mentalwelfare
commission for scotland

VISIT AND MONITORING REPORT

People with learning disabilities with intensive support packages

Our aim

We aim to ensure that care, treatment and support are lawful and respect the rights and promote the welfare of individuals with mental illness, learning disability and related conditions. We do this by empowering individuals and their carers and influencing and challenging service providers and policy makers.

Why we do this

Individuals may be vulnerable because they are less able at times to safeguard their own interests. They can have restrictions placed on them in order to receive care and treatment. When this happens, we make sure it is legal and ethical.

Who we are

We are an independent organisation set up by Parliament with a range of duties under mental health and incapacity law. We draw on our experience as health and social care staff, service users and carers.

Our values

We believe individuals with mental illness, learning disability and related conditions should be treated with the same respect for their equality and human rights as all other citizens. They have the right to:

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

What we do

Much of our work is at the complex interface between the individual's rights, the law and ethics and the care the person is receiving. We work across the continuum of health and social care.

- We find out whether individual care and treatment is in line with the law and good practice
- We challenge service providers to deliver best practice in mental health and learning disability care
- We follow up on individual cases where we have concerns and may investigate further
- We provide information, advice and guidance to individuals, carers and service providers
- We have a strong and influential voice in service policy and development
- We promote best practice in applying mental health and incapacity law to individuals' care and treatment

The purpose of the visit

The Same as You? (SAY)[1], published by the Scottish Executive in May 2000, was a national review of learning disability services outlining a ten year plan to transform service provision to people with learning disabilities.

The key principle of the review was that people with learning disabilities should be able to live normal lives. SAY acknowledged that people wanted their own homes in the community, that very few people would need long-term care and treatment in hospital settings and that the numbers accommodated in other forms of shared living should reduce over time. Traditional day services needed to modernise and focus more on education, employment and opportunities for personal fulfilment. This has led to the firm expectation that people should receive support to live as independently as possible in their local community, with access to education, employment, recreation and opportunities for relationships and friendships.

At the centre of this was a major shift to person-centred and needs-led approaches, which put the individual at the heart of any decisions made. The role of services needed to change to include people with learning disabilities in the community, to support their personal development and choices, and to support their carers. Effective partnerships between agencies, professionals, users and carers were required, particularly to support people with more complex needs.

More recently, greater flexibility in funding mechanisms to support people in their own homes has become available. In addition to Independent Living Fund (ILF) funding, direct payments, originally introduced in 1997, were increasingly taken up from 2003 onwards by people with learning disabilities. The introduction of self-directed support in 2007 aimed to increase take-up of direct payments as well as choice and control for service users.

In 2010, the Scottish Government set up an evaluation team[2] to review the evidence on progress made by SAY to date, and the challenges that remained. They produced three reports which are summarised in the SAY? 2000 - 2012 Consultation Report[3]and led on to the publication in June 2013 of the strategy for the next ten years, the Keys to Life[4]. Some of the key achievements noted include:

- the closure of long stay learning disability hospitals
- a fall in the number of adults with learning disabilities in care homes from 3,100 in 2001 to 2,100 in 2010.

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[1] The same as you? A review of services for people with learning disabilities (2000) http://www.scotland.gov.uk/Resource/Doc/1095/0078271.pdf

[2] http://www.scld.org.uk/SAYevaluation

[3] The same as you? 2000-2012: Consultation Report Scottish Government http://www.scotland.gov.uk/Resource/0039/00393998.pdf

[4] http://www.scotland.gov.uk/Publications/2013/06/1123

- in 2011, 56% (12,108) of people with learning disabilities known to local authorities were not living with a family carer[5]
- 23% (5,508) of people with learning disabilities known to local authorities were living in supported accommodation[6]
- health boards and local authorities providing more specialist services to support people with challenging behaviour, complex disabilities and high support needs in the community
- an increase in people getting alternative day supports and a decline in those attending day centres. In 2011 more than 6,164 people were accessing alternative day opportunities and more than half this group do not use 'traditional' day services at all.

Against this policy and funding background we wanted to look at the quality of life, the opportunities and the choices being experienced by people who have been traditionally labelled as having high or complex support needs. This includes people with learning disability who have additional mental illness, behavioural difficulties, or significant physical or sensory problems. We were also interested in people with Autism Spectrum Disorder (ASD), and people with forensic issues linked to their learning disabilities.

We visited 202 individuals in 29 of the 32 Scottish local authorities. We looked at various aspects of the arrangements in place to provide care and support including:

- living arrangements
- the support provided and how this enabled people to live a more independent life and make choices as far as they were able
- participation in the planning and review processes by the individual and the professionals, particularly those from the local authority
- how risks were identified and managed
- rights and restrictions and the legal authority for these
- access to mainstream and specialist health services

Evaluation and method

The sample was selected using three main criteria. The number of individuals selected per local authority area was based upon the known population for each area - we aimed to visit a minimum number per area, ranging from four in smaller authorities to 14 in the largest authorities (see Appendix 1, Table 3). Local authorities provided details of individuals with care packages of more than £1000

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[5] Statistics Release: Adults with learning disabilities - implementation of 'The same as you?' Scotland 2011 An Official Statistics Publication for Scotland Scottish Consortium for Learning Disability (SCLD) http://www.scld.org.uk/sites/default/files/revised_260213_2011_esay_statistics_release_-_learning_disability_statistics.pdf

[6] as above SCLD 2012 statistics release

per week. We then selected people across the range of care package costs to visit. We also aimed to visit an appropriate balance of men and women where possible. However, not all authorities provided initial details of individuals by gender. Some individuals were on welfare guardianship orders, others were not. We did not use this as a sampling criterion.

Information provided by local authorities revealed that 2050 people are receiving care packages over £1000 per week. We visited 202 people at home and interviewed the care provider and, where possible, the individual. Where the individual chose to have other people present, such as an advocate or a friend, relative or guardian, we also sought the views of those people. We gave all parties the opportunity to speak to us on their own, if they wished to do so. We saw support workers or managers from over 50 different care providers and 53 individuals with learning disabilities gave us their views. A further 33 gave their views with the help of another person.

We also looked at support plans and any other available records, such as an Essential Lifestyle Plan, a Person Centred Plan, daily records and activity programmes. Following the visit we contacted care managers (138 of 144 allocated care managers) or, where possible, reviewing officers (36) to get their views. We also spoke to most of the LA or private guardians involved (21 and 40 respectively).

Who we saw

We saw a total of 202 adults with learning disabilities, 69 women and 133 men. This ratio reflects that of the adult population of individuals with a recorded learning disability, where the majority are men (58%) and the smaller proportion women (42%)[7]. The gender balance of our sample was also broadly in line with the total population receiving packages of care of more than £1000 per week, according to details provided by local authorities.

Within our sample group of people, over a third of people had a diagnosis of Autism Spectrum Disorder (ASD) - a disorder more common in men than women (various studies have found male/female ratios ranging from 2:1 to 16:1)[8].

22% of people were in the 18-24 age group, 40% in the 25-44 age group, 31% in the 45-64 age group and 7% were over 65. Three people were from ethnic minority backgrounds.

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[7] as above SCLD 2012 statistics release

[8] http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/gender-and-autism.aspx

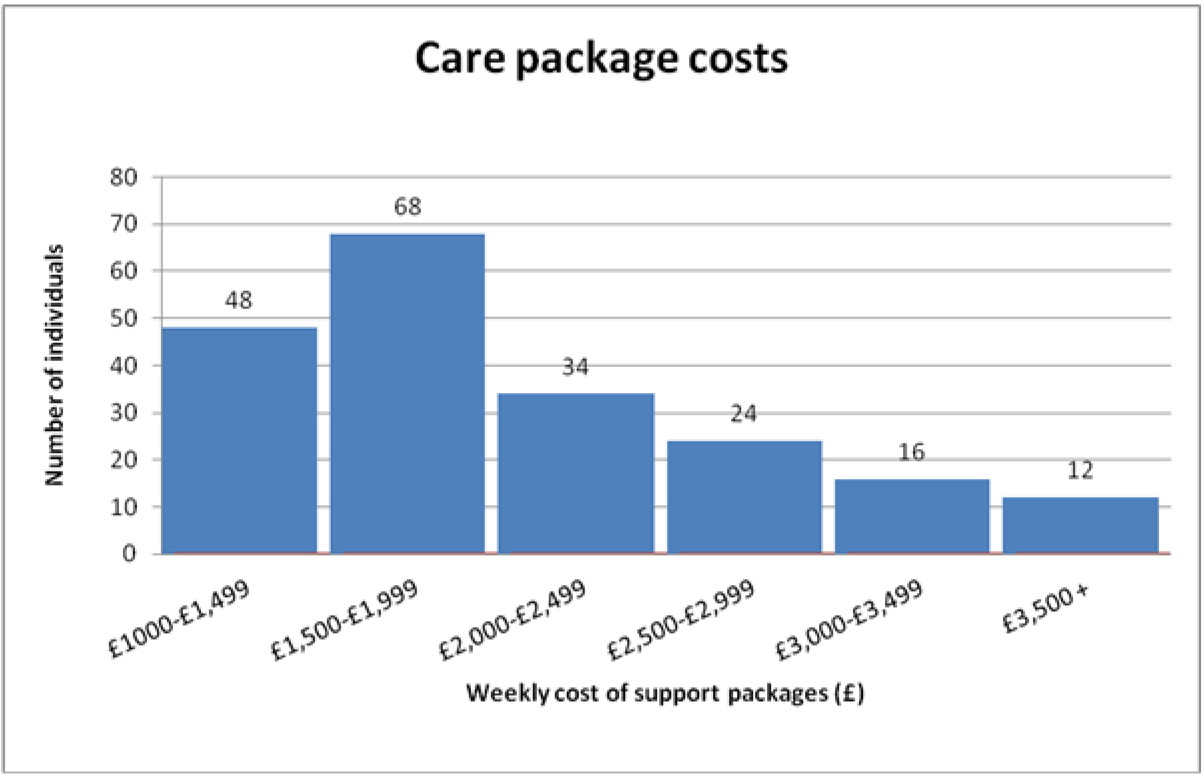
In addition to having learning disabilities, the table below shows the complexity of the needs of this group of people. Some people had more than one of these conditions.

Table 1: People with additional conditions to learning disabilities

Additional Conditions	Number	%
Challenging Behaviour	103	51
Physical/Sensory Disability	84	42
Epilepsy	83	41
ASD	72	36
Mental Illness	46	23
Forensic Issues	10	5
Other Conditions e.g. ADHD	22	11
	202	**100**

These needs are reflected in the high costs of the support packages. We selected proportionately the number of people we visited in each cost band, as a means of capturing the range and complexity of people's needs. The range of costs was from £1000 per week to one costing £5000 per week.

Figure 1:Number of People in care cost bands



When we have used examples to illustrate aspects of individual support, we have changed details, such as names, to protect the anonymity of the person.

Summary of findings

Positive findings

We were impressed overall with the support being provided to most of the people we saw. Particularly for those who had previously been in institutional care, the move to their own home had been literally life-changing. We saw people with very complex needs receiving some very robust support from providers, good input from specialist health teams, and valued input from local authority care managers.

- People with high support needs have benefited considerably from the changes in Government policy and funding over the past 15 to 20 years. All but a few of the people we saw were living in single (56%) or shared tenancies (42%). 58% had previously lived in institutional care.
- Accommodation was generally of a good standard. In a few instances, where this was unsuitable, this was being addressed.
- The vast majority of people had person centred support plans which were satisfactory and we considered over half the plans we saw were very good and took into account their needs, wishes and choices.
- We considered the support being provided to 62% of people was very satisfactory and to 33% was fairly satisfactory. There was evidence that service users were enabled to make choices as to their daily routine and their education, social and leisure opportunities. Similarly there were numerous examples of people learning new skills and becoming more independent. Feedback from service users, relatives, guardians and care managers was very positive overall. Where there were issues, there was general agreement as to what these were and discussion between care managers, providers, service users and relatives on how these should be addressed.
- We found that health and allied health professionals, particularly from Community Learning Disability Teams (CLDTs), and behaviour support teams provided an excellent service to individuals and providers in terms of advice, support and on-going treatment. Care providers also appreciated the support of allocated care managers who kept in regular contact and were ‘at the end of a phone for advice’. There were reports from various parties of the decrease in behavioural distress and the improvement or even transformation in people’s quality of life due to a change in their care setting and the provision of support from providers and specialist community services.
- Most people had good care for their physical health although we had some concerns about the legality of treatment (see below). ,

- There was no evidence that cuts in public spending had impacted on these complex support packages. There had been some increases and some decreases in response to assessed risk and changing needs.
- Families were the mainstay of people's social networks. In all but a few instances providers respected and included the roles of family carers. About a third of people had friendships that were important to them. Many were friends from the past, others were from accessing social opportunities organised by the provider or other community activities. The majority of service providers actively promoted opportunities for expanding people's social networks, though others appeared more ambivalent.
- There were significant risks due to the complexity of people's needs. These included physical health risks (51%), environmental risks (24%), risks of self-harm (34%) and people who presented potential risks to others (35%). We were impressed with the standard of risk assessment and management plans and behaviour support plans for the vast majority of people we saw.
- 44% of people we saw were subject to legislation. 77 people were on welfare guardianship under the Adults with Incapacity Act. 11 people were subject to the Mental Health Act, the Criminal Procedure Act or other legislation. In most cases there was appropriate legal authority for decisions on their support and treatment.

What needs attention

For some people we thought there was more that could be done to support the direction of travel toward good person-centred care and support. Some of these individuals could have more opportunities to expand their lives and make and sustain friendships. Also, all staff providing care and support should be well-trained and supervised. We found that some were not.

Local authorities must ensure that the services they commission continue to offer the most appropriate and best quality of service. They must review these care and support plans at least once a year. The review should address how the plan is being delivered by the provider and the involvement of the service user. Due to the complexity of people's needs, there must be close attention to their rights and the legal basis of any restrictions.

- Incompatibility of some tenants presented difficulties for individuals and providers. The possibility of alternative accommodation or efforts to ameliorate this, such as ensuring tenants have time away from one another, should be kept under regular review.
- A small number of support plans were out of date, only partially addressed the person's needs or were not person-centred. Similarly, a small number of people were not receiving support that met their

physical, social or emotional needs. Other people were receiving satisfactory support but it did not appear to aspire to the excellent practice that was evident from some teams of support staff. Where we had concerns these were raised with the care manager or the social work team.

- Promoting and facilitating opportunities for friendships should be a focus for providers. We saw examples of excellent ideas and practice from many providers but only a third of people were reported to have friends. Families are very much the mainstay of people's social network.
- Regular reviews by the care manager or reviewing officer are a vital part of ensuring the individual maximises the benefits of their support package. Providers reported that 15% of people had a review less than once a year. We find this unacceptable. In terms of external scrutiny of the care and support of people with the most complex needs as well as accountability for public funds, an annual review would seem to be the bare minimum. Where there was no allocated care manager (11%), there was less likelihood of regular reviews involving the local authority.
- There was poor compliance with the legislative requirements of Part 5 (section 47) of the Adults with Incapacity (Scotland) Act 2000, where a person lacked capacity to give informed consent to medical treatment. GPs should ensure that a certificate of incapacity and a treatment plan are completed and the service provider should have a copy of these documents in the person's file. In most cases the provider is assisting or administering the person's medication and should be clear on the legal authority of this.
- A small number of people were restricted in terms of leaving the building, with doors and windows locked or alarmed and access to mobile phones, cameras or the internet limited. Nine people were restrained on an occasional basis, and three on a more regular basis. One person was secluded on an occasional basis and another was subject to observation by CCTV. The majority of the restrictions were lawful and risk management plans were good. We had concerns about seven people where the protection of a legal framework for the restrictive measures being imposed needed consideration. Care managers need to seek their Council's legal advice where there are intrusive measures in place. The Commission's view is that such measures should be specified in a welfare guardianship order so there is proper court authorisation where there is a deprivation of liberty.

Living arrangements

What we expect to find

- Most people will be living in their own tenancy or sharing with other people they have chosen to live with or they get on with
- Accommodation will be of a good standard, suitable to that person's need in terms of indoor and outdoor space and they will have choice in the décor and furnishings of their home

What we found

- Whilst 56% of people we visited had their own tenancies, 42% were in shared tenancies. Seven of these people were sharing with four or more other people
- The quality of accommodation was generally good and met the person's needs. Most people had been involved as far as possible in choosing the décor, furnishings and in making a house their home
- In several instances the compatibility of tenants presented some difficulties both for the individuals concerned and for providers. In other instances this had been addressed and the number of tenants in the property had been reduced
- For a small number of individuals the configuration of the accommodation was unsuitable and alternatives were being sought
- Some tenancies had limited communal space or lacked a garden or safe outdoor space

Detailed findings

The living arrangements of the people we saw demonstrated the changes in provision resulting from the recommendations of SAY. The majority of people had previously lived in hospital (38%) or registered care (19%). 22% had been, and just 2.5% still were, in their parental/family home. 10% had had a previous tenancy and 3% came from other accommodation such as foster care.

We asked how long people had been in their present accommodation. 10% had been there for 15 or more years and indicated that good practice in person centred planning had been happening prior to SAY. 18% had been in their current accommodation for 10 to 14 years, 32% for 5-9 years and 40% had been there for less than five years. This very much reflected the drive towards hospital closures, the decrease in people living in other forms of institutional care and the growth in individuals living in social housing.

Well over half the people we saw were living in their own single tenancy and a small number were living with their families. Two out of five (42%) were in shared tenancies and of these just under half were sharing with one other person, and slightly over half were sharing with two or more people. Seven people were sharing with four or more others.

In general the quality of the accommodation was good. Most people were living in comfortable, well maintained and homely surroundings and had enjoyed making choices about their own décor and furnishings. In some cases the choice was to have a rather sparse environment due to the person having ASD and poor tolerance of the clutter of daily life.

In discussion about support arrangements, some concerns were raised with shared accommodation. These included issues about the compatibility of tenants, and the availability of communal space and a garden. For instance one visitor from the Commission observed:

> ‘This man has ASD and quite challenging behaviour. He is living in a four bedroom flat with two others. Each has their own bedroom and the fourth bedroom is used as a sleepover room. There is little compatibility between the tenants. One is quite intrusive into other people’s personal space and on occasions scratches other tenants and staff. Although there is a living room and a dining room, the corridors in the flat are narrow and there is no garden or outdoor space. Each resident has 1:1 staffing during the day, so when six people are in the flat or one of the tenants is upset and agitated, it feels quite cramped and confined.’

Space, both indoor and outdoor, is very important, particularly in shared tenancies. When one tenant becomes upset, this can cause other people to be distressed or agitated.

In general, care providers, individuals and relatives commented positively on relationships with neighbours and the local community. There were six instances where there were difficulties, which are expanded upon later.

Some providers and relatives expressed concern about the phased changes to housing benefit regulations, particularly the introduction of the ‘bedroom tax’, as there were a number of people who had an extra bedroom in their house. This had usually come about through a reduction in the number of people in the tenancy because of the incompatibility of tenants. In one case consideration was being given to the continuing need for sleepover staff. A decision that this was no longer necessary would then create an ‘extra’ bedroom in the house. Care providers and relatives were anxious about the financial implications of this policy change or the disruption that moving to a smaller house would entail for the person.

Quality of support

Support plans

What we expect to find

- a person centred support plan that meets the person’s needs in terms of their physical, mental and emotional well being
- the person’s wishes, choices and aspirations are fully considered in their support plan

What we found

- Two thirds of plans were good - clear, detailed and very person centred. They addressed the individual’s needs holistically and actively looked at how to maximise their choices and decision-making
- A small number of plans were poor. They failed to address aspects of care such as support for daily living skills, expanding social and recreational activities or how to enhance communication and choice for the service user

Detailed findings

We asked the Commission visitor to make an assessment of the quality of support being provided to each individual. To do this we looked at whether the plan adequately met the person’s needs in terms of their physical, mental and emotional well-being, addressed their wishes and aspirations, and gave them choice and control as far as possible. Where the person had a person centred plan, we looked at how this was reflected in the support plan.

The levels of support provided are detailed in Tables 4 and 5 in Appendix 1. Almost half the people we saw had 1:1 support during day time hours. Over a quarter had 1:1 with varying amounts of 2:1 support and 9% had 2:1 support. Only 2% of people shared staff with another tenant during the day. Five people attended a day centre, two of these five days per week. At night 60% of people had a sleepover member of staff, whilst 37% had a waking member of staff.

We were impressed with the quality of the support plans. We thought two thirds of the support plans were good, about a third were average and we only identified four that were particularly poor.

Most providers had their own format for writing person-centred support plans. Most had an outline of the person’s daily routines with details of how they liked to be supported with personal care, getting up and going to bed and at mealtimes, and how to offer as much choice as possible in these. Most had good information on the person’s likes and dislikes, what they enjoyed doing, what they would like to do in the future and the steps to be taken towards this. Many had timetables for the week which included household activities along with social and educational pursuits and work and reflected their interests. Many plans had an excellent section on communication - how the person communicated, what their behaviour might indicate, how best to communicate with them, particularly in supporting them in decision making. In Appendix 2 we have included the sections on Routines, Senses and Communication from an anonymised support plan by way of example. Where relevant, most plans had a detailed and individualised Positive Behaviour Support Plan or a Behaviour Management Plan. We also expected to see relevant risk assessments alongside support plans and we have commented on these later in this report.

The examples below identify some of the positive aspects of people's support plans, particularly the detailed observations of people's preferences in the routines and activities of their daily life and how they communicate their wishes and decisions.

> 'Care plans were well written and clear. All specific plans explicitly record what the adult is able to do independently, areas where she needs support from staff and where she is to be encouraged and enabled to make choices. There is also a lot of good information in the communication section about how she communicates and in particular about how she communicates when she is anxious and when her anxiety is at a low, medium or high level. She has a weekly planner which has a range of activities. Certain personal care tasks are very structured - for example she likes a bath in the morning, so this is part of her daily routine. She assists with household tasks. She will hoover and polish and helps preparing meals and washing up and also helps wash her clothes. She has a number of leisure based activities during the week, such as swimming and going to a social club. She meets a friend every week and goes out for a meal. Staff had a record of what was called 'a person focussed workshop' held recently which adult participated in - this identified activities she likes doing. She does find it difficult to identify new activities or opportunities she would like to try, but if staff introduce something new and she likes it, she makes this clear. She is also clear if she is not interested in something. She likes holidays and a break is planned once a year. Next year she has said she wants to go to Butlins. She went there as a child with her family.'

> 'His support plan has clear support requirements for all aspects of personal care and for routines during the day. He has no verbal communication so it is difficult to judge how aspirations are being met. The provider has produced an individual passport with good information on the following areas - "How I Communicate" and "Things I Like" and there is a lot of details for support staff about his preferences, as staff have built up a picture of

> what he seems to like and what has been tried. Staff have also been expanding the use of objects of reference in communication with him.'

> 'Before moving to her current accommodation she had been an in-patient for many years and a special environment had to be created in the ward to enable her to be nursed safety and in isolation. Personal care is particularly difficult. Support plans are very detailed. Clear guidelines are in place for providing support at all times during the day and for providing support for specific tasks i.e. helping her to dress, helping her to wash. The format of her support plans seem good - for example plans detail what she might do when staff are providing support, what this behaviour might mean. Risk assessments are filed with each appropriate support plan. She has very complex needs. The service provider commissioned a specialist assessment last year from an autism specialist. She provides training for staff and provides guidance on how staff could interact with this woman, focussing on communication and the language to use and giving her as much control as possible over how support is provided.'

Where relevant some care plans were in a format that was accessible to the person:

> 'The support plan in place is good, covering his needs and wishes. He is able to access this as it is simply written and has pictures and photographs to enhance his understanding of it.'

We asked providers how they encouraged people to be involved in decisions about their support. Most people were involved in choosing what they wanted to wear, buying their food and items for the house, what they wanted to do and when. Some were able to discuss this verbally and were involved in more complex decisions about management of their own finances, or who they would like to support them.

> 'Bert is involved in the recruitment process of his staff at the informal stage e.g. he will go for coffee with them and give his views'

> 'Stanley was unhappy with the selection of staff that were involved in his support and there was a change in staff following his discussion with the manager'

We saw examples of good practice using a variety of communication aids where people's verbal abilities were limited, such as using object signifiers, Boardmaker symbols, pictures, photos and Talking Mats. In other instances, where service users could not use aids, staff might offer two or three options in terms of food or items to wear, to allow choice, or they may have to determine from people's behaviour and cooperation the sorts of things they like or dislike. We saw clear guidance in many instances on communication with the individual, such as the use of Makaton signing, gesture, use of short sentence or one word prompts. The section on the review of support plans gives service users' views on how they thought they were involved in planning their support.

About a third of the support plans were thought adequate. Some of these did not address all aspects of the support. In some there was less focus on developing daily living skills, particularly where people had very high support needs. In others it appeared that staff were not proactively looking at other opportunities for the individual or their own practice. For example -

> 'There was also an activity planner and this included the range of meaningful activities that he routinely completes. They included household and functional tasks such as personal care, diet, hoovering and drying the dishes, going to the gym, leisure and enjoyable activities such as walking, joining small group outings and eating out. There was nothing about education or employment opportunities or aspirations that he may have regarding these. The support worker who was in attendance for the visit had known him for many years and appeared pro-active in considering new opportunities for him, however the consistency of staff involved in his care impacts on this; if there are 'bank' staff, they are less likely to prompt and encourage him to suggest alternative and varied things to do or to prompt him to engage in meaningful, beneficial activities such as going to the gym or out for walks.'

There were a small number of poor support plans. In some cases the plan had not been updated to reflect changing needs. Others concentrated on basic needs but were poor in terms of giving or expanding choices or developing skills, or specialist input had not been included in the support plan. For instance

> 'This young man had very high support needs. All support plans are for physical care - nothing in relation to anything else at all. He could not provide information himself and there was no evidence of any attempt at all to gather information from his father to develop a more holistic support plan'

> 'This support plan concentrates largely on her physical care needs and her daily regime. However it has not been updated for over two years and there have been significant changes within that time in her physical health'

> 'Support plan covers aspects of daily living and current activities but it is not focussed on what skills he is working on. For instance laundry facilities are in an area of the house used for storage and general clutter, so only staff can go in it - although Peter gathers and brings down laundry, he cannot put it in or take it out of the machine. There is a lack of imagination and structure in planning activities. For example, Peter loves water and has long baths sometimes twice daily. He used to go swimming but this has stopped due to an incident on one occasion at the pool and has not been looked at again.

> The manager feels staff tend to say they have already tried things and she is encouraging them to try again.
>
> The SALT (Speech and Language Therapist) has been involved with staff on several occasions but this is not reflected in the support plan. There is no structured daily timetable to try to help Peter understand what was happening next. Similarly there were recommendations from the SALT to use some object signifiers e.g. towel for bath but these are not being followed through consistently.'

The comments below relate to planning the support of another young man to develop his independent living skills.

> 'I was expecting to see more detailed plans on the work staff were doing to try and promote his independence but there seemed to be variations on how staff approached this. For example one worker said she gets him to help wash the dishes, tidy up, and help in preparing snacks. But none of that is written down with the aims and outcomes of the activity. And because it isn't written, how do you know if other staff are doing this is the same way?'

Where we had concerns, as with some of the examples above, these were followed up with the care manager after the visit.

Delivering the support plan

What we expect to find

- The support plan is being delivered by the care provider
- There is clear evidence that the service user's choices are being respected and are central to the way the service is being delivered

What we found

- We considered that the support received by 62% of individuals was good - it met their needs and was delivered according to the person's wishes. Staff often showed great imagination and ingenuity in supporting people to achieve their aspirations
- A third of people had adequate support but there was scope to expand their opportunities and skills
- Support was poor for 2% (5) of people. This was due to either the lack of training or expertise of staff to meet the complexity of the person's needs or the poor management and supervision of staff.
- Care providers expressed serious concerns about the difficulties of working with, or getting, DWP benefits from a small number of relatives
- Others outlined a number of challenges in providing good support. These included staff retention, getting staff with appropriate skills and expertise,

finding a range of activities to engage the service user and the lack of input and regular review by care managers

Detailed Findings

We asked the Commission visitor to assess whether the support plan was being delivered for the individual. We examined daily records, daily and weekly programmes, review minutes and other documentation to gather a view on the opportunities and involvement people had in determining the structure of their day, their leisure, education, employment and community pursuits, their opportunities for developing their skills and independence and expanding their relationships. We asked as many individuals as possible about the choices they made in their lives and what they did. We asked the views of relatives and others that were present on the day of our visit for their views, as well as welfare guardians and care managers. We discussed with staff how they encouraged choice, particularly with people whose verbal abilities were very limited.

For nearly two-thirds of the people we saw, our visitors were very satisfied that support was being delivered in a way that maintained their physical, mental and emotional wellbeing whilst maximising their opportunities and choices. Most of the remainder were fairly satisfied, but in a small number of cases (2%) the visitor was dissatisfied with the service delivery. There was no obvious link between the cost of the support and the quality of the support.

In some cases the person was able to tell us how they were supported. The examples below are typical of the excellent support provided by many agencies, and demonstrate the range of opportunities and choice that the majority of service users experience.

> ‘Plans have a good clear structure, with precise details of how support is provided. William is very able to converse and discuss his care plans and he confirmed that the support described is delivered.
>
> William is clearly able to articulate his wishes and aspirations. He is obviously very proud of his home and likes it to be clean and tidy and he described to me what household tasks he does - hoovering, tidying etc. He is also very clear about the activities he likes to do. He has a very full programme of structured social and leisure activities. He has one day a week during the week when he is at home - when he will do housework and shopping. He attends a day centre four days a week. He will do some centre based activities but there are also outreach activities from the centre. He has a work placement at the local supermarket one afternoon during the week and a half-day on a Saturday. He has a lot of social activities - accordion, knitting club and a social club where he meets up with friends. On Sundays he has regular contact with extended family who live locally. He also goes on holiday regularly and flew to France to spend Christmas and

> New Year with his sister and family last December. He clearly enjoyed this and spoke about the markets he visited. He went on the plane himself - staff took him to the airport and he was met in France by his sister.’

We met another young man, who was again very able to express what he wanted and staff appear to have made every effort to support him in this. The Commission visitor recorded:

> ‘He enjoys keeping fit - attends gym, walks, horse riding weekly, involved in touch rugby through doing bronze and now a silver award in a local scheme which aims to give choice and achievement in variety of areas - he has done touch rugby, cookery which he loves and a job placement, mucking out at stables – all in 6 week blocks.
>
> He gave examples of aspirations expressed in his Essential Lifestyle Plan which have been fulfilled – a skydiving event for charity, go karting as a step towards driving.
>
> He wants a job – has registered with a volunteer agency and employability team but has not had much success to date. He attends ‘dates and mates’ events to expand his social network. He attends to his own personal care, shops, cooks, cleans, banks etc with prompting.
>
> He has completed a painting and decorating course at college and is painting his own house with supervision from one of his support workers, who is a trained decorator.’

Mary had more significant learning disabilities, epilepsy and behavioural difficulties but the move from residential care to a shared tenancy with support had brought considerable changes to her quality of life:

> ‘A specific matching process was undertaken prior to all 3 residents moving in. Mary has a large bedroom with an en-suite facility. The quality of the environment is high with it being new and spacious. It is an improved placement /plan from Mary's last residence which was a residential facility with a number of residents. The support plan identifies needs following a detailed assessment on file and looks at improving aspects of her independence, increasing activities, expanding her relationships, and how best management of some challenging behaviours etc. She is involved in basic household chores and helps with preparing her meals with supervision. Staff report that breaking down activities into small tasks for Mary aids this process. Mary is presented with choices each day re clothing, food, activity options and shopping. Her day and week are structured and she has a number of activities which she has been observed to enjoy over time. These include horse riding, reflexology, cinema, baking and going out

> to do her regular weekly shopping. Her routine is highly personalised and this is in contrast to her last placement.
>
> Staff commented on differing approaches they have employed to address some of her difficulties. Seemingly she was rewarded for ‘good’ behaviour in her last placement by regularly being given chocolate. This in itself led to poor diet and challenges for her (if she did not get chocolate, her behaviour would deteriorate). Health concerns appear an important part of the plan with an emphasis on good diet, exercise and regular health monitoring, particularly epilepsy. Good contact and communication is maintained with family members.’

As mentioned the delivery of about a third of support plans was judged as ‘fairly satisfactory’. In some cases we felt that the opportunities could be expanded upon and that staff needed to look at fresh ideas from time to time. For example:

> ‘All Paul’s physical healthcare needs are being met and any interventions are well recorded. There is a note of likes/dislikes and limited aspirations provided by his parents. He has very limited verbal communication but can let staff know if he is unhappy or does not want to do something. There is some evidence of inclusion and encouragement to be involved in basic household tasks e.g. hoovering and some cooking. Good record of activities he enjoys and of participation. Activities happen in the home and on community outings e.g. shopping, but somewhat limited to a few things staff know he enjoys e.g. puzzles.’
>
> ‘John loves walking and staff ensure he gets out for a long walk each day in the local area. However there does not seem any thought of getting him further afield or looking at hill-walking or something more challenging for him, even though he has access to a Motability vehicle. I felt that staff were slightly stuck in a routine that they were comfortable with’

We had concerns about a few providers whose staff wore uniforms. Whilst protective clothing may be necessary in assisting people in their own homes with certain tasks, we felt it was inappropriate to accompany people to social and leisure activities in the community in uniform.

In some instances changes were being encouraged by the manager of the service:

> ‘I assessed the support being provided fairly satisfactory. However the new manager is working hard to move the plan forward. The most significant change has been around structure and daily planning. This has been fully risk assessed and staff now follow a diary. This has only been in place for 6 months. She identifies a big challenge with moving some of the staff team forward, some staff struggle with introducing new activities for Gerry citing that there are too many risks involved. It is this anxiety and the balance

> between containment and promoting independence that she is tackling and has insight into. Seemingly Gerry has been involved in far more in the last number of months and new activities have been introduced. If diaried activities do not take place, then the reasons are clearly recorded as to why.’

We were concerned that some of the people we saw had support which was not meeting their needs. In some cases this was due to staff not having the training, confidence or expertise to deal with the severity and complexity of the person’s difficulties.

> ‘The support plan indicates that Elspeth has 2:1 support provided during the day. However when discussing exactly how his support is provided, it was clear that the actual support provided is significantly less than this. Staff always go into her flat in pairs, but much of the support is provided for short periods e.g. staff will go into the flat first thing in the morning, then withdraw after breakfast and after providing support with personal care. They will go back in again on a 2:1 basis a further five or six times during the day, but for regular periods during the day she will be by herself in her flat. There are significant issues regarding the lack of structured activities. At the time of this visit she was not getting out, apart from when staff took her out for a drive in her Motability car. She can access a secure garden area from her flat, but apart from very occasionally going into the garden, or going out for a drive, she engages in no activities.’

In other instances we considered the standard of support was less than satisfactory due to poor management and supervision of staff in putting the support plan into action. For one woman, redundancies and transfer of staff had left her with an inconsistent staff group. Although the manager was agreeing that the person needed structure and more to do, there was no evidence of the issues being robustly addressed. Comments from the Commission visitor included:

> ‘Beth’s weekly planner is not kept any more – white board in the sitting room is blank. There was acknowledgement that this “fell by the wayside”. Photos of staff that should be used for her to know who is coming on shift are outdated - many are of staff who have left.
>
> In the daily notes going back the previous 10 days: there was only one outing recorded. Other entries related to staying in the house, watching DVDs, singalongs with a favourite DVD and several entries about being in bed in morning. I asked about the lack of recent outings and was told there was an issue with carers who are not trained in administering her epilepsy medication and therefore cannot take her out (this is the case with agency staff).
>
> Beth has issues with self-care and there are considerable difficulties for staff in persuading her to shower. As a result a relative often assists her. The

> relative had injured herself two weeks previously and although Beth had had a wash, she said did not think Beth had had a shower, or her hair washed, in that time. There was a note entry “please record in file notes when offers of help to wash are given and also if Beth is refusing help”. There was no structured recording of assistance with self-care and a teeth-cleaning chart was not consistently being kept.
>
> There was an OT assessment for kitchen equipment which had been provided three or four weeks before. Using this with Beth had not been taken forward by carers and I was told “we’ve not had a chance to have a good practice at it”.’

Again, we are discussing these individuals’ support with their care managers and will be monitoring their care and support.

Challenges for Service Providers

Care providers were asked about any concerns they had about the support people were getting. Two-thirds had no concerns, nearly a third had some minor concerns and there were a small number who had more serious concerns about the interaction with relatives and funding issues, which the local authorities were aware of and were addressing.

The more minor issues were around the stability of staffing (6%), where providers often had to deal with a turnover of staff and the impact this could have on the service user. Ideally this was managed by having a slow transition but, where several staff left at one time, this was not always possible. 5% talked of other staffing issues, such as having drivers on duty, the difficulties of establishing a core team and the impact of having too many staff in a team, getting staff with the right level of expertise, and the stress on staff of doing quite long shifts when people are ill or their behaviour is very challenging.

Support by the manager of the service was also mentioned and one group of staff had had quite a number of managers over the last five years and felt they had minimal support.

A small number (5%) commented on issues relating to activities and outings, such as finding activities that engage the person, or working towards more focussed goals. Other issues raised by a small number of service providers included concerns about:

- the lack of an allocated care manager or annual review, particularly where there were issues of risk management
- accessing the individual’s full benefit entitlement where they were other appointees or financial proxies in place.

- the lack of garden space or the configuration of the service and where incompatible tenants were sharing accommodation
- the impact potential spending cuts could have on the person they were supporting.

What Providers feel works well

We asked providers what they felt worked well for the service user. Over half commented on the importance of having the right levels of staffing, a consistent staff group, staff who had the appropriate training and knew the individual well, and the need for good relationships between the person and the support workers. A third thought the involvement of the service user in care planning was very positive and a quarter felt the support plan itself worked well. There were comments from two thirds of the providers on the improvement in the person’s quality of life in terms of the activities and opportunities they had, their increased independence from having their own home, and the growth in their skills and abilities. Some of the comments below indicate the satisfaction support workers had in supporting an individual

> ‘The highlight is seeing her happy, getting out of life what she wants and seeing her do things she has not done before’
>
> ‘He has a lovely house, great access to a large garden, a car to go anywhere and opportunities to experience anything and everything’
>
> ‘He now has his own bank account with savings-he never had any money before’
>
> ‘Picture board helps him make choices; he can really enjoy his weekends with pubs, clubs, football, racing, the golf range and more’

Views on support

What we expect to find

- Satisfaction with the quality of accommodation and support being provided.
- Where there are issues, these are identified and are being addressed.

What we found

- There was very positive feedback from service users, care managers, private guardians and other relatives in the majority of cases.
- There was general agreement between parties about the elements of the support or accommodation that were not working. Some of these had been, or were, in the process of being resolved. Others were being discussed or monitored, such as the level of educational, social and leisure opportunities enabled by the provider and the training of support staff.

- There was disagreement between the person and the multi-disciplinary team on some issues - where service users wanted time on their own but there was felt to be public protection issues, and private guardians who felt they were not listened to.

Detailed Findings

We gathered views on the provision of the accommodation and support from service users (86), care managers (138) and reviewing officers (36), local authority guardians (21), (of whom 18 were also the care manager), private guardians (40) and other relatives (29).

All groups were overwhelmingly positive about the support being provided and many highlighted the huge improvement in the quality of life, particularly for people who had previously been in more institutional care. The comments in each section below reflect the level of satisfaction expressed by the various parties.

Only a very small number of people across all the service users, providers, care managers, private guardians and relatives raised issues on any particular topic. Issues raised concerned the suitability of accommodation (related to 5 people), availability of activities (5), management of and expertise/suitability of support staff (5), waiting lists for specialist health input (4), management of health issues by the provider (1), and a couple of general expressions of discontent.

In most cases the issues raised were being addressed by the care manager or the care provider, or at least were under discussion. More details of these are detailed below.

From service users

A third of people were able to give us their views on their accommodation and support. Half of these were able to express their opinions in a more limited way and were assisted in communication by people who knew them well.

All but ten people were very positive.

Most commented on having their own tenancy:

> ‘It’s been a lot better since I was living in my own place - I was in hospital before. I like it here’
>
> ‘I love having my own space, I love my allotment, I love having my things around me’
>
> ‘I am happy in my house and like my staff’

Others expanded on what a supported tenancy had brought to the quality of their life:

> ‘I like my house and it is good to have friends nearby. We spend time on computer games and sport. I have my own space and can have it as I want it. I get to do lots of things I have always wanted to do. I like going to the pub and college. I like swimming, gym, football and rugby at weekends. My worker is helping organise my first proper job and I am starting in a few weeks time’

> ‘I have been in this house for six years. I like my house. I like the way it is decorated. I’ve known staff a long time. I like going out with them to different places’

Ten people wanted some element of their support changed. Five of these wanted or needed, because of health problems, to move to different accommodation, for instance, a more rural setting, a house with a garden, or a house without stairs. Four of these requests were being looked at. It was felt impractical to move one man who wanted to be nearer his favourite football team in another city.

Three people said they would like less support and to be able to go out on their own, though were able to tell us the reasons why this was currently not happening. All had forensic histories and they were assessed as presenting a risk to the public if unescorted. All were living very full lives. As one man described it:

> ‘I like going for fish and chips. I like going to the gym and college and have a job, one day a week at the kennels. I co-edit a newsletter. I am busy, busy, busy’

Two people were generally unhappy about where they were living and their support, though neither was able to articulate what they would like to happen. One was on welfare guardianship and the professionals involved assessed the current placement as meeting his needs. We advised that advocacy should be involved to help him present his views. We requested that the local authority allocate a care manager to review the situation of the other service user and consider whether a legal framework was required.

From care managers

In the vast majority of cases the care manager was positive about provision to the service user. These are reflected in some of the comments below:

> ‘Everyone is working together for her benefit and she has a good quality of life. There is good input from other professionals when needed.’

> ‘Very good service. Works well. Provider very committed.’

> ‘There will always be blips but these are less frequent. Considering the chaotic lifestyle she had before, she has come on leaps and bounds.’

There were some concerns raised by care managers about the care and support of 13 people. From our visits we had concerns about a further three people and, when we raised these with care managers, they agreed to act on or look into these.

For seven people the concerns were about the delivery of support by the provider. These included issues such as enabling activities and providing opportunities to develop daily living skills. The sustainability and suitability of the staff in relation to the complex needs of the service user caused concern in three instances. In an equal number there were concerns about the management, supervision and support of the staff group. The management of epilepsy and medication by the provider was an issue for one person.

In four instances there were concerns about the suitability of the current accommodation due to the design or the provision of equipment, and this was already being looked at by the care managers. Delays in accessing allied health professionals due to waiting lists was raised by four care managers but the majority of these had been resolved.

From local authority guardians

We contacted 18 local authority (LA) guardians, three of whom raised some concerns about the support being provided, which are already covered in the section on the care manager's views. All other LA guardians were very positive about the support being provided. Comments included-

> '*Support is working very well. The package is expensive but has made a real difference to his life.'*
>
> *'Great package, meets his needs and gives him a real quality of life'*
>
> *'His experience has been incredible. Previously he was not speaking and was socially isolated. He has moved to his tenancy with intensive individual support and the providers have done wonders for him.'*

From private guardians

We gathered views from 40 of 49 private guardians. In 34 instances the responses were very positive and the comments below give a flavour of that -

> *'The support for him is superb. He has a lot of community outings and contacts and his self-confidence has improved with 1:1 care in his own home.'*
>
> *'It is good. I have had to fight hard through transition to get the right support in place, but it is there now, and it's been a learning curve, handing over some of her care to others, and seeing her grow and benefit from that. I never thought anyone else would do it as well as me, but they do, and they make it fun.'*

> *‘There are lots of positive changes for my daughter since she moved to her flat. She has more skills and abilities. She is able to help with domestic tasks and to access the community in a way which she did not do before, when she was often very agitated and difficult when out in public.’*

There were concerns expressed by six private guardians. Three guardians were unhappy with the management of the support staff and two of them felt their views were not listened to by the local authority and the provider. Two were concerned about the expertise and experience of the staff and one with the lack of a core group of staff, and the lack of structure and activities for the service user. The local authorities were aware of these issues and were addressing them as far as possible.

Comments included:

> *‘I have concerns about too many changes in staff, the lack of experience of staff, and the availability of drivers not always there to allow him to go to football etc. I feel communication with the provider is not great.’*
>
> *‘Overall - good. The right worker makes a big difference. The management is not so strong. ‘*
>
> *‘General support is good but I would prefer workers to be full-time to offer more consistency. ‘*

From other relatives present on the day

There were a number of private welfare guardians who were present on the day of our visit and their views are reflected in the previous section. We also saw 29 other relatives during our visits.

27 of the 29 relatives were very pleased with the support being provided and the impact on the person’s life. Only two had anything negative to say about the support provided. One person felt the person’s activities could be extended and new activities introduced. The other relative had concerns about some inconsistencies in the care package and her relative’s medication regime (we recommended that staff ask for a medication review).

Positive comments included:

> *‘I am delighted at how he is being supported’*
>
> *‘Excellent - good team and they are reliable. Activities are good and they encourage his involvement. Staff are respectful and I can raise any issues with them’*

Seven contrasted the changes in their relative’s life from their previous care setting. They commented favourably on the accommodation, the improvement in the standard of care and support, the decrease in behavioural issues and the increase in social and recreational opportunities. For instance one visitor from the Commission wrote:

> ‘Her sister is very happy with the care and support. She previously lived in a group care setting and she moved from there to her own tenancy about 8 years ago. Her behaviour was apparently quite disturbed in her previous care setting - "She was like a different person. She used to scream and bite herself, throw herself on the floor. When staff were not involving her, she was vying for attention. She has become much more settled over time since she moved from her previous care setting but it's been a journey. She is now in a peaceful place in herself and she trusts people. She's more the sort of person that she should always have been. Now she tells the staff what to do".’

Health

People with a learning disability have higher than average rates of a range of medical conditions. The prevalence rate of epilepsy amongst people with a learning disability has been reported as at least 20 times higher than for the general population. Approximately 40% of people with learning disabilities are reported to have a hearing impairment, with people with Down’s syndrome at particularly high risk of developing vision and hearing loss. 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 mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population, with mortality being particularly high for young adults, women and people with Down’s syndrome. Due to this different health profile, strategies to improve the health of the general population are unlikely to have a significant impact on the health of those with a learning disability[9]. 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, is therefore extremely important and we were pleased to have positive feedback from service providers about the input from CLDTs and GPs. The Keys to Life strategy makes a number of recommendations with regard to health inequality, which will hopefully lead to further improvements. These include putting a targeted health screening programme in place for people with learning disabilities and ensuring that by the end of 2015, NHS Boards have a dedicated primary care

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[9] http://www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf

liaison resource to support general practice and primary care teams in providing equitable services to people with learning disabilities.

In Scotland, GPs currently have two specific requirements in their contract as part of the Quality Outcome Framework which are specific to people with a learning disability, although there are others which they may be included in such as the requirements regarding the treatment and management of people with epilepsy[10]. For people with learning disabilities, general practitioners are required to maintain a register and to ensure that adults with Down's syndrome have an annual check of their thyroid function. Despite the potential complexity of health issues for people, particularly those with more severe learning disabilities, the evidence for the value of a routine annual general health check was not considered to be strong enough when determining the Quality Outcomes Frameworks. However, it is important for people with identified physical needs to be able to access appropriate care and treatment. In addition, care providers need to be alert to the physical and mental health needs of the people that they support. We say more about this in the section on Risk Assessment and Management.

What we expect to find

- People with a learning disability have the same right to health care as the general population including participating in national screening programmes
- Regular (usually annual) specific health checks determined by the individual's needs
- The person can access specialist input where this is required
- For anyone prescribed medication, either, the person is able to give informed consent, or there is a legal authority for the medication under the Adults with Incapacity (Scotland) Act 2000 (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, usually completed by the GP, should be evident in the person's records.

What we found

- There was good access to primary health care and specialist input from CLDTs
- Those eligible had participated for the most part in bowel and breast screening but not in cervical screening
- There was poor compliance with the legislative requirements of Part 5 (section 47) of the AWI Act.

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[10] http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/

Detailed Findings

Despite the evidence for annual health checks being very limited, we asked how many people had received an annual health check from their GP. Fourteen percent of people reported that they had received one. Although this seems low, as we note further on in the report, care providers were positive about the support that they received from health professionals and it is clear that this support comes from a variety of health professionals. We asked providers whether those eligible for national screening programmes had participated in these. All those eligible except one had had bowel screening. The majority had had breast screening, though there were difficulties carrying out mammography for two individuals. The majority of eligible women had not had cervical screening. There had been discussion with the GP and in most cases with relatives or guardians, before a decision was taken about this. None, however, were reported as being sexually active.

We looked at what medication individuals were being prescribed. Nearly a third (30%) were being treated with anti-psychotic medication, and 15% with anti-depressants. In many cases people were being treated on a combination of medication for physical and mental health care needs.

Where a person is unable to give consent and is not being treated under the Mental Health Act, a section 47 certificate and treatment plan under Part 5 of the AWI Act should be completed by the prescribing doctor, usually the GP. It would be good practice, as the provider in most cases is administering medication, to have a copy of this in the person's care plan. Over a third of the people we saw (37%, 76) had no section 47 certificate and for an additional 30 people (15%), the care provider was unaware if one had been completed by the GP. Of these 106 people, at least half required a certificate and this should have been readily accessible in the records.

Review of support plans by local authorities

What we expect to find

- Every person should have at least an annual review of their care and support.
- The review should involve the local authority care manager or reviewing officer, support staff, welfare guardians and significant relatives, relevant health personnel and the service user
- Efforts are made to ensure the service user's views are heard

What we found

- Care providers reported that one in seven (30) people had a review of their support by the local authority less than once a year. The costs of these packages were between £64,012 per annum and £133,120 per annum

- In four local authorities about half the people we saw had a review less than once a year
- Where there was an allocated care manager (138, 68%) there was more likely to be regular reviews, and over half of these cases were reviewed at least once every six months (73, 53%). Care providers were more positive about support received from allocated care managers
- Over a quarter of people attended their reviews. The majority of these felt they were listened to and changes were made in response to their views. Three people felt that their views were not fully taken into account.

Detailed Findings

Care providers told us that 15% (30) of people had a review of their care package less than once a year. When we checked with the local authorities, there was agreement that this was the case in all but three instances. The cost of these 30 packages ranged from £1,231 to £2,560 per week. This is concerning both in terms of the lack of scrutiny of the support of a very vulnerable group of people, and in terms of accountability for public spending.

There were three local authorities, one larger and two smaller ones, where at least 50% of the people we saw had not had a review in the last year. In one instance the allocated worker had passed the case to a review team three years previously and there had been no review since then. A fourth local authority had also been unable to carry out annual reviews for over 40% of the people we saw. They told us they had recently reassessed support packages as part of the self-directed support (SDS) agenda, and had been unable to carry out reviews due to the drive to complete these assessments.

The allocation to a care manager was a significant factor in regular reviews being held. We found that only just more than two-thirds (68%) of people had an allocated care manager. 18% of people were allocated solely for review to a social worker in the adult or learning disability team or a review team. 11% (22) had no care manager or reviewing officer. We were unable to make contact with a care manager for 3% (6) of people during the period of our study, so the status of these individuals was unclear.

Where there was no care manager or reviewing officer, the care provider was told to contact the duty social worker if there was a problem. Several care providers commented that there was little point, if you wanted to discuss a difficulty, in phoning a duty social worker who had no knowledge of the person. Another said they had recently had the first review for years and felt the social worker had ‘parachuted in and the review was more about direct payments than the support’. Others commented that where reviews were allocated as ‘one off’ pieces of work by a social work team, it was possible to get a different social worker each time. Some authorities also allocate six monthly guardianship reviews, which are a legal requirement, in the same way. Whilst teams try to allocate reviews to the same worker, it is possible for adults on guardianship to have three reviews in a year with three different social workers. Providers generally commented more positively on the support and advice they got from allocated care managers who were more aware of the complexity of people's needs.

The need for robust annual reviews and good communication between providers and care managers is demonstrated by a young woman with a history of being sexually exploited who was living in a single tenancy. She had 1:1 care for most of the day but had a period in the afternoon, where she had time on her own. We were concerned when we visited that she was at risk of both sexual and financial exploitation due to the 'friends' she was meeting up with during that time. She had no care manager and there had been no review for 18 months. The provider had been told to phone the duty social worker if there were issues but had not done so. Following our visit, a care manager was allocated to review the risks and the support package, a CLDN was involved to look at her sexual knowledge and the provider became appointee for her benefits. The provider commented subsequently that it was helpful to have an allocated care manager with whom they could now discuss the on-going issues.

We asked individuals who were able to give us their views what they thought of their reviews. 58 people told us they attended and contributed to their reviews and three attended for part of the review, depending on their concentration or anxiety.

We saw examples of good practice in trying to involve them in the process. Most care providers spent time with the service user prior to the meeting identifying what they wanted to raise at their review. They could then support them on the day to make sure these items were discussed.

There was an excellent example where one user had a folder which identified both the items he wanted to discuss, the decisions taken and the action to be taken in a format that he could understand.

> 'There is a monthly support plan folder that describes the meetings, lists who attends and notes the topics for discussion. The last meeting, held in December 2012 talked about relaxation, social outings and risk assessment. There are lots of pictures of him and pictorial representation of the different topics under "what I want to talk about" which then goes on to "what we talked about" and then moves to "what we need to do" so that his requests can be actioned.'

There were a variety of adjustments made to encourage participation; for example, not having too many people at the review, using different communication aids, or having small monthly meetings which gave users experience of meetings before their review, and involvement of advocacy. Out of the 58 people who attended their reviews, ten said they had an advocate who came with them. For instance, one man told us:

> ‘Sometimes I feel I can’t speak if there are too many people, so only the staff manager comes to my meeting. My advocate always comes - I have known her for years and get on well with her. Everyone listens to me’

We asked people if they felt listened to at their reviews and if they could tell us about anything that had happened as a result of their views. Three people felt they were not listened to. One felt that he was listened to in the ‘small things but not the big ones’. Another, who has an advocate, said:

> ‘They barely listen to me, they listen a wee bit. I wanted to come off my order but I was told no. I asked about stopping my medication and it was reduced by half’

And the third told us:

> ‘My advocate asked if they had any reasons for me to be locked in my flat with alarms on and asked if I was detained. It was then agreed that the alarms would be off in the day and only on at night. If it wasn’t for the meeting the alarms would still be on now’

The Commission have been following this up, as there appeared on the day of our visit to be restrictions on this individual that were not legally sanctioned.

The majority of people gave examples of things they had wanted to do that had been responded to - e.g. one man stopped attending a day centre, another reduced his working hours as it was too tiring, a number of people went on holidays, one man had a helicopter ride, another went on the bridge of a ship, several went to college, one wanted more contact with his brother, and another wanted to go to a musical. One man said:

> ‘They asked me if there was anything I’d like to change in my life. I just said everything is going nicely for me’

Changes in support packages

What we expect to find

- Changes in the support package are in response to assessed need
- Service users, welfare guardians and significant relatives are involved in these decisions

What we found

- There had been no change in the majority (81%) of care packages in the past 12 months
- There was an increase of support in 8% of care packages and a decrease in 10% of them in response to changing needs which had been agreed by all parties

Detailed Findings

Due to the economic climate we expected to find that there had been reductions in people's support packages over the past year. In fact, most remained unchanged. Whilst 19 packages were decreased slightly, 15 were actually increased in response to changing needs. It would appear that for people with high support needs, the risk factors negate any great reduction in their packages.

There were, however, a lot of comments made by providers, relatives and guardians about the considerable anxiety that the self-directed support process generated and the length of time that elapsed before personal budgets were confirmed. Local authorities need to consider how information is given to carers and how some of the procedures can be streamlined.

Where there had been a change we asked care managers about the reasons for the changes. The reasons for an increase in the care package were due to a move from other accommodation, such as residential school, hospital and the family home, which required a newly commissioned package of care (5 people); a move from shared to single tenancies as they were not working (2 people); and increases in 1:1 or 2:1 time to expand the range and nature of activities, where someone was no longer attending day centre (3 people) or their physical or behavioural support needs had changed.

The decreases generally related to the person's behaviour being more stable. Eleven people had 2:1 staffing reduced to 1:1, due to the decrease in their behavioural difficulties. Similarly four people had moved from having a waking to a sleepover member of staff. One person wanted some time on her own at the weekend and this was being tried, and another was having half an hour on his own in the middle of the day. There were no instances where either the service user or their relative or guardian had disagreed with the change.

The other major changes in packages involved the introduction of a new service provider. In one instance this was in order to facilitate a new care plan, but in four other cases this was due to dissatisfaction or concerns about the service being delivered by the previous provider. This again reinforces the value of regular review by local authorities.

Informal support networks – relationships and friendships

What we expect to find

- The importance of friends and family is recognised by the care provider and efforts are being made to expand the person's social network

What we found

- Most people were heavily reliant on their families for social contacts
- 5% had no involvement with people beyond their paid carers
- Only a third of people had friends
- Most providers supported people in maintaining past friendships and many made new friends through social networks and events set up by the provider

Detailed Findings

We asked people if they were involved with immediate family, other relatives, friends, befrienders or others and what efforts were made to expand their social networks. We found that very few people (5%) had no involvement with anyone beyond their paid carers. The majority (79%) had involvement with either one or two of the groups listed, whilst 15% had involvement with three or four of these groups.

In a survey conducted by the Scottish Consortium for Learning Disability (SCLD) in 2006 (Curtice, 2006), having friends and the possibility of a romantic and/or sexual relationship were among the priorities for people with learning disabilities.[11] Around a third of people we visited (35%, 71) had friends. Some of these were friends they had made whilst in hospital, in previous accommodation or from schooldays. We found that many providers made considerable efforts to sustain these friendships. For instance, one man had two friends from his time in hospital and staff ensured these contacts were maintained by supporting him to visit them, ensuring birthdays were remembered and sending postcards when on holiday. Another provider told us:

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

> *‘he is friends with another service user resident in the block of flats, has a friend who works in the supermarket and visits him, and we are trying to trace a friend he wants to see again through that person’s service provider’*

We found that the other main source of friendships was through social networking between people receiving their support service from the same provider. Many providers organise regular social events and friendships have developed through these and are supported by staff. There are often clusters of tenancies with providers, which give greater scope for linking up with someone with similar interests, such as two young men who developed a friendship through fishing. Some providers have activity programmes which can widen the opportunities for people with ASD for example, who often struggle more to develop friendships.

Other close social contacts included three people who had befrienders and several people who went out or were visited regularly by people who had previously worked with them or volunteers.

People were generally known in their neighbourhood and had positive community ties. Typical comments were:

> ‘*Neighbours are tolerant and friendly despite some challenging behaviours from Danny’*
>
> *‘No difficulties from the community who are very supportive.’*
>
> *‘Rory is very accepted by the local community and neighbours always say hello and look out for him. The local community is very supportive to Rory and on the few occasions he has gone missing they have gone out and looked for him’*

A few people have more involvement. For instance one man told us:

> *‘he went to the pub with his neighbour, met people at church, chatted to the lady next door, cleared the path for a lady that is housebound, and had given his plum jam to a neighbour, as she gives him soup.’*

These provided valuable acquaintances and social contacts rather than ongoing support and friendships.

There remained a strong dependence on family, with more than four out of five people (85%, 171) having social contact and support from their immediate family and one in five (21%, 42) from other relatives. We saw some excellent examples of providers involving family members in the person’s life.

For instance, a relative contrasted the difference between visiting her sister, Ann, in hospital and her current involvement in her sister’s life. She told us of the grimness of hospital visits, where there had been ten patients, and staff were largely limited to dealing with personal care needs and had little opportunity to take patients out of the ward. Her sister would be sitting or lying in a big hall, sometimes with her clothes in disarray as she used to strip off her clothing. She describes her then as being 'like a caged animal'. In contrast she now has her own single tenancy with 24 hour support and she can pop in to see her several times in a week. Her husband does the garden and has built a barbeque area. Ann comes to her house for a meal at weekends or they go out to lunch, and they have been able to go on holiday abroad together with Ann's support workers.

For a large number of people their only close relationship was with relatives. A small number of people had no friends or relatives. In some cases the nature of their difficulties or behaviour was a barrier to forming friendships. For instance one provider told us:

> '*Bert has no friends as his challenging behaviour and autism-related responses mean that he has difficulty managing any social contacts.'*

This did not mean that efforts were not being made. For example, another provider said:

> *'David does not like meeting new people but staff ensure they try out social gatherings and activities keeping his preferences and needs in mind.'*

Similarly another reported

> *'Carol has a peer group she meets at various activities but she does not have anyone she herself identifies as a friend'*

In some instances, however, the importance of developing and promoting friendships did not appear to be given priority by support staff. We also had some concerns about a few of the shared tenancies we visited, where providers stated that the tenants had little in common, yet they were often sharing their social and leisure activities with these same people. The expansion of befriending services and developing natural social networks is one of the recommendations in the Scottish Government's new ten year strategy.

Bullying and harassment

We were informed of six cases involving bullying and harassment in the local community. Three involved local youths vandalising the person's property and two related to issues with particular neighbours, one involving an incident with a child and the other a complaint about noise. The police had been involved in each of these cases and the housing authorities in two; the response of both agencies was said to have been helpful. In the sixth case, a member of the public had photographed the distressed behaviour of the service user in a shop. The care provider indicated to us that the police were generally unhelpful when this individual's behaviour became difficult in the community and, on this occasion, they had refused to intervene and had commented that ‘she shouldn’t be in the community’.

It is generally thought the level of harassment of people with learning disability is high. There are reports by Mencap of as many as 9 out of 10 people with learning disabilities having reported some type of bullying or harassment at some point in their lives[12]. The lower levels reported from those we saw may be due to the high support needs of these individuals and the presence of support staff.

There were also three instances where staff had been moved or dismissed due to verbal or physical abuse of the person they were supporting. There were two people who were felt to be bullied by other service users either at home or at their day centre and one where the person was made fun of by students at college. These cases had all been taken seriously and the issues addressed.

Risk assessment and management

What we expect to find

- Risk assessment and management plans are in place to address all significant risks.
- The individual and the service provider have access to a range of professionals, where specialised input or advice is required.

What we found

- There were significant risks due to the complexity of people’s needs - physical health risks (66%), environmental risks (24%), risks of self-harm (34%) and people who potentially presented risks to others (35%).
- We were impressed with the standard of risk assessment and management plans and behaviour support plans for the vast majority of people we saw.
- There were a small number of people whose physical health risks were not being adequately addressed and a few where there were concerns about the ability of the provider to manage the person’s challenging behaviour.
- There was good support from a range of health and allied health professionals and providers commented positively on the responsiveness of the CLDTs and valued their input.

Detailed Findings

Physical Health Risks

Two-thirds of the people (66%, 133) we visited had complex physical health problems. These included epilepsy, difficulties with swallowing and choking, eating

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[12] http://www.mencap.org.uk/campaigns/take-action/stand-me

disorders such as Prader Willi Syndrome, mobility problems and a group of people with multiple problems. 29 people had a variety of health related issues such as GORD (gastro-oesophageal reflux disorder), heart problems and sensory disorders.

Table 2: Physical health risks

Physical Health Risk	Number of individuals	Percentage
Epilepsy	34	26
Swallowing choking or eating disorders	22	17
Mobility problems	28	21
Multiple problems	20	15
Other health related issues	29	22
Total	133	100%

Care providers were largely very positive about the input they got from health professionals. For instance, 23 were currently receiving a specialist epilepsy service. Of the 22 people with swallowing or eating disorders, seven currently had input from a dietician, six had input from a SALT and five had input from both. Of the 20 people who had multiple health issues, seven had a specialist epilepsy service, eight had physiotherapy, six had dieticians, nine had SALT and 12 had CLDN input.

In general the risks were clearly identified and addressed in the risk management or support plan. For instance, we saw one young man with severe epilepsy which, despite a lot of specialist input and different medication, unfortunately remained poorly controlled. He had a very detailed epilepsy protocol. Staff recorded his seizures in detail. This was reviewed monthly by the staff with the epilepsy nurse and there were very clear guidelines for the use of his wheelchair and his specialised chair when he was unsteady before or following a seizure.

There were only a few instances where we felt the support plan was quite basic, not individualised or did not address the issues. For example, one woman who had multiple health problems had a specialised chair that was unsuitable and could not be used. This meant she was in her wheelchair all day, and carers had to put her into her bed at 4-5pm in order to preserve her skin integrity. This situation was resolved following our visit. The same individual had had contractures in her legs, which had led to her being bedbound for a number of months and the specialist had commented that she should have been referred to him at a much earlier stage.

Environmental Risks

There were no significant environmental risks noted for the majority of the people we saw (76%). A few people (17%, 35) had challenging behaviour which could cause damage to property and consequently themselves or others. This included throwing items such as furniture and other household objects, punching and kicking walls and destroying furniture. For example

> ‘The decor is now lighter and less oppressive. His room had limited bedding, curtains, and soft furnishings but some of these have been added in specially adapted tear resistant fabrics. The curtains are on Velcro so they can be put back up if he tears them down’

These were all risk assessed and addressed by a variety of means, for example appropriate staffing levels and behaviour management plans, the use of plastic cups, the purchase of heavier and sturdier furniture, encasing TVs and computer screens and padding areas of wall.

There were significant safety and fire risks for a very few people (7%, 13). This included dismantling electrical equipment, wanting to access sharp items and two people who had histories of fire setting. Again, there were appropriate support plans in place, which in some cases included locking kitchen or bathroom doors and for two individuals restricting access to matches and lighters.

Risk of Self Harm

There was a risk of self-harm for around a third of the men (42) and a third of the women (27) we saw. Behaviours included self-hitting, scratching, biting, nipping, repetitive rubbing, skin/nail picking and throwing themselves to the ground or against sharp corners. Three people had a history of self-harming by cutting and two by swallowing sharp objects.

Care providers reported that input from health care professionals was good. There was current input from the CLDN service (in 40 of 69 cases), psychiatry (44), SALT (23), psychology (21) and challenging behaviour/ behaviour support teams (9). There were two cases where the person was on a waiting list for allied health professional input (one for SALT and one for OT) and one case where the provider was uncertain if the SALT would continue to see the person due to an incident of assault.

Providers appreciated the range of support on offer. For instance, one young man with ASD and an eating disorder would try to cut himself if he became very anxious. There were good risk profiles in place and behaviour support guidelines had been drawn up with input from the behaviour support team. Staff used ABC (Action, Behaviour, Consequence) charts to record incidents and the psychologist regularly reviewed the guidelines. As a result the man was much calmer and there had been fewer incidents over the past two years.

Similarly, a clinical psychologist had drawn up a behaviour management plan with staff for managing a young woman’s self-injurious behaviour and provided staff with training on implementing this. In addition the SALT had been involved in assisting with communication to reduce the person’s anxiety level and had developed a communication guide for staff.

We found that there were very few instances where emergency, as required, medication was used and there were only four people who needed to be held on an occasional basis to prevent self-harm. Of these, two people required seated restraint on a more regular basis, though this was less than once a month.

In addition one person required arm splints on a very occasional basis, and another, the use of a lap strap in her wheelchair as she would throw herself out when agitated.

Risk to Others

There were just over a third of people (71) we saw whose behaviour could potentially put others at risk; this could be staff, other residents or the public. There were proportionately more males (82%, 58) than females (18%, 13) with these difficulties.

Ten people were potentially a risk in terms of inappropriate sexual behaviour, 29 could potentially be physically aggressive in some way and five could potentially exhibit both inappropriate sexual behaviour and physically aggressive behaviour. 17 others presented a risk in other ways such as throwing things at people, grabbing people if agitated, alarming others by screaming and over familiarity with strangers.

Again there were well considered risk management plans in place which included avoidance and anticipation of situations, 2:1 staffing for 25 people when in public and/or at home and detailed behaviour management strategies of diversion and de-escalation. Although physical restraint was written into a number of behaviour management plans, only four providers reported use of this and it was on a very occasional basis, only when other measures had failed. One person needed to be restrained on a more regular basis in relation to personal care and one person occasionally required seclusion.

Rights and restrictions

What we expect to find

- For the majority of people where there were restrictions in place, we were satisfied that these were being carried out lawfully
- Any restrictions are necessary and the need for these regularly reviewed
- Restrictions should be legally sanctioned to ensure the rights of the individual are protected

What we found

- We had concerns about four people where we considered the restrictions on their freedom to leave their house, use mobile phones and internet access were not legally sanctioned
- We considered there should be a legal framework for the use of CCTV for one individual
- We recommended the frequency and duration of restraint for a further two people was monitored before considering the need for legal measures
- In all other instances restrictions were within a legal framework or were being carried out under a duty of care

Detailed Findings

There are a large number of people in this group whose behaviour, forensic issues or both, can challenge services and who are subject to some degree of restriction in their own homes. We looked at these restrictions, the reasons for them and their legality.

Legal Status

Just over half of the people we saw (56%, 113) were not subject to any legislation.

Over a third of people (38%, 77) were on welfare guardianship orders – 49 of those had private welfare guardians and 28 had a local authority welfare guardian. The service providers in all but three instances were aware that the person was on guardianship. However, 19 did not have a copy of the powers of the order (4 LA and 15 private). The service provider should have a copy of the powers and have had discussion with guardians as to how they wish to exercise or delegate their powers.

Service providers did not know the name of the guardianship supervisor from the local authority, if indeed there was one, for 13 of the 49 people on private welfare guardianship. We are aware that some local authorities are not fulfilling the legal requirements of supervision under the AWI Act or, in some instances, where supervision is allocated to a team rather than to an individual social worker.

Considering the complexity of people's needs and the assistance required with decision-making in their lives, we do not think this is acceptable.

One person had granted a welfare power of attorney.

Of those with private or local authority welfare guardians, 34 people also had financial guardians (of which 26 were relatives and 8 were solicitors).

Six people were subject to the Mental Health Act (MHA), and three to Compulsion Orders under the Criminal Procedure (Scotland) Act 1995 (CPSA). One person was on a Community Payback Order and one on a Sexual Offender Protection Order (SOPO). One person was at the time of our visit involved in Adult Support and Protection proceedings.

We looked at the powers granted in welfare guardianship orders to ensure they addressed the decisions and actions being taken in terms of the restrictions below. Again we considered whether the powers under the Mental Health Act, Criminal Procedure Act and Sexual Offences Prevention Order sanctioned the restrictive elements of the person's care and treatment.

We had concerns about four people where we considered the restrictions on their freedom to leave their house, use mobile phones and internet access were not legally sanctioned. We considered there should be a legal framework for the use of CCTV for one individual. There were a further two people where we recommended that the frequency and duration of the restraint measures should be monitored to consider whether legal measures should be in place. There needed to be consideration of whether the frequency, nature and duration constituted a significant deprivation of liberty for the person. Due to the intrusiveness of these various measures we think specific powers to address these restrictions should be included in welfare guardianship orders under the AWI Act.

Locks and alarms

Ten people had their bedroom doors alarmed at night to alert staff if they were up and needed staff support. In addition a number of people had pressure mats (8) by their beds, epilepsy alarms or sensors in their house at night. This was to alert staff to their care needs.

We found that ten people had their kitchen door locked during the day and two had it locked at night. In all cases this was for safety reasons, which included preventing access to sharp objects, dismantling of electrical equipment, accessing water and taps for someone fixated on them, and accessing cupboards and fridges for several people who would eat compulsively.

We looked in more detail at seven people who had doors and/or windows locked due to forensic issues and potentially posed a risk to themselves and/or the public if unaccompanied. Three of these were subject to CPSA and Multi-Agency Public

Protection Arrangements (MAPPA), one was on a Community Payback Order under CPSA and one was on a SOPO under the Sexual Offences Act 2003 with the restrictions legally sanctioned.

We were concerned about two of these people who were managed by the Care Programme Approach (CPA) but for whom there was no legal basis for restrictions in place. Both were restricted on leaving their flats unescorted and had access to the internet restricted, and one had additional restrictions on their use of mobile phones and landlines. One voiced his objections to the alarm on his front door and not being permitted to go to the nearby shop unescorted. The other person had been subject to legislation, but this had been allowed to lapse as he was generally compliant with the measures and not voicing any objection. Whilst risk assessments had been carried out and appropriate risk management plans were in place, we felt the legal basis of these two plans needed re-examined due to the level of intrusion and restriction.

Mobile Phones

Seven people were restricted in their access to mobile phones. Five of these had a history of forensic issues, such as making sexually inappropriate phone calls or sending obscene text messages. Two of these did not have the restrictions legally sanctioned. One, as previously mentioned, was not on any order; the other was on welfare guardianship but with no specific power to restrict access to his mobile or landline, and this has been raised with the local authority guardian. The Commission’s view is that such powers should be specified in a guardianship order to allow any concerns to be openly examined in court.

Two people were curtailed in how often they could use their phones due to the frequency with which they were using them and issues of affordability. This could debatably be seen as a duty of care, but care managers should seek their council solicitors’ opinion on this.

Internet access and photography

Seven people had their access to the internet restricted due to forensic risks. Four were legally sanctioned. Three of these people were subject to criminal orders and one was on welfare guardianship with the specific power to ’decide the frequency and duration of access to electrical and IT items and other forms of communication’.

Three people had their access to the internet restricted although there was no legal basis for this. Whilst they were not objecting to these measures, our view is that consideration should be given to whether there is a need for specific legal powers to authorise this. The adult should also have access to advocacy.

Two people were not permitted to take photographs - one was on CPSA and subject to MAPPA, the other was not on any order.

CCTV

One person had CCTV covering his bedroom. This was due to his epilepsy and was judged to be less intrusive than the previous practice of going into his room at 15 minute intervals. We questioned whether this was the best way to monitor his epilepsy and alert staff to any problems, and had concerns that the welfare guardianship order did not have specific powers related to CCTV. We were concerned that the evidence for these measures was outdated and it appeared there had been no multi-disciplinary discussion of this since 2006.

The Commission, the Care Inspectorate and the Scottish Human Rights Commission have issued guidance on the use of CCTV in care facilities and the need to ensure the legality of these measures and this applies equally to supported accommodation[13].

Restraint

Of the 202 people we visited, 103 were reported to have behavioural issues.

We found that nine people were restrained physically on an occasional basis due to behavioural issues, including aggression towards other people or self harm. In all cases positive behaviour support approaches were being used, focussing on the prevention of behavioural incidents through a variety of diversionary and de-escalation techniques. The use of as required medication with physical intervention was a last resort response, used to safeguard the welfare of the service user or others. All staff had had CALM (Crisis, Aggression, Limitation and Management) or similar training, including breakaway and restraint procedures[14].

Restraint for one person was by the occasional use of splints to prevent self harm when all else had failed and, for another, a lap strap on the wheelchair constituted a restraint at times when she tried to throw herself out of her chair due to agitation. One woman, who had no speech but was comforted by holding hands, wore taped gloves to prevent her scratching people. We felt this was a minor restriction, requiring multi disciplinary discussion and a better written care plan, which should be regularly reviewed.

There were two people who required to be physically restrained on a more regular basis (less than once a month on average) and we advised that these instances needed to be monitored as to the frequency and duration of restraint measures. Where someone is regularly restrained it is the Commission's view that there should be specific powers that relate to this in a welfare guardianship order.

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[13] http://www.mwcscot.org.uk/media/90969/joint_statement_on_the_use_of_cctv_in_care_facilities.pdf

[14] http://www.calmtraining.co.uk/

One person was restrained on a regular basis (more than once a month on average). She had previously been nursed in isolation on a ward and now had her own flat with 2:1 staffing and on occasions with 3:1, due to her extremely agitated behaviour around her personal care. This was authorised in the guardianship order with the specific power to ‘supervise and monitor the use of restraint on the adult which is used when required to protect the adult and others working with her from coming to harm’.

One person was subject to seclusion on an occasional basis, which included restraint to move her to a safe space. Unfortunately, due to weather conditions, we were unable to meet with the service provider, but the Commission had previously been in discussion with the multi-disciplinary team, the guardian and the provider about this. The guardianship order had been varied to include the powers to escort the person to her room, when all other interventions had failed and ‘support the adult there by means of environmental restraint (seclusion), which would include locking the door and observing the adult through a window in the door’.

Our follow up

Adults with Incapacity Act

There were a number of issues under the Adults with Incapacity Act which we felt required follow up:

- There was poor compliance with Part 5 section 47 of the Act and we asked providers to speak to GPs to ensure section 47 certificates of incapacity and treatment plans in relation to medical treatment were completed where necessary and a copy put in the person’s support plan.
- Part 5 section 48 provides authority for some specified treatments under the Act. We followed this up for one person with his consultant psychiatrist.
- Part 6 AWI Act Guardianship. There were a number of issues related to welfare guardianship.

We asked some care managers to consider whether certain restrictions that were in place such as egress, restrictions on use of the internet and phones, the use of CCTV and the use of regular restraint, were necessary and, if they were, to consult with their Council’s legal section on whether guardianship was necessary. In some instances we discussed whether the powers should be varied due to certain restrictions.

We enquired about the MHO capacity in some authorities to provide reports for private guardianship applications and to supervise guardians.

We asked a number of providers to ensure they had a copy of the welfare guardianship certificate and a copy of the powers and to clarify with the guardian how they wanted the powers to be used.

Other Issues

We followed up a number of concerns that arose from our visits. The most significant related to the lack of regular reviews and we contacted care managers or the responsible social work team when we considered there were urgent issues that required to be dealt with (11). We also raised issues including lack of activities (3), health issues (1), suitability of staff (2), management of staff (2), provision of equipment (1) and financial matters (4).

We will continue to monitor a number of these ongoing issues.

Conclusion

We were pleased to see the success of the Same as You? report in terms of the quality of provision in the community for people with complex needs, many of whom had previously been in institutional care. There was good evidence of the move to a more person-centred model of care that the report envisaged.

Overall their accommodation, support plans and the support services, including input from specialist community learning disability teams, were good. In many cases people's lives had been transformed, their social networks and opportunities to develop skills and participate in meaningful activities had expanded, and behavioural issues had decreased significantly. Service users and their families were generally very positive about the opportunities and choices they had in everyday life though, for some, developing friendships and relationships beyond their family remained an aspiration but not a reality.

We found many service providers offered good quality support to people with quite challenging behaviour and/or forensic issues. Whilst the support from CLDTs was often good, we had concerns that some local authorities were not providing sufficient support and oversight. 15% of people had not had a review by the local authority in the last year and we do not think this is acceptable. Reviews, at least annually, are important to ensure that the provision is not only meeting changing needs but is maximising people's choices and opportunities. Close attention also needs to be paid to legal issues under Part 5 and Part 6 of the AWI Act to ensure people's rights are properly protected.

This report shows the great benefit of well-resourced person-centred support for individuals with learning disability. The Scottish Government should pay attention to our findings when implementing the revised strategy for people with learning disabilities. When implementing strategies for other care groups, e.g. the dementia strategy and mental health strategy, the Government should consider what can be done to improve individuals' quality of life through the types of support outlined in this report.

APPENDIX 1

Table 3: Visits by Local Authority

Local Authority	Number of Individuals	% of Total People Visited
Aberdeen City	14	7%
Aberdeenshire	9	4%
Angus	6	3%
Argyll and Bute	5	2%
City of Edinburgh	12	6%
Clackmannanshire	3	1%
Dumfries and Galloway	5	2%
Dundee City	7	3%
East Ayrshire	6	3%
East Dunbartonshire	5	2%
East Lothian	6	3%
East Renfrewshire	5	2%
Falkirk	6	3%
Fife (LA)	12	6%
Glasgow City	16	8%
Highland (LA)	10	5%
Inverclyde	4	2%
Midlothian	4	2%
Moray	4	2%
North Ayrshire	7	3%
North Lanarkshire	10	5%
Perth and Kinross	6	3%
Renfrewshire	4	2%
Scottish Borders	5	2%
South Ayrshire	6	3%
South Lanarkshire	11	5%
Stirling	5	2%
West Dunbartonshire	4	2%
West Lothian	5	2%
Grand Total	**202**	**100%***

*Figures do not quite add up to 100% because of rounding

Table 4: Staffing Levels during Day Time Hours

Staffing level	**Individuals**	
	No.	%
All hours shared	4	2
Majority of hours shared with some 1:1	7	3
Majority of hours 1:1 with some shared hours	18	9
All 1:1	97	48
1:1 with under 15 hours 2:1 per week	24	12
1:1 with 15-29 hours 2:1 per week	13	6
1:1 with 30-80 hours 2:1 per week	20	10
All hours 2:1	19	9
Total	**202**	**100%**

Table 5: Staffing Levels during Night time Hours

Staffing Level	**Individuals**	
	No.	%
On call only	3	1
Sleepover	121	60
Waking night staff	45	22
Waking night staff and sleepover	30	15
Null-Parental home	3	1
Total	**202**	**100%**

APPENDIX 2

EXAMPLE OF PART OF SUPPORT PLAN

With thanks to Sense Scotland

ROUTINES

ROUTINES

Having a routine is very important.

I have an activity planner that shows what activities I undertake on a daily and weekly basis. My activity planner is kept in the daily folder please support me to follow my activities as it is good for me to participate in activities out with my home.

Keeping to this routine helps me to know what to expect. It allows me to do the activities I enjoy, to do the activities I need to do, and to try new activities.

Look in the diary on a daily basis in case there are other things that I need to do that day.

Use the activity planner and diary to plan the day. Be aware of my mood and be prepared to be flexible, but try to help me stick to it as much as possible.

Help me to pace myself throughout the day. Gauge my mood as to whether I undertake stimulating or more relaxing activities, and help me to wind-down and relax towards bedtime.

Plan how you are going to work together and how each of you will have time for a break.

Morning Routine

In the morning I like to have some time to waken up and not be rushed.

Most mornings I wake up myself. Sometimes if there are plans for the day I may need to be woken up. Wake me in plenty of time, as I really do not like to be rushed in the morning.

When I wake up I will come out of my bedroom and come downstairs. You can support me to the toilet, to freshen up, change my pyjamas if required, and put on my dressing gown and slippers, if needed. Sometimes I may prefer to just wander around first and wake up a little before having my pad changed.

When changing my pad have everything ready beforehand and then support me using turning & guiding if necessary to go into the downstairs toilet. Standing behind me, ask me to put my hands on the washbasin and remove my bottoms and pad from behind. Leave the bathroom door open so that your colleague can assist if I become distressed and if there is a second person on shift with you. Ask me to sit on the toilet and allow me some time to urinate or do a BM. When I stand up, ask me to wash my hands in the basin and while I am doing so, fit a fresh pad, standing behind me. Personal care can often be a time when I become distressed so please be aware of your position at all times. When finished ask me to wash my hands and put the paper towel in the bin.

Sometimes I like time in the morning to waken up before having anything to eat and drink. Usually I like a cup of coffee and then breakfast some time later normally around 9am.

BREAKFAST

- Offer me a choice of 3 cereals and ask me to choose one.
- After I have chosen prompt me to get my bowl.
- After I have my bowl using hand over hand (HOH) support me to put my cereal into my bowl.
- Prompt me to get the milk from the fridge you may have to use HOH, if required prompt me to pour my milk over my cereal.
- Prompt me to get my spoon from the drawer and my mat and ask me to put them on the table.
- Prompt me to get my apron and for me to put it over my head then sit at the table.
- You can then prepare my medication and finish my breakfast if necessary i.e. porridge.
- Show me the photo of my medication and explain to me that you will now administer my meds.
- Give me a spoonful of my cereal to ensure I will eat it.
- Administer my medication along with some cereal. Please ensure you tell me the name of my medication as you give it to me.
- After I have taken all my medication give me another spoonful of cereal to make sure all my meds have gone.
- I will then eat the rest of my breakfast by myself.

After breakfast follow Personal Living (Section 8) meal-times to allow me to get back into my routine. Please also put the photo of the cup underneath my bath / shower photo so I know I will get a cup of tea after I have my bath / shower and get dressed.

I have gone through phases where I am sick in the mornings. If this happens regularly then I should have my medication half an hour before I eat breakfast.

I do not need a second helping as I am currently on a weight reducing diet and I do not get anything extra on my cereal such as a banana or raspberries for example. Please read the Health section for further details on my diet.

I should not have my medication later than 10am. Sometimes if I sleep late, I can have my medication first (perhaps with some banana or yoghurt) and breakfast afterwards. If I seem to be sleeping very late, it may be a good idea to check on me and take my medication up to my bedroom and give it to me there.

BATHTIME

I have a bath after breakfast and medication. Prepare the bathroom and my bedroom before you support me to come for my bath. Lock the outside door and pull the curtains in the living room. This maintains my dignity if I come downstairs naked. Leave the blind down in my bedroom until after I am dressed.
At times I am reluctant to go for my bath. This may be difficult for you to understand because the reasons I may not want a bath are difficult for me to communicate to you. It has been decided at team meetings that you should always support me to have a bath for my personal hygiene. It is important that all staff are consistent in this approach, this gives me the opportunity to learn that although I can have choices in lots of areas in my life now, a bath is something that I must have.

The bath & shower photo should be on the board and it may be a good idea for you to put up the photos of what I will be doing after the bath. If there are 2 staff on one staff member should busy themselves with household tasks whilst the other prepares my bath and tells me it is bath time. You should say clearly to me ‘Katie, it’s bath time’ and support me to go upstairs for my bath. The other staff member should remain downstairs but be alert to what is happening upstairs in case I become distressed and your colleague needs assistance. While supporting me with bathing please allow me to do as much as I can for myself. Put the shampoo on my hand and encourage me to rub it into my hair, encourage me to wash my body and to brush my teeth.

When I am getting dressed you can support me to do as much as possible for myself. When you are preparing my room, please take out two tops and two pairs of socks so that I can choose which one to wear. Having choices is quite new to me and I am starting to get involved with this more. Do not offer me more than a choice of two for the time being as I may not yet be at a stage to cope with this. Sometimes you can now support me to choose my clothes before my bath.

When dressing, I put my arms into tops and T – shirts and then you can ask me to pull it over my head. I can pull up my trousers although I need some support getting them right up at the back and fastening them.

When supporting me to put on my pad, please ask me to stand and face away from you, towards the other support worker, if she is in the room, who will hold my hands and interact with me, or towards the cupboard door you will then be able to secure my pad and fasten my trousers in safety.

Please always be aware of your positioning when supporting me with personal care and dressing as it can be a time when I may become distressed.

During the day my activities vary.

Each day I will have a different plan you will find this in the daily folder and diary. Support me to understand what the plan is by using Makaton and directing me to the Communication Board. I have an activity planner, which is kept in the daily folder, and you should support me to do the activities and chores for that day. Please read the community & leisure section for details of how to support me with individual activities and also read the risk assessments before undertaking an activity.

Evening Routine

I usually have dinner around 6pm.

Support me to become involved with the dinner preparation as much as possible.
I am currently under the review of a dietician and I am on a weight-reducing diet. This means that when I have dinner half of my plate should be vegetables, one quarter carbohydrate (such as potatoes or rice) and one quarter or less should be protein. I have my 5pm – 6pm medication with my dinner.

Please see the section on Health for further details of my healthy eating plan.

7.15pm

Prepare my clean pyjamas and vest along with basin, face cloths and towels for when I return from my activity. You should also prepare my bedroom with the 2 pages of a magazine and pulling back the covers.

After the evening staff come in you can support me to go for a walk or do my evening shopping, please refer to my activity planner for this.

8.15pm

On return from my walk / shopping please support me to go straight through to the toilet. You should have had everything ready prior to leaving.

- 1 staff should support me to take my jacket etc off in the hall.
- 2nd staff should fill up the basin.
- Lead staff should support me to go into the toilet.
- Open my trousers and remove my pad, ask me to sit on the toilet.
- While seated you can then remove my top, vest & bra.
- Wash my face & hands and dry them.
- Put on my clean vest and pyjama top.
- Remove my shoes and trousers and put on pyjama bottoms.
- Ask me to stand up 2nd person to wash & dry vagina and bottom area.
- Lead person to hold my arms while 2nd person puts on my pad and fastens my popper vest then pulls up my trousers.

8.30pm

Staff should then prepare my hot chocolate and medication and administer my medication in the living room as normal. I only have two spoons of the chocolate powder in my drink – this means that I get fewer calories but am still able to enjoy a chocolate drink. If I am signing hungry you can offer me a healthy snack but this is not routinely given.

Support me to relax by sitting in the living room with me prior to the television being switched off.

9.00pm

Switch off the television unless there is a programme I appear to be really enjoying, you need to gauge this yourself on shift as sometimes if I get overtired I can display behaviours that are challenging.

Support me to relax by giving me a foot massage to relax. All doors should be closed before you support me to go to bed and only the photo of the staff member on shift and also my bed photo should be on my communication board.

At the moment I like to take the two white cushions and my yellow blanket to bed with me.

Prompt me to go to bed. If I do not go up with you it is best if you go up and wait for about 15 minutes if I do not come up then come back down, take me by the hand and tell me verbally and sign ‘it’s time for bed now, come upstairs’ If I start to display challenging behaviour then it is normally best to tell me you are going to bed and leave me as I will normally go up within half an hour. You can then come up and make sure I am tucked up in bed and then activate the telecare alarm.

In the evening support me to keep calm with relaxing activities such as gentle movement and rocking, massage, or yoga. If I am watching something on the T.V., please support me at bedtime by switching it off at the end or a natural break in the programme because I can get distressed if you switch it off when I am enjoying watching something.

I usually go to bed around 9.00pm but sometimes earlier if I am particularly tired or later if I have been out for an activity. It is easier for me to make the transition from daily activities to bedtime and sleep if you encourage me to spend some time with the lights low, and perhaps some soft music. Discourage activities such as playing with balloons, and gradually reduce the level of stimulation, keeping your voice soft and interacting less.

When I show signs of being tired tell me to come upstairs, show me the photo of my bed and reinforce using Makaton signing. Just now you are offering me a magazine to take to bed with me this seems to be working really well. There are magazines in the sleep over room that are soothing for me to look at bed time. It is important not to give me a magazine that may have pictures that cause me to become over stimulated at bedtime. Support me by not stimulating me, but gently interacting and quietly reminding me by signs and verbal prompts that it is bedtime. Before I get into bed I will have had my wash in the downstairs toilet and will be changed into my pyjamas.

I may go upstairs myself, or I may take your hand and lead you upstairs. You can encourage me to go upstairs using verbal prompts and Makaton. I may like to collect items to take to my room when I go to bed.

If I do not come upstairs with you then the support staff can go and get themselves ready for bed and when I come up, you can support me to get into bed, using minimal interaction.

When I am in bed I sometime like to have my night lights on.

If I am sick staff should turn on the monitor in my room before saying goodnight and closing the door. If you wish, you can use monitor in the sleepover room.

Sometimes, particularly when I am over tired, I might get out of bed and wander around and try to interact with you or play with something. Encourage me to go back to bed. Reinforce this with the Makaton sign and the Communication Board. This might happen several times but be consistent and do not interact with me other than to encourage me to go back to bed. If you meet me on the landing upstairs you can try turning and guiding me back into bed.

During the night I might get out of bed and go downstairs.

At night time only one support staff is now sleeping in my house. I wake up during the night on occasions.

Sometimes this is because I require support with personal care, or may be hungry or thirsty and at times there is not a clear reason what has disturbed my sleep.

You can hear when I leave my room when the telecare alarm is activated.

Currently one support worker is ‘on call’ but you do not need to get up immediately that I do. At a Team meeting you decided to allow me to go downstairs and use your judgement about when to get up to support me back to bed. Give me some time to realise that there is no one downstairs and to make my own way back up. If I have not done this in about 30 minutes then you may wish to come out to support me back to bed.

You should keep the lights dimmed, the curtains closed, blinds down and not have the TV on, as this may indicate to me that it is still night time.

If I am not communicating that I may need anything keep your interactions low-key with me as I may get over-excited and may not want to go back to bed.

Keep your voice low, talk as little as possible and keep your body language relaxed.

Try to re-enact my bedtime wind down and support me to relax by you being relaxed, in a relaxed environment. Use Makaton signs and words to say it is still bedtime. Show me the photograph of my bed on the communication board. Sometimes I like to take something up to bed with me – a cushion, blanket, a picture etc

If a situation arises in the night that you are not happy with then call the other sleepover person with the team mobile and ask them to help you. I can sometimes be very distressed during the night and present with very challenging behaviour. It is important that two support workers are there to support me and to support each other if necessary. Record any night time events in the daily sheets. (*You are recording on an ABC form my activity between December 2012 & February 2013 this is to get a picture of why I am displaying challenging behaviour at the moment).*

It is important to me that your approach is consistent. All staff should use the same approach.

Tea & Coffee

It was recently discussed to monitor the amount of tea / coffee I can drink. You need to use your own discretion but it is important you monitor my behaviour because I have displayed challenging behaviour recently, the general guide-lines to follow are:-

- A.M.- Coffee after pad change, tea/coffee on staff changeover, tea/coffee after bath prior to going out.
- P.M. – Drink with lunch, tea/coffee on return home in the afternoon, cup of milk with dinner, hot chocolate @ bedtime.

Other drinks as required but not to excess.

Handover/Changeover

In the past shift changes where a difficult time for me. Just now, I have a mix of both long day shifts and day / evening shifts, I appear to be coping well with shift changeovers however please remember not to hang around after your shift has ended and the new staff member has come in as this can cause me much distress.

I can appear to become stressed with people coming and going throughout the day in my house so if you need anything from my house then please phone the team mobile and my staff on shift will pass it out to you.

SENSES

SENSES

Vision

I have excellent peripheral vision and I am very aware of what is going on around me.

I love watching people, especially children playing.

There have been questions asked about whether my good peripheral vision is making up for poor central vision but no one knows the answer yet.

I have never shown that there is a problem with my central vision. My staff have noticed that I often look at magazines and photos upside down. This is something that my multi-disciplinary team will be looking into. Any observations you make will be useful.

Hearing

I have very good hearing although I can be sensitive to some noises like children crying or playing or dogs barking.

I will put my hands over my ears to block out noise. This does not mean that I am not enjoying myself it might just mean the volume is loud.

Be aware of my environment and the noise levels and encourage me to block my ears if the noise is getting loud. Alternatively you can use distraction techniques to draw my attention away from any potential distressing sounds.

Be aware that if there is a lot of noise such as the washing machine, tumble dryer and radio on all at once, I can become over stimulated and may become distressed. In these circumstances it may be a good idea to lower noise levels to enable me to stay calm. Likewise, if it is near my bed time and there is something very exciting/noisy/distressing on T.V., then it may be a good idea to lower the volume or turn the T.V. off at a convenient interval. This will aid me to relax before bed.

Touch and smell

I use touch and smell to explore the world. I have a very good sense of smell.

I like to use it to investigate people and objects.

I may sniff you closely.

I smell my food before I eat it and if I don’t like the smell I will push the plate away.

If I am exploring something by touch I may put it in my mouth.

COMMUNICATION

COMMUNICATION

General points to remember

- Always use my name, and establish eye contact first to focus my attention on what you are saying.
- Use SIMPLE LANGUAGE AND INSTRUCTIONS. Say it once and then give me time to process and respond.
- Makaton and my communication board are my forms of communication. This is how I communicate: you have to communicate with me in this way.
- Be aware of the environment, is it noisy/distracting?
- Be aware that I have absence seizures so I may not pick up on what you say to me.
- Give me time to process and do not try to rush me.
- If I have two support workers with me I may find it confusing if you both talk to me at once or repeat instructions the other has said.

How I communicate with other people

I use

- Makaton
- Communication Board
- Photographs
- Eye contact
- Facial expressions
- Body language
- Behaviour
- Vocal sounds
- Pointing

Eye contact and facial expressions

When I want to engage with you I will make eye contact with you.

My facial expressions can be a good indicator on how I am feeling.

If I am becoming upset I may break off eye contact, put my head in my hands, my eyes may widen and I may pout my lips.

I appear to enjoy making facial expressions for you to imitate, along with gestures and head movements. This seems to provide a positive way to engage in “conversation” with my staff and other people in my life.

Vocal sounds

I may also use sounds (uh uh uh) to attract your attention.

I may make other sounds which you can repeat back to me so that we are holding a conversation.

Body Language and behaviour;

I will point to, look at or lead you by the hand to wherever I want you to be so that you are aware of what it is I want to draw your attention to.

I may jump up and down when I am enjoying myself or am excited.

Tapping my teeth may be an indicator that I am anxious about something in my environment.

When I have had enough of something I will move away from it.

Makaton

I use Makaton as a means of communication and have used this system for many years. I do however rely on my own version of some of the Makaton signs. You should always respond to my communication by using the correct Makaton sign and not copy my own sign.

Sometimes I will use signs out of context just as a means of communicating with you. You should support me by using Makaton signs in context and reinforce this with photographs. This will help me to understand and improve my own Makaton signing.

Remember this is how I communicate, I may not understand all the signs but I rely on you to help me expand my signing and communication.

Communication Board

I have begun to use photographs in a more structured way to help me to communicate, understand what is happening next, and make choices.

My Communication Board helps me to understand sequences of events and to know what is happening next. It is my timetable for the day.

You can sit with me before breakfast and after lunch and dinner and help me to plan the day by supporting me to put the photos onto the board.

The photos will stay on the board and when each activity is completed you can support me to take down each photo and encourage me to put it beside the photo box so that I understand that an activity has finished. It is important to try and remember to take the photo off the board as soon as that activity has finished. Although you currently have the photo box in the sleepover room this is an activity worth re-trying as I used to do this in the past.

The activity that is happening immediately next should be at the top left hand corner of the board and the proceeding photos should go below that photo in order.

As each activity is started show me the photo to reinforce what is happening.

Use Makaton signing with **LIMITED** verbal communication. Short, straight forward instructions work best with me as I may not be able to understand long elaborate instructions. Always use concrete language not abstract as I may not understand this style of language.

On the right hand side of the board should be photos of the staff on shift. If someone is coming in to support me with a specific activity, his or her photo should be placed next to the photo of that activity.

Any visitors expected should be used in the sequence with the activity photos on the left hand side of the board.

You can support me to make choices by showing me two photographs of possible activities or destinations that we may go to in the car, and allow me to choose one.

I can also make choices for things such as what to drink or which top to wear. You do not need to show me the photograph for this – just show me the items and I will point to my choice.

Please remember that when I choose my choice must be followed so that my understanding of what happens becomes reinforced.

Use photos when we are out and about to show me where we are going next, e.g. Co-op, or a picture of e.g. the Community Clinic. The photos should always be reinforced with verbal prompts. Again after each visit the photo should be put away. The "home" photo should always be used when we set off for home, along with an explanation that we are going home, and the Makaton sign.

How you can communicate with me

I understand…..

- Makaton
- Communication Board
- Simple vocabulary
- Facial expressions
- Your body language

I do not enjoy being left out of a conversation so always include me in your conversation. I may not understand what you are saying sometimes but will respond to your tone of voice and your body language**.**

When you are asking me to do something use simple language reinforced by the Communication Board.

I may understand more vocabulary than you think but my main communication is using photographs and Makaton signing.

Do not have expectations that I understand more or less, this may lead to frustration.

I often mirror body language so be aware of your own body language when you are communicating with me.

Always take my communication pictures out and about with me to re-enforce my understanding of what we are doing and what is happening next. For example: We may be driving to the community hall but I may think we are going to see dad and this can lead me to become distressed.

What can we talk about?

Communicating about boats

I may want to communicate about boats a lot, as I love to go on boats.

I sometimes have difficulty in understanding that I can't do things now. When I sign for boats you must be clear if I will be going on the boat that day or not.

If I am going on the boat direct me to the communication board, tell me what is happening now and what is happening before going on the boat.

If I am not going on the boat, be clear in your verbal and non verbal communication with me that we are not going on the boat today, say, 'no, but today we are...' and then direct me to the communication board and show me what is happening now. Do not ever say ' no, we are not going on the boat' because it is likely I will pick up on the word 'boat' and assume I am going on the boat. This may lead to me becoming confused about what is happening and I may become distressed. You must communicate like this any time I am signing for something that I cannot get or is not happening.

Examples

I am signing my sister –

<u>DO SAY</u> & SIGN – 'No, you are going horse riding today' – then direct me to my communication board.

<u>DO NOT SAY</u> – 'No you will not see your sister today'

Ensure that you and your colleague are both aware of this communication as I may become distressed if I cannot do something that I want to do.

Communicating about Family

Use the same approach as communicating about boats.

Make sure you are clear about whether or not there will be family contact that day. Use Makaton signs and Communication Board.

Communicating about mum

My Mum died recently. I visited her when she was very ill and attended her funeral. Although I did these things, it is unlikely that I will have an understanding of what ‘dead’ is. I may sign and communicate about my mum frequently. Currently, under the advice of our community LD nurse, when I am signing ‘mum’, you have not to re-act, or say anything. Just direct me to what we are doing and support me to engage in another activity. It is really important that all staff members support me in the same way. My family will also be communicating with me about my mother in the same way.

Communicating about trains

I have recently started doing the Makaton for trains. Again you must be clear in your communication to me when I sign train. If the train is going past and I do the sign, you can acknowledge that this is the train but be clear that I am not going on it.

With all my communication it is important that you acknowledge what I am trying to say but please ensure that you do not confuse me by giving me the impression that this is what/where we are about to do or go.

Saying “No”

It is important that I understand the word NO!

You can use this when I am signing for someone or an activity that is not going to be happening that day.

If I am signing for something that is not going to happen on that day, then you firmly say “No” and do the Makaton sign. Then you can direct me to the Communication Board, sign and verbally explain what is happening now or next.

It is important that people can say “No” to me because it makes it clearer what is and isn’t going to happen.

You can also use “No” when my behaviour becomes more challenging, for example, if I try to harm you or others.

It is also important that you think about why you are saying ‘no’ to me. If I want to do something and it is possible, please do not deny me just because you feel it is best. Remember I am an adult and you are supporting me to live as independently as possible in my own home.

This means that you must support me in my choices, if at all possible – not in what you may have planned or is convenient for you.

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