the remaining 12% that they had not.

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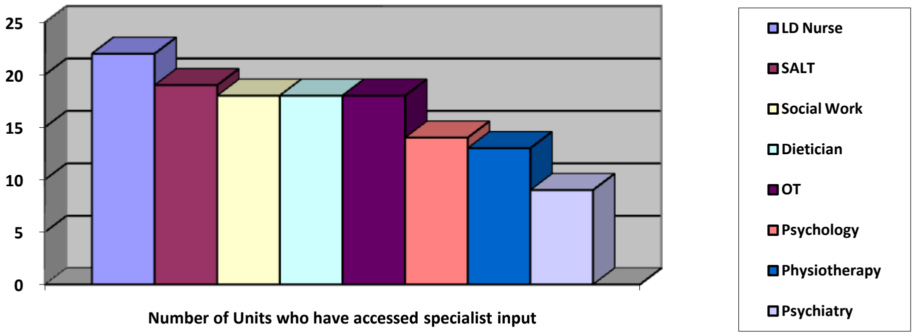
[5] Emerson E., Baines S. Health Inequalities in People with Learning Disabilities in the UK:2010, Improving Health and Lives: Learning Disability Observatory, 2010

Specialist input:

Overall, units had good access to specialist services. The following specialist input was reported to have been available ***when required***:



Some also had had input from continence nurses, epilepsy nurses, diabetic nurses, podiatry, dentistry, opticians, specialist RNIB assessments and specialist autism teams.

Four units reported difficulties accessing services, one in relation to podiatry, one for psychiatry, and two for psychology services. There appeared to be a difficult dynamic between one unit and the local CLDT/Health Board, and Commission visitors saw several people with significant behavioural difficulties who they felt would have benefited from psychology and OT input, which they were not getting.

Healthy lifestyles:

All units reported on their efforts to promote a healthy lifestyle. This was reflected in the menu choices and staff encouragement to buy healthy food, with residents involved in this. Units encouraged fitness through walking, swimming, Wii fit, use of the gym, yoga, keep fit classes, rebound trampolining or other exercise. Good practice examples included:

Exercise groups organised on a daily basis by Magdalen House and St Vigeans, a Health Action Week organised by Townend to raise the profile of healthy living, and several units which were providing assistance with smoking cessation.

Units generally monitored weight and identified those with high BMIs or other health issues, referring them on to a dietician where necessary. Our concern about one unit’s inability to offer appropriate sport and exercise was mentioned earlier.

Consent to treatment:

Twenty-five per cent of the 138 respondents did not require a section 47 AWI Act Certificate of Incapacity because they were either able to consent, were not receiving any treatment or their treatment was covered by the Mental Health (Scotland) Act 2003. Fifty one percent of people had section 47 certificates completed as they were unable to give informed consent to treatment; however, many of the certificates did not have treatment plans attached, as required under Part 5 of the Act. We were very concerned to find the remaining 24% of people had no section 47 certificate in place at all, though they were unable to consent to the treatment being prescribed.

Approximately half the units had a policy on administration of covert medication and around half were aware of the Commission's guidance on *Covert Medication.*

Key message 3: Participation in care planning and review

Service providers need to maximise the person's participation in this process. This includes preparation and assistance to enhance the person's communication and involvement and better access to independent advocacy, particularly where the person has no friends or relatives.

Local authority social work services should be involved in reviews, at a minimum, on an annual basis or, where the person is on welfare guardianship, at no more than six monthly intervals. Local authorities need to ensure that the quality of care, the care plan and placement are meeting the person's needs and wishes and that, where there is a welfare guardianship order, the powers are being used appropriately.

Detailed findings

What we expect to find

Each person has an individualised care plan.

- The plan is reviewed at a minimum on an annual basis and the care manager/social worker from the local authority should be involved.
- The person contributes as far as possible to that plan and to the regular review of it, along with relevant professionals and family, where appropriate.
- Preparation and assistance is provided to enhance the person's communication and involvement in the process.
- Access to advocacy.
- Where there is a plan for the person to move on, this is supported by their care plan.

What we found

Care plans:
Although there were care plans in all the files we looked at, these varied in quality. Some were excellent and very person-centred. A number were based on Essential Lifestyle Plans or Personal Life Plans and reflected the person's wishes about how they wanted to live. Others, as stated before, were largely nursing-based and did not holistically address the person's needs and choices. They addressed the person's physical needs and the provision of a number of activities but gave no feeling of the person as an individual by including such things as the person's likes, dislikes, important relationships and how they communicated.

Care plan reviews:
Eighty-three per cent of the 142 respondents had had an internal review of their care plan in the last six months; 14% in the last 12 months; 3% had not had a review in the last year. However, many of these reviews only involved care home staff and did

not involve the care manager/social worker from the local authority. There was concern about the lack of involvement of some local authorities as detailed below.

Participation and involvement of service user in review process:
Sixty-two percent of people had attended their review and 38% did not. Records indicated only 6% of people had independent advocates who attended the review, either with the person or to represent the person's views.

Staff told us they usually discussed the review with the person to gather their views and wishes, and went over their written report beforehand. Some units do not produce written reports, which made it more difficult to evidence that the resident's views have been considered. The Care Commission has requested that these units prepare written reports. Staff generally explain the process of the review to the person, if in attendance, and the outcomes of the review afterwards.

We saw some good examples of efforts to maximise the person's input to the review. These included:

In St Vigeans the person completes a client contribution form with their keyworker before the review and has a 'goal planner'.

March Glen used a reflection sheet to record the dialogue between the person and their keyworker to share issues which can be discussed at the review.

The use of Boardmaker software to create printed symbol-based communication, as well as photos, was used by a number of units to aid discussion and choice.

In Magdalen House symbols were used to help the person express how they were feeling about their review.

In Camphill Blair Drummond, the Speech and Language Therapist was trying to increase engagement by using Storyboard to explain the review process.

Professional and family involvement in reviews:
We would expect the local authority to be involved in at least an annual review. We looked at the 20 people (14%) who had had a review within the last 12 months, where local authority attendance could be expected. We found that 25% of these reviews had had no recorded input from the local authority social work service.

Some homes reported good input from social workers/care managers. However, social work input to reviews was inconsistent across local authorities. There were 4 authorities which regularly did not provide input or where it had been two years or more since they had been involved in a review.

Two local authorities had reviewing officers, rather than allocated social workers involved. They reviewed everyone from their authority in that home on an annual basis. Some of these reviews were really thorough. Others were very superficial, appearing simply to confirm the continuation of the same care plan without exploring how the person's skills, interests and opportunities could be expanded to enhance their quality of life. The manager of one of the homes was also concerned about this.

One parent travelled a considerable distance by taxi on a weekly visit to her daughter, at a cost of £40. She complained about the unwillingness to coincide the review with her visit, which meant that she had been unable to attend. In another home, the duty worker from the local social work team came to the reviews, so there was not the same degree of consistency for the service user.

Of the 142 responses, parents or relatives attended 45% of reviews. Psychiatrists, community learning disability nurses or other members of the CLDT attended 14% of reviews.

Advocacy:

Access to, and availability of, independent advocacy services varied. Two units reported that they had no access to independent advocacy services, several reported good access and most of the other units reported very minimal use. We felt that, particularly for a number of residents without friends or family, accessing independent advocacy would have had benefits for them.

Moving on:

Eighteen people were considered to be able to move on to less supported accommodation 'in the future.' Plans for 4 of these people were well advanced and this was reflected in their care plans. It was seen as a medium/longer term option for the remainder. One person's current placement had broken down and he was waiting for alternative accommodation to be identified.

Other opportunities for participation:

Residents meetings or house meetings were held in all units. The frequency varied from weekly to quarterly. They considered issues such as furnishings and environmental improvements, outings and events, holidays, menus and activities. Some units both wrote and symbolised the minutes of these. Some clearly reviewed the issues raised at the previous meeting and reported back on the progress made.

- Some units had tried to make policies and paperwork, such as care plans, more accessible by using pictures and symbols.
- Some units produced newsletters to inform residents and relatives of events or issues
- Some units involved residents in interviewing for new staff
- Other aspects of choice and participation have been commented on under the Quality of Life section below

Key message 4: Quality of life

Living arrangements

This is the person's home. Living arrangements should be as homely as possible and the person should be given the opportunity to participate in all aspects of normal day to day home life. Staff should think carefully about how to minimise the institutional aspects of their unit; for example, through the creative use of space or improvement in the physical environment, consideration of noise levels or the necessity for staff uniforms.

Staff attitudes to involving people in day to day tasks and the ethos of the unit are also important in shaping living arrangements. Ways of increasing residents' involvement in the day to day running of their home and training for staff in person-centred approaches to care should be considered.

Day to day activity

Being active and involved is important to everyone. An individual should have a plan of day to day activities that reflects their choices, needs, age and abilities. This should include opportunities for educational, social, recreational and work activity, as appropriate, alongside opportunities to maintain or develop skills of daily living. While we found some excellent examples of this, there were some units where such opportunities were very limited and improvement was needed.

Transport

Availability of appropriate transport is fundamental to regularly accessing community resources, particularly in rural areas. We found that a minority of people were not getting out and about due to transport difficulties. Staffing levels and lack of local community facilities also limited some units. Service providers should ensure staff and transport are available to enable people to use community resources on a regular basis.

Relationships

We found staff were helpful in supporting relationships with relatives. More emphasis on developing friendships outwith the unit would enhance people's quality of life, especially where they have no family contact. Relatively few residents had friends from other areas of their life who visited them at home.

Staff need to have greater awareness of the rights and issues of consent in sexual relationships. The commission has recently produced some guidance on these issues in 'Consenting Adults?,' which is available on our website.

Detailed findings

Quality of life - living arrangements

What we expect to find

For a high proportion of the people we saw, their current residence was regarded as a long term placement and so it was very much their home. We therefore had a number of expectations for people living there. These included:

- Personalised bedrooms, choice of décor and somewhere they could chose to spend time
- A variety of sitting areas affording the opportunity to socialise or find a quiet, more peaceful space
- Dining areas that are pleasant places to eat
- A safe, clean, homely environment

- Access to a well maintained garden space
- Choice of food and access to tea/coffee/snacks when wanted

What we found

Bedrooms:
All but 5 people seen had their own room. The 5 who shared rooms seemed happy to do so and included 2 brothers and 2 friends who had been in hospital together for many years. Nearly all bedrooms were personalised with people’s photos, pictures and personal belongings, and most had their own TVs, DVD players and music systems. There were a few people who chose, or needed, more spartan rooms, due to their difficulty in tolerating more stimulating or cluttered surroundings.

Most people (81%) had some choice in the décor and furnishings in their rooms and could spend time in their rooms when they chose to (88%). For example one woman commented:

‘I have a key to my own room. I have all my own things in it and I chose my duvet cover. I have my budgie. I have pictures on my wall and have an Elvis calendar.’

Communal areas:
With the exception of one unit, all had a variety of sitting areas. The exception had been purpose-built and catered for a number of people with challenging behaviour, where additional quiet sitting areas would have been useful when individuals became anxious or agitated. In some units, particularly several of the communal ones, residents tended to congregate in a large sitting room or by the entrance. This gave the units a very institutionalised feel. Staff had tried various strategies to encourage residents to use some of the alternative sitting areas with limited effect. There were concerns about one unit which, despite having other quiet areas, had what was described by the Commission visitors as a **‘***barn-like central day area, where most of the residents congregated, which was noisy and echoed’.* Several people living in this unit also commented on the noise.

Homeliness:
Most of the dispersed units were described by Commission visitors as very homely with more ‘family-sized’ sitting and dining rooms. As mentioned above, some of the communal units felt very institutional, but some, such as Newhouse, had managed to create a homely environment. One of the Commission visitors commented:

‘*They make the best use of an existing country style house with large add on extension. It's very homely with good use of domestic furniture, fireplaces, pictures and a high standard of décor. Residents had been involved in choosing the décor and furnishings for their bedrooms and the living rooms. The austerity of the big bathrooms holding hoists and specialist bathing equipment was minimised with the use of colour, window dressing, coloured towels, shelves with toiletries and candles.’*

Similarly, Rymonth was said to have ‘*a very homely feel with nice furnishings even though the main unit had 13 people living together’.*

One unit had particularly poor bathroom facilities with only two showers and one bath for 21 people. This resulted in 3 people having to be bathed by the night staff before they went off duty at 7.30am, and it was obviously not meeting service users' needs. This unit also had set seating arrangements for meals, which we were told was due to conflict between residents.

The wearing of uniforms by staff in some units detracted from a sense of homeliness.

Garden:
All units had garden areas, some with patios. Some were set in extensive grounds. Townend, for example, was set in *'beautifully maintained grounds and residents made a lot of use of the garden area, including a sensory garden.'*

Some residents were able to get involved in garden work. Others, at Garvald West Linton and Camphill Blair Drummond for example, were involved in gardening and estate maintenance.

One or two garden areas would have benefited from redesign or better maintenance to maximise their use.

Access to kitchen/involvement in food preparation:
Sixty per cent of people were free to use the kitchen to make drinks or have snacks. Most of those who did not have access were living in the communal homes. Here, drinks were provided at least three times a day, in addition to mealtimes, and residents could ask for drinks at other times if they wished. There were a number of reasons given for providing a trolley service: the availability of suitable kitchen space for residents, safety issues and the ability of residents to use such a facility. We saw a good example in one of the communal homes, St Vigeans, where individuals had been assessed as to who required assistance and guidance to use the kitchen and who was able to make their own hot or cold drink or snack.

All units offered a choice of food on the menu. Feedback from people on the quality of food was largely positive, though in one unit people were unhappy about the choices on offer. Where residents could use the kitchen, they were generally much more involved in shopping for the food, as well as preparing and cooking the meals. There was more involvement of residents in the dispersed homes. In general, the communal homes tended to have central preparation of meals, making involvement more difficult. Residents did, however, contribute to menu choice through residents' meetings and some assisted with tasks such as setting and clearing tables. There were a range of staff views on the value of involvement as well as managing the practicalities of it. The following two comments from staff illustrate the spectrum of views.

'*Our ethos is to support and encourage residents to have as much of a say in their living arrangements as possible and to spend time and use the kitchen as much as possible.'* and

‘One resident used to help clear tables and take the trolley down to the kitchen but I was told that this was stopped "by the powers that be" out of concern that he would "touch the food"’.

Quality of life – day to day activity, transport and money management

What we expect to find

Active involvement in the tasks of daily living, in work or training, or in educational, social and recreational activities, all enhance a person’s quality of life, their self esteem and their feeling of being valued. Everyone can make a contribution to the tasks and activities of daily life, if there is a good understanding of their abilities, likes and interests and the right support is provided. We expect the person to:

- Have a structured day, appropriate to their age, ability and wishes.
- Be able to choose social, educational, recreational, work and training activities and be supported by staff to pursue these.
- Have access to local community resources as well as activities at home.
- Be able to maintain or develop their daily living skills, with appropriate staff support.
- Have a care plan which identifies how and when these opportunities will be provided.
- Have a copy of their daily plan, where appropriate, and in a format which reflects their communication skills.
- Have access to transport.
- Receive their full entitlement to benefits and that the management of their money is in line with the principles of the Adults with Incapacity Act, i.e. it is being used for the benefit of the person, in a manner that maximises their skills and in the least restrictive way.
- Benefit from the use of any savings they may have.

What we found

Structured plans:
Staff in 16 of the units said people had a structured activity plan. Two of the 6 without structured plans had an older population and felt that a less structured approach was appropriate to the age group. Eleven units said they provided the person with a copy of their individual weekly plan. We found 81% of people in dispersed homes, compared with 57% in communal homes, had structured activity programmes. This difference was only partly related to the slightly younger age group overall in these units.

Work and activity:
There were considerable differences in the degree of structure and the level of activity within units. For instance, the units based on the principles of Rudolph Steiner (Garvald West Linton, Corbenic, Beannachar and Camphill Blair Drummond) all had workshops on site, including a bakery, woodwork, candle making and gardening. The ethos was that everyone was able to make a contribution through work. This meant that people of all abilities participated in workshops according to their skills and interests. People also attended college and had a variety of

community based activities. Everyone had an individual timetable, which included their workshops, educational, social and recreational activities and daily living tasks in their house.

Moorpark, which like the Steiner units has a younger age group, had an activity centre on site, which included a sensory room, games room, gym, art and music therapy and space for social activities. People had individual weekly planners, including use of these resources, community resources and time for daily living tasks. This degree of structure was suited to a service providing for people with ASD.

Other units had activity coordinators who, along with staff, organised a programme of activities both in-house and using community resources. The programmes were clearly displayed, some with photos and pictorial symbols to help people decide what they wanted to take part in. Some units employed seasonal workers for music therapy, art and gardening, though in some cases residents had to contribute to the cost. Participation was generally recorded by activity coordinators to ensure that people were afforded the same opportunity to access both in-house and community activities. Some coordinators saw the current programme as a step towards each person having an individualised weekly plan.

In 2 of the units, the majority of people attended local day centres and in addition had various social and recreational activities.

In others, the care staff were responsible for developing activity plans with the individual; some had developed very good programmes of activity reflecting the person's interests and background.

Some examples of good practice included:

'A young woman, whose previous placements had broken down due to her challenging behaviour, had a varied weekly programme, which included attending a Zumba fitness programme, contemporary jewellery making, a college course on recycling and individual art therapy. Visual aids developed by staff and the Speech and Language Therapist were used to indicate to her what activities she was doing each day.' (Dunvegan)

'Staff have worked to support his interest in birdwatching, organising trips to do this, supporting him to buy a birdfeeder and bird bath for outside his window and to write about birds he sees.' (St Vigeans)

Other people had very limited programmes. Commission visitors commented on several units where quite a number of people were observed sitting around doing very little for most of the day with a TV on in the background.

We particularly had concerns about one unit where lack of transport was having an impact on people being able to take part in activities outwith the unit. Timetables appeared to be filled in ways that demonstrated very limited resources e.g. '*watching DVDs, board games, time in her room, listening to music*'. Several very fit young men said they would like to go swimming or horse riding or simply go out more. They had very little opportunity for sport or outdoor activities suitable for their age and ability. Staff said that they had raised the issue of transport and funding for activities with the owners but the situation had not changed. In the case of one man we were told by staff, '*medication is used regularly to manage his behaviour. He will ask for medication but staff think a lot of the time he would be better if he had more to do.'* Three of the 4 residents interviewed in this unit said they wanted more to do.

We asked staff to identify any difficulties in providing a programme of activities. These included lack of staffing (2 units), transport issues (2 units), staff culture (one unit) and finding suitable activities in the local area (2 units).

Transport:
Two units did not have their own transport. One of these in particular, as described above, was seriously curtailed in the opportunities it could offer people because of this. Three units charged residents mileage costs for using the minibus and occasionally escort costs, if *extra* staff were required to accompany the residents. In a fourth unit, the minibus was owned by an associated voluntary group and residents paid mileage costs. Other units did not charge mileage.

Daily living skills:
Units placed very different emphasis on maintaining or developing daily living skills. For 66% of the people we saw, the commitment to training to assist independent living skills was clear in care plans. People were involved in day to day tasks from personal care to laundry, cleaning, shopping, handling money and meal preparation. For instance in Millburn, where it was evident residents were encouraged to maintain their skills, one person with severe disabilities was working on dressing herself and using a spoon to eat her food. In St Vigeans. life skills were included in the care plans and we saw one woman who was being supported to wash and dry the dishes, hang up her washing, set tables and clean her room. In Rymonth, we saw life skills included in the care plan and a particularly good task analysis for someone who was learning to prepare a snack for himself.

Some examples of good practice included:

Tina is a woman in her late 30s with some behavioural difficulties. Staff said 'She needs assistance with personal care, dressing, laundry, cooking etc but as far as possible she is expected to do as much of this as she can. Each event in everyday life is centred on improving Tina's living skills and confidence.'

Robert is a middle-aged man with Down's syndrome. Staff said 'We encourage him to maintain his skills and encourage him to do chores. He likes hoovering and we support him to do the dishes, tidy his room and so on. He is much more actively involved than he was in his previous placement where he had bed sores from sitting too much.'

In other units, the physical limitations of the buildings and the provision of 'hotel services', such as meals on a trolley from the kitchen, bulk buying of food, industrial rather than domestic laundry facilities, cleaning of bedrooms as well as communal areas by domestic staff, curtailed the opportunities of involvement by residents. This was more apparent in units with a communal model of care. There was proactive support for developing life skills for 47% of the people we saw in communal homes, compared with 82% of the people we saw in dispersed homes.

Environmental difficulties and a slightly older age group in communal homes contributed partially to less involvement in day to day living skills. However, it was apparent that some units managed to work proactively in this area and that the attitudes and ethos of the staff group had a significant influence.

Money management:
Table 3 shows how people's funds were managed and the different pattern between communal and dispersed homes. Those in dispersed homes are more likely to manage their own money, or have a family member or other person manage it. Those in communal homes are more likely to have staff in the unit as their appointee. Table 2 showed there was no difference in the distribution of people by disability between homes, nor was there a difference in those who had contact with relatives. The difference in money management seems partly related to the younger age group and partly due to differences in organisational and administrative procedures between communal and dispersed units.

There were no reported issues for service users in accessing their full entitlement to benefit. Two units reported difficulties in setting up bank accounts for some people.

There was some inequality in the charging arrangements for transport and some activities. Service users in 4 of the homes paid for mileage costs and, occasionally, extra escort costs from the mobility component of their Disability Living Allowance, if they received it, or their personal allowance. For others, there were no charges for using the unit's transport and it was covered by the care home fees. In 2 homes, people paid for a horticultural therapist who ran gardening and art groups, whilst in other homes there were no charges for very similar activities. Where music therapy was offered, there was generally a charge on residents in all units for this. Such charges are obviously more significant where people are only in receipt of their personal allowance or the low rate of DLA mobility component. In contractual terms, local authorities should be clear with both the provider and the service user what is included in the core cost of the service, what are additional services which might be paid for by the local authorities and what are additional services or extras that should be paid for by the service user.

Use of savings:
Some residents had significant amounts of savings from being in hospital care for many years or from legacies. Others saved from their personal allowance and the mobility component of their Disability Living Allowance. Money was spent on clothes, toiletries, taxis and social and recreational activities. Many people saved for holidays and quite a number of people had had holidays abroad. Some units, Millport and Millburn for instance, tried to ensure everyone had an annual holiday; in some others, it had been some years since anyone had had a holiday. A number of homes had encouraged people to buy funeral bonds. Some people with larger amounts of savings had bought specialist equipment. In 2 units, several people, who had considerable savings accumulated from their time in hospital, were paying for a support worker to enable them to get out on individual activities.

There were examples of imaginative spending. One young woman, who loved playing the piano, after consultation with her family and staff, was able to buy her own piano. Another person had recently enjoyed a holiday which included going out in a speed boat, fly-fishing and beachcombing.

Quality of life - relationships

What we expect to find

We would expect that the person:

- Is supported to maintain and develop relationships with family and friends, both to visit them and to invite them to their home.
- Is supported in their communication with friends and family.
- Is supported sensitively to express their sexuality in an appropriate way.
- Has access to information, education, contraception and support, where they wish to have a sexual relationship, bearing in mind their capacity to consent to this.

What we found

Friends and family:
Ninety-one per cent of people we visited had contact of some sort with family and/or friends and it was clear staff were highly committed to supporting people in maintaining these contacts. This involved helping with phone calls, assisting with visiting arrangements, welcoming visitors with coffee and tea and including them in meal times, keeping family informed of any concerns, events or generally updating them where residents agreed to this, inviting them to social events, providing support to attend significant family celebrations, and keeping memory sheets for family birthdays and anniversaries.

Some examples of good practice included:

In Millport, one gentleman, whose only relative was in Australia, had a phone in his room so he could get daily calls from her. When she had visited him in Scotland, staff arranged to go on a short holiday with the gentleman and his sister so they could have time together.

Staff were also arranging to support another resident on an overnight stay with her parents who lived on one of the islands. The visit would not have been possible without this flexible staff support.

In Millburn a resident's social worker had managed to re-establish contact with their only relative and staff were providing transport to enable them to have monthly contact.

Several units assisted people in keeping in email contact with relatives who lived far away. Some used Skype to keep in contact with family members.

A number of units had accessed befrienders for people who had little or no contact with family or friends.

Sexuality and sexual relationships:
We asked staff about how they addressed sexuality and sexual relationships with residents. There was general recognition that residents may require privacy or guidance on the appropriate place to engage in solo sexual activity. In some cases, but not all, this was addressed in the person's care plan so it was then managed in a consistent way.

Only 3 units indicated that one of their residents currently had a sexual relationship. Several others had relationships with a partner or friend which had not developed into a sexual relationship at this stage.

The Commission had been concerned on a previous visit to one unit, where a man had been living for over a year whilst sheltered housing was being sought for him and his wife. She was still living at home. He had been very distressed as his mobile phone had been removed on admission as part of a 'blanket policy', he was only being allowed one supervised phone call per day, he was only seeing his wife once a fortnight and there were no firm plans for his return home. The Commission had discussed the legal and ethical issues with his social worker and staff in the unit, and we found on this visit the situation had improved. He had his own mobile, which he could use without his calls being monitored, was seeing his wife more regularly and she was occasionally staying overnight. Unfortunately, the housing situation had not progressed.

Around half of the units provided information and education, organising sexual health and relationship groups themselves or referring individuals to Community Learning Disability Teams to provide this. A number of units had supported people to access contraception in the past.

Around half of the units indicated that they had or would involve the CLDT where they had concerns about a person's capacity to consent to a sexual relationship. Nine of the units had arranged staff training or held discussions on the rights and risks in sexual relationships and 9 had policies relating to sexuality and relationships.

Action points for service providers and local authorities

We recommend that service providers and local authorities take the following actions to address the key messages in this report:

Service providers

1. **Service providers should continually review how they might maximise the homeliness and minimise the institutional aspects of their unit, for example, by:**

- **The creative use of or improvement of the physical environment.**
- **Giving consideration to noise levels.**
- **Deciding whether uniforms are necessary.**
- **Providing training for staff in more person-centred approaches.**

- **Identifying ways of increasing residents' involvement in the day to day running of their home.**

2. **Service providers should ensure that person centred plans are in place for each individual, which include opportunities to maintain and develop daily living skills as well as social, recreational, work and educational activities.**

3. **Service providers should ensure they have access to adequate transport facilities and sufficient staff to enable people to use community resources on a regular basis.**

4. **Service providers should ensure there is training for staff on legal frameworks so staff are aware of the rights and safeguards for people whose decision-making capacity is impaired.**

For local authorities and service providers

5. **Where someone is being restrained on a regular basis, or where other intrusive measures such as CCTV or restricting contact with relatives, are being operated, services should review with the appropriate local authority social work service whether the proper legal framework is in place.**

6. **Local authorities should be involved in a review of the resident's care, at a minimum, on an annual basis or, where the person is on guardianship, at no more than 6 monthly intervals. Reviews should include looking into the management of the individual's funds.**

7. **Where there is a welfare guardianship order, the service provider should know who is carrying out the role of guardian and guardianship supervisor, have the powers of the order clearly documented, and have discussed how the guardian wishes to operate or delegate the powers. The local authority guardian or supervisor should ensure the service provider has this information and understands their duty in this regard.**

8. **In contractual terms, local authorities should be clear with both the provider and the service user about what is included in the core cost of the service, what are additional services which might be paid for by the local authorities and what are additional services or extras that should be paid for by the service user.**

Conclusions

Care providers and commissioners of care services should have regard to the key messages and recommendations in this report when reviewing the care packages of individuals with learning disability. This report confirms that there is much to be positive about, but it is clear that the provision of individualised care for people in larger settings requires attention to detail, a personalised approach and in-built flexibility. However, our visits have confirmed that such

aspirations are not unreasonable and, indeed, are being achieved in larger care settings. The Commission will continue to visit people in such settings and will review progress on an individual basis.

Appendix

Table 1
Age and gender of individuals we saw

Age group	Female	Male	Grand Total	% in each age group
18-19	2	5	7	5%
20-34	15	24	39	26%
35-49	12	12	24	16%
50-64	16	28	44	29%
65+	10	14	24	16%
Age not recorded	10	3	13	8%
Grand Total	**65**	**86**	**151**	**100%**

Table 2
Number of individuals seen, by diagnosis and type of unit

Diagnosis	Communal units (more than 7 places)	Dispersed units (7 or fewer places)	All Units	% of those seen with each diagnosis
Mild Learning Disability	16	18	34	23%
Moderate Learning Disability	28	31	59	39%
Severe Learning Disability	19	16	35	23%
Not Recorded	11	12	23	15%
All	**74**	**77**	**151**	**100%**
Mental Illness and LD	15	10	25	17%
Challenging Behaviour and LD	12	13	25	17%

Table 3
How people’s money is managed

Percentage of individuals seen (n=144), by method of money management and type of unit	Dispersed units	Communal units	All units
Manages own	17%	3%	10%
Unit DWP appointee	40%	71%	55%
Family DWP appointee	28%	19%	24%
Other	15%	7%	11%

	100%	**100%**	**100%**

Table 4
List of registered residential units visited

Name of unit	**Local authority area**	**No. of residents at time of visit**	**No. of people seen by MWC**
Beannachar Camphill	Aberdeenshire	18	8
Blackwood Care Centre	S. Lanarkshire	26	7
Camphill Blair Drummond	Stirling	32	9
Corbenic College Camphill	Perth and Kinross	27	4
Dunvegan	Falkirk	32	13
Fairburn House	Highland	26	5
Forse House	Highland	26	1
Garvald West Linton	Scottish Borders	30	10
Lunan Bay Care Home	Angus	24	10
Magdalen House	Dundee City	24	3
March Glen Care Centre	Clackmannanshire	14	9
Millburn Homes	S. Lanarkshire	12	7
Millport Care Centre	N. Ayrshire	32	10
Moorpark Place	N. Ayrshire	19	9
Newhouse Residential Home	E. Ayrshire	19	6
Rosebank Care Home	Dundee City	33	8
Rymonth House	Fife	18	4
St. Vigean’s	Angus	25	8
The Gables	Angus	21	4
The Grange	Perth and Kinross	28	2
Dalguise	Perth and Kinross	9	4
Townend Care Home	S.Ayrshire	21	10
		516	**151**