

# Missed opportunities

**Findings from our visits  
to people with Acquired  
Brain Injury and Alcohol  
Related Brain Damage**

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## Who we are and what we do

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

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

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

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

## Our work

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

## Our visits

One of the ways in which we monitor individual care and treatment is through our visits programme. We visit people in a range of settings throughout Scotland; at home, in hospital, or in any other setting where care and treatment is being delivered. This report reflects our findings from a special programme of visits to people with acquired brain injury (post-acute ABI) and alcohol related brain damage (ARBD). The aim of themed visits is to enable us to compare care and treatment for particular groups of people across Scotland. Our aim is to help services learn from good practice and to respond to any common issues that are identified. This report provides an overview of our findings from a series of visits that took place across Scotland between 1 September 2009 and 22 January 2010.

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

## Our interest in ABI and ARBD

### Acquired Brain Injury (ABI)

Brain injury is an issue that has attracted a lot of interest amongst clinicians and other practitioners particularly at the acute stage. In 2006 a national clinical network for traumatic brain injury (TBI) was established to coordinate the NHS response to head injury in Scotland. In February 2009, the Managed Clinical Network (MCN) published two important documents for traumatic brain injury: 'Standards' and 'Service Mapping Report'.<sup>1</sup>

The effects of brain injury can be physical, emotional, cognitive and behavioural and can pose significant challenges for the person and their families. Some people appear to be able to adapt and deal with the physical effects of an injury more easily than the emotional, cognitive and behavioural effects. A complex mix of problems often means there is a need for more than one type of service to provide support.

We have heard from liaison psychiatrists and social workers in general hospitals about problems assessing and finding appropriate placements for people who come to hospital some time after the original incident, but who are still living with significant consequences of the injury. Sometimes we also hear from people who contact our advice line because they cannot obtain services for their relatives with ABI.

<sup>1</sup> 'Traumatic Brain Injury Standards' and 'Traumatic Brain Injury Service Mapping Report' [http://www.sabin.scot.nhs.uk/index.php?option=com\\_content&view=article&id=103&Itemid=30](http://www.sabin.scot.nhs.uk/index.php?option=com_content&view=article&id=103&Itemid=30)

# Once the acute stage is over people with ABI may not fit into any specific service and their problems can be easily missed.

Another group of people with ABI are individuals subject to guardianship under the Adults with Incapacity (Scotland) Act 2000. We monitor the exercise of guardianship powers for these people by looking at the paperwork related to legal applications and reviews.

Once the acute stage is over, people with ABI may not fit into any specific service and their problems can be easily missed. They can be left to cope with multiple attendances at A&E and primary care services, or emergency social work if their problems escalate. If they are still in touch with their families, family members can feel frustrated and unsupported. We only get to know about these situations if and when mental health services become involved and legislation is used to provide a legal framework for care, or if staff or carers contact us to discuss their problems.

## Alcohol Related Brain Damage (ARBD)

There is no equivalent clinical or practice network for ARBD as there is for ABI, and there are very few dedicated services for people with ARBD. Addiction services generally do not cater for people who have sustained cognitive impairment as a result of on-going alcohol misuse, as they operate on the basis that people need to be capable and motivated to work on their own problems. While there are many services for people with organic impairment due to dementia, these services do not specifically cater for people with ARBD. The profile and needs of someone with ARBD may be very different from someone with Alzheimer's, vascular or Lewy Body dementia. In particular people with ARBD tend to be younger than those with dementia.

We have long been concerned about the care arrangements for people with ARBD. In 2000, Dr Alan Jacques, Medical Commissioner, wrote a paper 'ARBD – The Concerns of the Mental Welfare Commission'<sup>2</sup>. Our investigation into the care and treatment of Mr H was published in 2008<sup>3</sup>. It highlighted the negative consequences for a man whose ARBD went unrecognised, despite many contacts with health and social work services. We are concerned that as well as the tardiness in identifying ARBD, illustrated by this investigation, we frequently hear from practitioners about a lack of resources available to support people once a diagnosis has been made.

The Scottish Government published 'A Fuller Life' in 2003. This report was the result of an expert group brought together to look at the issues for people with ARBD. This led to a commitment by the Scottish Government to move the agenda forward, as described in commitment 13 of the Mental Health Delivery Plan<sup>4</sup>.

<sup>2</sup> 'ARBD – The Concerns of the Mental Welfare Commission', Dr Alan Jacques, Alcohol and Alcoholism Vol. 35, Suppl. 1 pp. 11-15, 2000

<sup>3</sup> Investigation into the care and treatment of Mr H <http://reports.mwscot.org.uk>

<sup>4</sup> "Mental Health in Scotland Closing the Gaps – making a difference" Commitment 13 link: <http://www.scotland.gov.uk/Publications/2007/12/10141643/18>

### Why link ARBD and ABI together?

ABI as a result of traumatic head injury is usually a single event and the date of onset is clear. The onset of ARBD may be more gradual and less easy to diagnose in its early stages. People with ABI may have several physical disabilities as a result of the injury. People with ARBD often have additional chronic health problems.

There can be a lot of overlap between the two groups as people with ARBD can also suffer ABI through falls and other traumatic events. People with ABI may also have, or develop, alcohol and/or drug problems in response to their difficulties. It may be necessary to know the history of the person in some detail to be able to make the correct diagnosis. The needs of people with post acute ABI may correspond more closely to those of people with ARBD than with dementia. For people with ABI and ARBD, unlike people with dementia, there is the possibility of cognitive and functional improvement if the right environment and care is provided.

We decided to look at these two groups together because, despite the different origins, once the acute phase of ABI is over the two groups often present similar care challenges.

### Scope of our visit

For the purpose of this themed visit, we defined acquired brain injury as an injury acquired traumatically by whatever cause, but excluding people whose brain injury was a result of illness such as stroke or a neurodegenerative condition. We have focussed on the post-acute stage and the person's care needs during longer term rehabilitation.

There are many different terms used for cognitive impairment due to alcohol. In an unpublished study of people subject to guardianship in 2003 we found 40 different wordings used by doctors in medical certificates for guardianship applications. The expert group which produced the report 'A Fuller Life'<sup>5</sup> used the collective term alcohol related brain damage or ARBD and we will do the same.

Although we acknowledge that there are many people over the age of 65 with ARBD, and there are young people under the age of 16 with ABI, we decided to focus the visits on adult services, rather than young people's and old age services as well. A small number of people aged 65+ were included in the visits because they were using adult services.

<sup>5</sup> [www.alcoholinformation.isdscotland.org/alcohol\\_misuse/files/ARBD\\_afullerlife.pdf](http://www.alcoholinformation.isdscotland.org/alcohol_misuse/files/ARBD_afullerlife.pdf)

# We found a significant number of people with ABI or ARBD enjoying a considerable improvement in their quality of life.

## How we identified the people to see

In the spring of 2009, we collected information from NHS boards and local authorities about the services they provided directly for people with ABI and ARBD and the ones that they were aware of in the independent sector.

We also looked at our own records to identify people on guardianship who have a diagnosis of ABI and/or ARBD. From this information we set up a programme of visits to see people in hospitals and care homes and individuals in the community, either living in supported accommodation or in their own homes.

In all, we met with 167 people and for 159 of these we collected information systematically using questionnaires. Of these, 130 people could give their views on some, if not all, matters. A higher proportion of people with ARBD than ABI could express their views. The views of people who were willing and able to engage in discussion are included in the following sections. We also gathered information from looking at the care records and speaking to staff, as well as observing the environments in which people lived.

## Profile of the people we saw

The majority of people we met had been diagnosed for some time and all were in receipt of services. Just under one third were women. A large majority were in the 45-64 age group – the youngest person we saw was aged 20 and the oldest was 81. The younger age group (under 35 years) were all people with ABI. Generally people with ARBD were older. 128 out of the 159 people (80%) seen were in care homes. (See Appendix, Table 1) Out of a total of 64 people with ABI, five had acquired the brain injury in the previous year,

compared to 10 who had lived with the injury for over 10 years. (See Appendix Table 2 for details.)

Only eight people we saw with ARBD had been diagnosed for one year or less, although they may have had the problem for longer than this. 14 people had been diagnosed for 10 years or more. For a total of 23 people there was no information in the notes, and no life history to indicate how long they had the problem.

## Key messages

We established a number of important findings during this themed visit. We found a significant number of people with ABI and/or ARBD enjoying considerable improvement in their quality of life with the provision of individually focussed care. Many people who were receiving care in specialist settings spoke positively about the care they received.

We also found very patchy access to the following essential elements of good care:

- specialist expertise;
- appropriate care arrangements;
- recognition of individual differences; and
- knowledge of law relating to incapacity.

We therefore identified eight key messages:

### Key message 1 Specialist assessment

Professionals with ABI and ARBD expertise should be involved in multi-disciplinary assessment and, when appropriate, re-assessment to assist generic staff develop care plans.

### Key message 2 Appropriate placements

Commissioners of services should ensure sufficient availability of specialist expertise to meet the range of needs of people with ABI and ARBD. Services should ensure there are clear pathways to minimise delay in implementing care plans.

### Key message 3 Care planning, coordination and review

All people with ABI or ARBD should have multi-disciplinary care plans, with a named coordinator. Care plans should be reviewed at appropriate intervals to ensure they continue to meet the person's needs as these may change over time.

### Key message 4 Participation

The person should be encouraged to participate in treatment and care decisions and have their individual circumstances and wishes taken into account.

### Key message 5 Living arrangements

Living arrangements should respect the individual's need for privacy, dignity and safety. The environment should be pleasant and friendly, whilst offering individuals scope for their own personal space. Meals should be nutritious and varied.

### Key message 6 Day to day activities

Activities are an integral part of being alive, contributing to a person's quality of life. Activity plans must be individually tailored, looking at therapeutic, social and everyday activities.

### Key message 7 Staying in touch

As far as possible people should be supported to keep in touch with family and

friends and if appropriate re-connect with lost contacts. Relatives should be provided with appropriate information, support and where indicated, a carer's assessment.

### Key message 8 Legal framework

Every person should make their own decisions with regard to welfare, medical treatment and financial matters, as far as possible, but if someone lacks capacity to make certain decisions and these need to be made by others, this must be done in line with the law.

## Where we visited

### Hospitals

All but three of the 22 people we saw in hospital settings had ABI. We visited three hospitals defined as neuro-rehabilitation services:

- Robert Fergusson Unit (RFU) an NHS Service, the RFU is a ward within the Royal Edinburgh Hospital, a large psychiatric hospital;
- Central Scotland Brain Injury Rehabilitation Centre (CSBIRC) a private service run by the Huntercombe Group, a part of Southern Cross; and
- Graham Anderson House (GAH) which had only just opened in Glasgow, a private hospital run by the Brain Injury Rehabilitation Trust.

We saw patients in four other hospitals. Three of which were psychiatric hospitals, of which one was a community hospital for people with dementia. (See Appendix, Table 2).

The four regional neurosurgical centres in Scotland were not included, nor were other



rehabilitation wards in general hospitals because their main focus is helping people recuperate at an early stage from the immediate effects of a brain injury. This stage was beyond the remit of our role and visits.

The ABI Managed Clinical Network (MCN) standards state that good standards and clear pathways contribute to effective care. When people are ready to leave a rehabilitation hospital they can either go home with appropriate support or go into care homes or supported accommodation. Most people are discharged from specialist ABI care at the point when the MCN pathway ceases.

We know that some people with ABI or ARBD become “stuck” in general medical and surgical wards and also admission wards in psychiatric hospitals. It was not possible to include all these wards as part of this visit but we hope that areas discussed in this report will be relevant to them and will help to improve care in these settings.

### Care homes

The majority of the people we saw were residents of care homes. We met 46 people with ABI, 64 with ARBD and 16 with both ABI and ARBD in care homes. Table 3 in Appendix 1 gives details of the NHS board areas of the people we met.

Many people with ABI or ARBD are under 65 and are not suited to mainstream care homes which are mostly for older people, nor do they fit well into units for young physically disabled people, or for younger people with a learning disability. The Care Commission does not register homes specifically for the categories of ABI or ARBD. Some homes have developed units

for ABI or ARBD in response to demand in their local area. Others have, by virtue of taking in a number of people with these conditions, come to be seen locally, or even regionally, as specialists by experience if not by designation.

There are no specific care standards for care homes looking after people with ABI or ARBD. However, we would expect as a minimum the Care Commission standards for other groups to be met.

### Supported accommodation

There are a small number of innovative services in Scotland that provide support to individuals in tenancies in the community, or in supported accommodation. We visited people in the following services:

- Options for Independence, Irvine, own self contained flat in care home, allowing for progression to greater degree of independence;
- SAMH ARBD flats in Inverclyde, self contained flats with communal areas and support on site flexible enough to respond to individual need; and
- SAMH ARBD project in Castlemilk, providing flexible support to people in mainstream flats.

Altogether we visited 11 people living in the community supported by projects such as the ones above. While this number is small and the 11 people we saw had very different histories and circumstances, we formed a positive impression of the way that individual needs were being met in these services.

### Specialist assessment and treatment services

We also talked with the managers of three specialist community services:

- Community Treatment Centre in Glasgow;
- Glasgow Alcohol Related Brain Damage Team; and
- West Dunbartonshire ABI Service.

These services provide assessment and treatment for people in their catchment areas. They also provide support and training for non-specialist services, including care homes in their area.

### Treatment and care findings

In this section we look at treatment and care in four parts:

- specialist assessments;
- appropriate placements;
- care planning, coordination and review; and
- participation.

#### Why this is important

Both ABI and ARBD involve damage to the brain which is associated with changes in cognition (memory and thinking), mobility and balance, behaviour and mood and a range of other medical and neurological disorders. Challenging behaviour occurs in a significant number of people with ABI. Brain damage may have an effect on a person's fundamental characteristics, so it is important when looking at the effect of brain damage to ascertain as much as possible about the person before the problem occurred. Medical,

neurological and social assessments are essential to determine the nature and extent of any impairment and to establish what treatment and therapies are needed.

Most improvements will come in the first two years after the injury, but with stability and good care there may be gradual improvements thereafter. If a person's social circumstances or health deteriorate after this time, however, the underlying brain damage may significantly reduce their ability to cope with these changes. ABI might make it difficult for the person to follow advice and treatment, to moderate their behaviour, or even to keep appointments.

The onset for ARBD is not usually as traumatic as in ABI, but develops gradually over a period of time<sup>6</sup>. The gradual onset gives the person a chance to develop adaptive behaviour, which can be positive or negative depending on circumstances. People with ARBD are not usually aggressive or disinhibited, and can appear articulate in interview. It is therefore easy for professionals with brief contact to miss someone's potential ARBD. At the other end of the spectrum there is a risk that assessing someone in an acute confusional or distressed state could lead to a premature diagnosis of ARBD.

We hope that clinicians and practitioners in primary care, A & E, psychiatry and in the alcohol field are aware of the potential for ARBD in order to arrange timely assessment for people whose problems might be a result of, or complicated, by ARBD. Currently there is no standard tool for assessing ARBD. Sole

<sup>6</sup> Unless in response to untreated Wernicke's encephalopathy

# Professionals with ABI and ARBD expertise should be involved in multi-disciplinary assessment and reassessment.

reliance on the mini-mental state examination (MMSE) can miss ARBD, as many of the tests covered in the MMSE apply to skills that may be retained by people with ARBD.

## Key message 1 Specialist assessment

Professionals with ABI and ARBD expertise should be involved in multi-disciplinary assessment and, when appropriate, re-assessment to assist generic staff develop care plans.

### What we expect to find

Specialist assessment should support medical, psychiatric and social assessments for people with ARBD or previous ABI, to identify the extent and effect of any impairment on their functioning and to ensure an appropriate treatment and care plan is put in place.

There are very few recognised courses or qualifications for ABI and ARBD. The exception is for psychology which offers clinical neuropsychology as a speciality. There are few ABI or ARBD 'specialists' from other disciplines. Doctors, psychiatrists, social workers, nurses and occupational therapists become 'experts' through the experience of working in a specialist team rather than through training.

ABI and ARBD assessments should include strengths as well as weaknesses. People with ABI need different input at different stages. Specialists should be accessible to review the care at appropriate intervals and especially at times when problems such as challenging behaviour undermine the existing care arrangements. Frontline practitioners should be alert to the possibility that ABI or ARBD may be affecting a person's ability to

make sound decisions about their need for treatment and care.

### What we found – specialist assessments

People with moderate to severe ABI are usually admitted to hospital after A&E care. Following this they may go for neurosurgery, intensive care, or rehabilitation. We saw a number of patients in the neuro-rehabilitation units all of whom had ABI assessments. Nearly all the people we saw in other hospitals had ABI or ARBD assessments.

However, we rarely saw evidence of specialist ABI or ARBD assessments in care homes' case notes. We could not always say whether there had been specialist assessment at an earlier stage, but if one had been done it would have been helpful for the care staff to have access to it. It may have been possible to help some people at an earlier stage if expert assessment had been provided. Frontline practitioners need to be alert to the possibility of ARBD and then have access to a service which can provide an ARBD assessment. In 2007 we investigated the care and treatment of a man whose case illustrated what can happen where the frontline staff are not aware of the potential and implications of ARBD<sup>7</sup>. For Mr H this had a serious negative effect on the care and treatment that he received. Once ARBD had been considered and assessed for, it was possible to provide services to improve his quality of life. Mr H was not an isolated case as the example overleaf shows.

<sup>7</sup> Not my problem <http://www.reports.mwscot.org.uk/investigationsreports/notmyproblem>

### Practice example: slow diagnosis of ARBD

*Ms A had a history of heavy drinking and her relationship with her partner was a turbulent one with occasional episodes of violence. Ms A's physical and mental health showed marked deterioration. A lot of time and energy were expended by frontline health and social care services, including many attendances at A & E, but the possibility of ARBD was missed. She missed appointments and could not follow agreed action plans. This response was interpreted as an informed decision to reject help. Although there were clear signs of physical and mental health problems the possibility of her having ARBD was not considered. There was no multi-disciplinary examination of her circumstances. If the information from each service involved had been put together, there might have been a greater chance of ARBD being identified. It was not until she was admitted to hospital with pancreatitis that this possibility was picked up by an alcohol liaison nurse who was asked to see her. Cognitive impairment resulting from alcohol use is a mental disorder and allows for the possibility of a guardianship order. This would have provided a legal framework, in the absence of her ability to give consent, for intervening to provide treatment and care at an earlier stage.*

### Re-assessment

We found a small but significant number of people with ARBD whose functioning had improved with good nourishment, abstinence and stability and whose social workers had difficulty arranging for re-assessment. We also found an example where a person had been diagnosed with ARBD despite no significant history of drinking.

### Practice example: inappropriate diagnosis of ARBD identified by care home staff

*Ms B was resident in a specialist ARBD care home. She spoke to us about her regret at being in the home. She admitted she had been drinking recently and was remorseful about this and accepted her diagnosis of ARBD and changed circumstances meekly. The unit manager said that from the start Ms B had fitted in well with the home's routine, but he saw no evidence of memory loss or impairment in her ability to look after herself. She presented no challenges apart from being somewhat low in mood. It subsequently transpired that Ms B had a physical illness which probably accounted for her symptoms. Her daughter confirmed that she did not have a history of alcohol misuse. Her personality had changed somewhat, and whilst her alcohol intake had increased it was thought she had been self-medicating. At the time of our visit the care home manager and her social worker were trying to arrange for a thorough cognitive re-assessment.*

Another group of people for whom re-assessment is vital are people whose past brain injury may be overlooked when their circumstances change. An old brain injury can make it difficult for a person to adapt to change, but if chronic cognitive impairment is overlooked by doctors and social workers the effectiveness of their input can be frustrated. A specialist assessment can be instrumental in ensuring that the right care is offered and that the person's capacity to accept or reject treatment and care is considered.

# Services should ensure there are clear pathways to minimise delays in implementing care plans.

## Practice example: problems when post acute ABI is overlooked

*Mr C was a patient in a general hospital medical ward. He had sustained a brain injury six years previously and after rehabilitation was discharged with no follow up. He returned to live with his wife and family. However his relationship with his wife broke down due to his aggressive and impulsive behaviour. He lived with other relatives until they were unable to cope. He was re-admitted to a general hospital in a run-down physical state and was treated successfully for chest infection. However he was now homeless and was referred to social work. The social worker had difficulty because Mr C would not cooperate with plans to move into homeless accommodation. One placement that was tried broke down after a few hours because of his behaviour. Mr C remained in hospital for many months. His disruptive behaviour was a matter of considerable concern to the hospital staff, but they largely managed him by allowing him to come and go at will. After some pressure was exerted Mr C was transferred to a mental health rehabilitation ward, which was the most appropriate of a number of inappropriate solutions. He stayed there while multi-disciplinary assessments were done and a care plan was established.*

## Key message 2 Appropriate placements

Commissioners of services should ensure sufficient availability of specialist expertise to meet the range of needs of people with ABI and ARBD. Services should ensure there are clear pathways to minimise delays in implementing care plans.

## What we expect to find

We would expect people to have access to care that meets their needs, provided by ABI or ARBD services or by generic services with access to specialist advice.

The range of needs is very varied, depending on the severity of the ABI or ARBD, the stage of rehabilitation and personal circumstances, so it is not possible to be prescriptive. Individually arranged packages of care offer the best opportunity for people with some ability to manage in the community.

## What we found – appropriate placements

Half the people we saw with ABI had been living with it for more than five years and there was little prospect of significant improvement in their functioning. The majority of this group were living in permanent placements. The other half had had the injury for less than five years and their circumstances were more varied.

We decided to examine in more detail the circumstances of the group of people who had suffered the traumatic brain injury less than one year previously. Altogether we saw five people in this category, all of whom were in regional neuro-rehabilitation units. They all illustrated the difficulty of arranging appropriate discharge, given the scarcity of facilities for younger people with ABI. The cases also illustrated the difficulty that regional centres can experience arranging specialist and social work input in people's home areas.

### Practice examples: shortfall in provision for people with relatively recent ABI

*Mr D was in a neuro-rehabilitation unit following an assault almost 10 months earlier. The assessment had been made that he could move to a tenancy of his own with support, nearer his family, but there was a problem in identifying a suitable tenancy and care provider. Unusually for many people in the regional unit he had an allocated social worker from the outset as he had been on probation prior to the assault. The delay in arranging a placement was due to lack of suitable community provision, not absence of social work input.*

*Ms E, had taken an overdose of insulin which had left her brain damaged. Plans were being discussed for her discharge from the unit. She was not able to engage in discussion about her care and there were significant disagreements amongst family members about future plans. She was on a Compulsory Treatment Order and the Responsible Medical Officer's formal care plan was very brief stating "Measures authorised by CTO – to receive hospital treatment". There was no social work input from her home area.*

*Mrs F, a professional, had had a road traffic accident nine months previously. After seven months in the unit she was ready for discharge. She was making progress physically but concern had been expressed about her discharge. This focussed on shortfalls in rehabilitation services in her home area, especially in relation to vocational assessment and to emotional instability. There was no social work input either from her home area or from the area where the unit was situated.*

*Mr G was ready for discharge after six months in a specialist unit but the nursing home in their neighbourhood that his wife considered acceptable could not provide care for him as Mr G needed occasional restraint. Mr G viewed the home as unsuitable because most of the residents were over 80 and the activities provided were unsuitable for him.*

*Mr H had been in the hospital for eight months. It was reported that he had made steady improvements initially but the pace of recovery had slowed and he was ready for transfer back to his home area. It was difficult to establish where 'home' was as Mr H had been homeless immediately prior to the fall which had left him with brain damage. He had come into the regional neuro-rehab unit from a city centre neuro-surgical ward and had no social work input at that stage. The local authority in which the unit was situated did not accept responsibility. The lack of a social worker was delaying the progress of discharge plans.*

We visited a number of people receiving services from innovative projects providing specialist community care and saw a very positive range of supports being offered in response to the unique circumstances of the people being supported. Some services provide accommodation while others support people in mainstream facilities. The support can be flexible, sensitive to the person's current needs and increased or reduced when necessary. Nearly all the people using community resources were very happy with the care and support they were receiving. The example below shows how a man with fairly severe ARBD, who in some areas would have

# Nearly all the people using community resources were very happy with the care and support they were receiving.

to accept 24 hour care in a care home, was supported to lead an independent life in his own self-contained flat. He was building up contact with family members which he had lost though the years of drinking and he was attending a vocational project.

## Practice example of innovative placement

*Mr J had a long history of drinking excessively and ARBD was diagnosed two years ago. He had lost contact with his wife and grown up children. After a year in hospital he moved into a community project for people with ARBD. Here he had his own flat which he described as “lovely, spacious and comfortable with very nice views”. The self-contained flat was one of several in a block with a communal sitting room and group room. Staff had an office near the street door which had a slow-pad entry and exit system. This ensured that they could see when Mr J was coming and going in a discreet way and could talk with him as he left or returned. (He was on guardianship so there would be legal grounds to prevent him going out, but the support workers were clear they would only prevent him if his state of mind or other factor showed there would be a risk.) Mr J had resumed contact with one sister who lived nearby and she came over on Thursdays to help with tidying, shopping, family contact and so forth. He was confident that through his sister he might soon see one of his daughters and her new baby. He also had 25 hours per week of formal support to help maintain the tenancy, deal with bills and appointments and advise on any other psychological or mental health problems. Both Mr J and the support workers said the placement was going fine.*

## Key message 3 Care planning, coordination and review

All people with ABI or ARBD should have multi-disciplinary care plans with a named coordinator, and care plans should be reviewed at appropriate intervals to ensure they continue to meet the person’s needs.

### What we expect to find

People with ABI and/or ARBD often have complex needs requiring input from a number of services. We would expect that, to help with care planning, everyone has a multi-disciplinary assessment, including assessment for ABI and/or ARBD.

For people with ABI assessment should be done when planning discharge either from hospital or from ABI clinical care. For people with ARBD assessment should be arranged when the condition is diagnosed. Assessments should look at risk factors and risk management plans should be developed. Risk plans should not only look at safeguarding against risks for the person and others, but should enable positive activities. The issues that arise from brain injury or brain damage regularly include problems of mobility, challenging behaviour, mood, communication, memory and thinking, as well as other less common difficulties. As a result professionals from many disciplines may need to contribute to treatment and care plans.

Given the complexity of most people’s problems we would expect to find an identified person to coordinate care using a robust method such as Care Programme Approach (CPA), at least until the individual is settled. We would hope that health and social work services have developed means to support

front line practitioners to manage and support people with complex conditions. Good coordination should facilitate integration of services, using the aspects of NHS, local authority and independent resources to best fit the individual's needs and preferences.

We would expect a good care plan to incorporate an activity plan that matches the person's needs and interests. Good care plans should recognise the person's strengths and resilience. The goal is to provide a therapeutic culture to build the person's capabilities to manage all the areas in their own life that they can manage, either independently or with support. Both ABI and ARBD create complex mixes of interrelated health and social conditions and care should be reviewed at appropriate intervals to ensure care responds flexibly and positively to improvements in function and changes in circumstances.

#### What we found – care planning, coordination and review

Care plans for people were variable and in only 56% of cases did we find clear goals for treatment, care and rehabilitation. For people in hospitals there was more attention to rehabilitation and care plans were usually comprehensive. This was also the case for people living in the community. For people in care homes the practice for reviewing care plans varied widely and the majority of people we saw were there on a permanent basis. We found a risk in some non-specialist care homes (where there was limited awareness of the effects of cognitive impairment) that some staff confused ABI/ARBD with dementia, leading to the possibility of recovery being overlooked.

Being on guardianship afforded some structure to care planning and review. Generally there were regular reviews for people on guardianship where the Chief Social Work Officer was the guardian. This was not as clear for people where there was a private guardian. This supports the findings from our reports: 'Guardianship and Young Adults'<sup>8</sup>.

Reduction in mobility is a frequent consequence of brain injury and the physical effects of prolonged drinking may cause peripheral neuropathy which affects mobility. Two-thirds of the people we met had mobility problems. We found some people whose care environments were not adapted well, e.g. for wheelchair use. We are following these up on an individual basis.

We did not take a detailed look at the specific medication and dosage people were receiving. Where this appeared to be an important issue for the person we discussed it on an individual basis with the appropriate doctor or care staff. If there was a problem, we followed up on this after the visit.

Very few of the people we spoke to in care homes were looking for any significant change in their circumstances and most care plans centred on achieving satisfaction in their current circumstances. In most cases we felt that care was being coordinated adequately given the permanency of most circumstances. However, we found 20 people where there was no coordination, including some cases where we felt that re-assessment was essential. We followed up these cases after the visit on an individual basis.

<sup>8</sup> <http://reports.mwscot.org.uk/visiting-monitoring/youngpeopleandwelfareguardianship>



### Practice example: the benefit and necessity of re-assessment

*Ms K had a history of heavy drinking. She had been neglecting herself and people in her locality had exploited her financially. She was reluctant to receive care and assistance but was admitted to hospital with pneumonia and while there was diagnosed with ARBD. She spent two years in hospital followed by a further year in a care home. By this time she was on guardianship, with a social worker acting as her day to day welfare guardian. She hated being in an institution. Two years ago the social worker thought her capacity had improved and pressed for a re-assessment of capacity and a new community care assessment. This multi-disciplinary re-assessment showed a significant improvement in functioning and soon after Ms K moved to sheltered housing. When we visited Ms K she had been living in her home for 18 months and she told us how happy and content she was now.*

### Key message 4 Participation

The person should be encouraged to participate in treatment and care decisions and have their individual circumstances and wishes taken into account.

#### What we expect to find

The principles of the Adults with Incapacity (Scotland) Act 2000 (AWI) state that the views of the adult should be respected and it is a matter of good practice to involve the service user in decisions where they are able to contribute. The capacity of people with ABI and ARBD varies from person to person and for any one person their capacity to participate

may vary according to the issue under consideration. We would expect people to be involved in decisions about everyday things and to be consulted more formally about key decisions. We would hope to find a record of the person's views in care planning meetings and reviews. We would expect that for major decisions, an advocacy service is available to provide assistance. The provision of user-friendly information and explanations enhances participation.

#### What we found – participation

We asked people how much they understood about the circumstances that led them to be in their current predicament. We were surprised at the number of people, especially those with ARBD (64 out of 87 who spoke with us) who, despite some memory problems and cognitive impairment, had enough grasp of their current situation to have some understanding and acceptance of the problems that led to them needing care.

The degree of understanding was varied and everyone had their own way of talking about their problems; they can be affected by the stigma that exists in society towards addictions. People in specialist care settings appeared more able to discuss the issues openly and this reflected the ongoing conversations they had with key workers and other staff. One man told us that he said he was not sure why he was there, but he was able to agree that he'd been diagnosed with Korsakoff's. Another man said "apparently they say it is brain injury, but it is to keep me out of Glasgow".

When we asked people whether they still experienced difficulties, few mentioned the alcohol problem or brain injury, because in their care setting these were no longer day to day issues. For many people with ARBD, but not all, the craving for alcohol is reduced. No one mentioned the desire for a drink as a current problem. Reassuringly, nearly three-quarters of those who identified current difficulties felt they were getting help to address these.

We asked people in care homes if they knew what medication they were on and why it was prescribed. Nearly half of the people we met did not know what medication they were taking. A third said someone had given them an explanation about their medication, but the others, perhaps understandably given the length of time some of them have been in care, either could not recall or said they had not been given an explanation. Of those who answered the question 'do you think the medication suits you', 69 said they accepted it and only 18 people said they did not agree with taking it.

Very few people we spoke to could remember attending reviews and for some reviews were very infrequent. However, most people felt there was someone coordinating their care, sometimes a family member, and most could identify someone they would turn to if there was anything worrying them. Overall, while some people were consistently unhappy with their situation, we found an encouraging sense of involvement and agreement with arrangements amongst our interviewees.

### Practice example: respecting the person's views

*Mr L, who was on guardianship, was living in a care home in a town about 30 miles from his former home. He thought the distance was a good thing "there is no temptation here for me to return to my old life. I've made a turnaround and I've kind of had to". He was positive about the experience of the home and felt he had a good balance of care and freedom. He was content to have meals provided and housework done, but he was still free to go into town and travel in the area. The staff in the home thought he had developed a new set of routines and was able to cope with this degree of independence. On a day to day basis they saw little evidence of memory impairment. We encouraged them to raise this in an imminent review and speak to the GP about re-assessment of capacity. Mr L said he did not think he would return to his old ways if he came off guardianship "I have come this far, I'm not going back to what I was". We discussed the options but left it up to him whether to apply for his guardianship to be recalled.*

### Individual wellbeing findings

In this section we report on what we found from meeting people with ABI and ARBD in hospitals, care homes and community settings. The majority of people with ARBD, and a significant proportion of those with ABI, were able and willing to spend time with us, reflecting on their experience. In this section we looked at:

- living arrangements;
- day to day activities; and
- staying in touch.

# Living arrangements should respect the individual's need for privacy, dignity and safety.

## Key message 5 Living arrangements

Living arrangements should respect the individual's need for privacy, dignity and safety. The environment should be pleasant and friendly, while offering individuals scope for their own personal space. Meals should be nutritious and varied.

### What we expect to find

There are a number of important factors to consider when arranging care for people with ABI or ARBD. We expect to find respect for a person's dignity, privacy, safety and individual preferences. We also expect that material things such as the environment and personal living space are well provided for. People with ABI or ARBD have very varied abilities and interests requiring a range of provision to be available. The fear of institutionalisation is very real for someone living in an inappropriate setting.

Food and nutrition is an important part of care for people, not just because it is such a basic human need, but also because some people with prolonged drinking problems have usually neglected their nutritional needs. The lack of vitamins poses a very real risk to their physical and mental wellbeing. A good menu can stimulate the senses and meal times are important social and therapeutic occasions. We expect that hospitals and care homes will provide a varied and wholesome diet, and that people living in their own homes will receive encouragement and support to prepare good nourishing meals.

### What we found – living arrangements

The majority of people we met were staying in care homes, 14% were in hospital and 6% living in the community. For 103 out of 127

people in care homes and nine out of 10 people in the community, the situation was viewed as permanent. Most people in hospitals were expected to move when ready and once a suitable placement was available.

We found that most people's living arrangements were generally suitable at the time of our contact with them. We felt that, overall 32 people were not appropriately placed, either because there was no specialist service or because funding was not available. The majority of people with a diagnosis of ARBD (47 out of 65 who could and did express an opinion) said that on the whole they felt their current living arrangements were satisfactory, whether that was in a care home, a hospital or a community placement. This was despite very few being offered any choice and almost half not being placed in their preferred location. For some people there is a tension between returning to known areas with a temptation to drink and forming connections in new locations.

### Practice example: dilemma of contact with old haunts

*Mr M, a man living in his own tenancy in Glasgow told us he was lonely and isolated as his flat was not near his old haunts. This was both a good and a bad thing; good because it allowed him a new start where he could benefit from a specialist support service, but bad because it removed him from familiar surroundings and away from the pubs he used to frequent. The ARBD community service provided communal activities and meals at their base near the tenancies and his key worker was working to help him get involved in a new social group.*

Of the 54 respondents with ABI (including 24 who also had ARBD) who expressed an opinion, 36 were positive and 19 negative or mixed about their current situation, all of these were in care homes. Many of those who expressed negative views did not acknowledge or understand the effect of impairment on their ability to manage independently.

Eighteen people with ARBD were very unhappy with their situation. The reasons for their unhappiness ranged from clearly unsuitable arrangements, dislike of the food, to irritation with 'rules' preventing them coming and going at will. Some people had a measure of insight into their situation, but others did not and could not recall the risks they had faced previously. As a result they could not accept the limits placed on their freedom. A significant number of people acknowledged that the intervention, whether initiated by family, medical or social care staff, had prevented them from more serious decline and that their social circumstances were much improved compared to the time when they were still drinking.

With regards to food and nutrition the vast majority of people who answered the question 'do you enjoy the meals?' were satisfied with the meals provided. 83 answered positively and only 15 answered negatively. It may reflect the improved social situation for many, particularly those with ARBD, of having regular meals compared to a previous period of social instability and under-nourishment.

The warmth and friendliness of a place can go a long way to mitigate the effects of living in an institution rather than in one's own home. It was reassuring to hear that an overwhelming majority of people in all

groups and settings reported that they found the atmosphere friendly and homely (104 out of 114) including people who would rather not be where they found themselves.

We asked people if they could identify the good things in their current situation to back up their positive comments. 63 people identified some positive factors, including some people who had mixed views about their care. The positive answers were varied and reflect people's interest in different aspects of life. Feedback included enjoyment of meals, the company and social events, and appreciation of the security and stability. Only 16 people could not think of anything positive to say about their situation.

We did not survey the physical environments in detail, as the range of settings we visited was so varied. These issues have been covered in other recent reports. For issues relating to care homes refer to the Care Commission inspection reports<sup>9</sup>. A joint Mental Welfare Commission and Care Commission report 'Remember I'm Still Me' reported on the care of people with dementia in care homes. This report can be found on our websites report hub<sup>10</sup>.

#### [Practice example: support to stay in one's own home](#)

*We met with Mr N in his house along with his sister-in-law, who was his guardian. Mr N had a long history of heavy drinking in addition to a mild learning disability. Mr N said 'brand new' in response to most questions. He presented as a very cheerful*

<sup>9</sup> [www.carecommission.com](http://www.carecommission.com)

<sup>10</sup> <http://reports.mwcscot.org.uk>

# Activities are an integral part of being alive, contributing to a person's quality of life. Activity plans must be individually tailored.

*person, satisfied with his quality of life. Following the death of his parents, he has been living alone in the family home and it provided a warm homely atmosphere.*

*Mr N's sister-in-law spoke very warmly about Mr N's achievements in getting on top of his drinking and said that his parents (now deceased) would have been very proud of him. She said that his life now was in sharp contrast to his life as recently as two years ago, when he was at significant risk not only from the effect of alcohol on his health but also as a result of the exploitation by local youngsters who would congregate in his house and 'tap' him for money.*

*The GP had referred him to the ARBD team and after full multidisciplinary assessment his sister-in-law applied for a guardianship order. Mr N now has four visits a day from a local care service. Some of these visits are brief to check he is OK and some longer to allow for shopping and outings. The care is managed by a local social worker. Neither the social worker nor the care providers are ARBD specialists, but they are supported by an ARBD team. Mr N's sister-in-law said that there is good communication between all those involved in the care arrangements and that the family is very happy with the care Mr N receives.*

## **Key message 6 Day to day activities**

Activities are an integral part of being alive, contributing to a person's quality of life. Activity plans must be individually tailored, looking at therapeutic, social and everyday activities.

## **What we expect to find**

Boredom and lack of purpose can sap both energy and self-esteem and can contribute to poor mental and physical health. One of the important principles of the Adults with Incapacity (Scotland) Act 2000 is that people who lack capacity should be encouraged to maintain the skills they have and encouraged to develop new ones. Good care can support these principles by providing an environment where people can make their own drinks snacks, take a role in tidying and gardening, etc.

Providing for the activities and occupation of people with ABI or ARBD is a very personal thing. A thorough knowledge of the person's capabilities and the effects of their particular impairment will need to be known. This requires the involvement and assessment of practitioners from different specialities. Risks will need to be assessed and managed. The use of individual activity plans to supplement unit activity timetables will help to ensure that no one is left without anything that fits their needs and interests.

## **What we found – day to day activities**

We found that just over half of the people we saw had a suitable programme of social and recreational activities, but over one third did not. (There was no information reported for the remaining 11%.) Activities were included in the care plans for most of the people receiving specialist rehabilitation in hospitals and for those living in the community. They were found less frequently in care plans in psychiatric hospitals or care homes.

### Practice example: inappropriate activities and counter-therapeutic environment

*Ms O was seen in an adult admission ward of a psychiatric hospital. She was very articulate, although somewhat repetitive in conversation (a characteristic of ARBD). She accepted she had experienced some problems prior to her admission having been assaulted whilst drinking. She did not accept she would need 24 hour care indefinitely and found the prospect of this very depressing. She said she was very scared in the ward and frightened of some of the other patients. She found the available activities demeaning and unsuitable for her. The environment was not therapeutic and not at all conducive to her engaging in rehabilitation or social activities. A guardianship application was in progress but once this was granted she would be likely to experience a long wait until funding and appropriate care were identified. There was no ARBD service in the area.*

We met some people who had little or no physical disability who would benefit from regular physical activity. For a number of them this was not available, which left them feeling very frustrated. We met one man who compared his current circumstances to being in prison. Some people reject the activities on offer as being unsuitable, especially group activities. Staff report that some people appear poorly motivated, even though they complain of being bored. Care staff frequently have insufficient time to try to identify and support people's individual interests.

A few people may be able to get back to work in the long run; assessment and a rehabilitation programme to support this prospect should

be in place. We met one man with ARBD who attended a supported work placement; he needed considerable encouragement to go as he easily became anxious.

Care homes are usually geared towards providing care rather than helping people to re-learn to care for themselves. We found some people who would have benefitted from undertaking some tasks such as their own laundry and making snacks. A minority of care homes were flexible enough to encourage people to do this. Small, specialist units did this well.

### Practice example: good individual activities

*When we met Mr P, who had suffered a serious brain injury from a road traffic accident, he was living in a small unit providing for people with ABI. Previously he had spent three years in a large care home with no ABI expertise. In the new environment Mr P was managing his personal care, his laundry and with support could plan and prepare his own meals. He was going out every day for physical and social activities, such as bowling, snooker, shopping, etc. Previously he had been confined to the care home with no activities apart from games and weekly trips out with his father. It was apparent both to himself, his father and social worker that his functioning and his memory were improving. He had been able to resume contact with his ex-partner and children. He continued to have significant vulnerabilities, but the care staff who knew him as an individual could see the triggers and cues and were working with the brain injury team to reduce the incidence of these difficulties.*

# People should be supported to stay in touch with family and friends and, if appropriate re-connect with lost contacts.

Activity programmes are easier to arrange for people in community settings, because these environments naturally allow for individual differences. The people we met in community settings retained a measure of responsibility for their household chores and where necessary received help from support workers to manage or work alongside them whilst doing tasks.

## Key message 7 Staying in touch

People should be supported to keep in touch with family and friends and, if appropriate, re-connect with lost contacts. Relatives should be provided with information and support, and where indicated, a carer's assessment.

### What we expect to find

We would hope that, from the time of the incident or diagnosis, family and friends are supported and provided with information about the condition and the services. We would also expect that they are supported with the emotional impact on themselves, as well as guided as to the best way they can help the person with the impairment. Where appropriate, carers should be offered a carers assessment. People with ARBD often have troubled relationships with family members because of years of problematic drinking and it may take a while for contact to be resumed, if at all. For ABI the incident leading to the brain injury can be traumatic for the family. Provision of information and support will help relatives to maintain or renew contact. When arrangements are being made to find living arrangements the location of the placement is an important matter. Wherever possible we hope the

person can live in a location that will help to maximise their contact with family and friends.

### What we found – staying in touch

We found involvement with family and friends very variable. Relationships with family members echo the nature of relationships before the onset of ABI or ARBD. We asked services about the contact they had and the information they provided for families. All specialist services provided family members with information and invited them to be involved in reviews where appropriate. There was no clear pattern about offering emotional help to the relative.

### Good practice example: information and support for relatives

*The Glasgow ARBD service has produced a range of very clear leaflets specifically designed, not only for users of their service, but also to help relatives understand the condition and the service they offered. It is their practice to engage with relatives as part of the treatment plan.*

A number of people we saw in care homes acknowledged that someone in the family had made the decision about the care home for them and they accepted this, admitting that it had been necessary. We also heard of families under strain who were trying to help the person as best they could, but who felt unsupported by services and resented by the person with the problem. For example, some tried to limit the person's drinking by controlling access to money, but ended up alienating the person.

### Practice example: the need for support for family

*One person we visited in a care home, Mr Q, was doing really well and was discussing options for moving out of the care home where he had been living for the last year. His family, one of whom was his guardian, was opposed to this discussion as they had experienced many years of anxiety and alarm when he was living alone, drinking excessively and getting involved in fights and disturbances. The family's cautious view was understandable. Progress towards more independence would be slow in any case as there was no specialist community resource in the area and specialist support would be necessary to prevent the person slipping back into former habits. Mr Q's case illustrates the complexity of this area of work, where the definition of benefit is not exact and where principles can appear to be in conflict. Family involvement was crucial and the local authority social worker had two responsibilities, one as Mr Q's care manager and the other as supervisor of the guardianship.*

Some families and friends were prepared to travel a distance to keep in touch. There were however a significant number of people who had lost touch with former friends and family. It was not always clear whether this loss was recent or longstanding, or whether there was any prospect of re-establishing previous links. We heard some examples of work being undertaken to re-connect people with lost contacts. These efforts often showed some success once the person was living in a stable or supported environment.

Some relatives did not appear to understand the impairment and felt that because the person appeared to communicate and reason well, they did not need the care or restrictions proposed by doctors and social workers. They would support the service user's plea for fewer constraints, putting strain on the relationships with professional staff. Some relatives have experienced considerable distress and difficulties themselves.

### Practice example: family member not accepting the diagnosis

*We met Mr R when he was living in a care home which had a unit for people with ARBD. The local authority had applied for guardianship when Mr R was in hospital and placed him there on an interim order. His sister, who had only resumed contact with him when he was in hospital could only visit occasionally as she lived 200 miles away. She disputed the need for 24 hour care and wanted Mr R to go into sheltered housing. Her wish was well intentioned and was driven by her conversations with her brother who was distressed at being in a care home. She could not accept the staff view that her brother was aggressive at times and needed prompting to manage his own self-care. It was her belief that he was neglecting himself because of his despair at his situation. The local authority guardian encouraged her to spend more time with her brother to obtain a more accurate picture of his capabilities. Unfortunately relationships between Mr R, his sister, and the professionals broke down. It was agreed to provide Mr R with as much opportunity as possible to take responsibility for tasks and to review the placement and his progress in six months.*



# If someone lacks capacity to make some decisions and these need to be made by others, this must be done in line with the law.

## Legal frameworks

Services and care providers need to know the rights of people who lack capacity and the laws and safeguards that exist to protect them. This section looks at three important areas where legal measures can ensure that the rights of people who lack capacity are respected:

- Guardianship under Adults with Incapacity Act;
- consent to treatment; and
- financial measures.

## Key message 8 Legal frameworks

Every person should make their own decisions with regard to welfare, medical treatment and financial matters, as far as possible but if someone lacks capacity to make certain decisions and these need to be made by others, this must be done so in line with the law.

## What we expect to find

Care providers must ensure that environments, practices and cultures are not overly restrictive. Any restrictions should be legal, proportionate and regularly reviewed. Staff should be aware of the provisions of the Adults with Incapacity (Scotland) Act 2000 (AWI) and of people's right to liberty under the Human Rights Act. Guardianship can provide a legal framework for supporting care plans for people with ABI and ARBD. It is important to remember that guardianship does not just facilitate moving a person into a care home, it can be used to underpin a package of supports that allow a person to live in their own home. Each person with ABI and/or ARBD is unique, by drafting individually

framed powers guardianship can facilitate individually focussed care. For example, where someone is able to run a home but lacks the ability to decide how they spend their money, or to protect their income from exploitation, powers can be drafted to respond to these specific issues. This is more challenging for services than providing standardised 24 hour care.

We would expect that when someone is admitted to a care home under guardianship, there is a meeting to discuss the use of guardianship powers and establish channels of communication between the person (if appropriate), the guardian, the manager of the home and the care manager.

The principles of the AWI Act, such as benefit, the least restrictive option and maximisation of retained skills must be respected when considering these ways of managing someone's money.

## What we found – guardianship

In very few cases was there written evidence that capacity to consent to welfare, medical and financial decisions had been formally considered. Of the people we visited 70 were subject to formal measures, 10 were on compulsory treatment orders (CTOs), nine were detained in hospital, and one was on a community order. 60 were on guardianship and a further four were awaiting the outcome of guardianship applications. Four people had relatives with welfare powers of attorney.

It is not in keeping with the principles of AWI to use powers to hold a person in unsuitable conditions. The case below shows how a poor placement can go wrong. Sometimes less than ideal arrangements have to be

Table 5 People subject to formal measures including guardianship

Legal context	ABI	ARBD	Both	All
Hospital CTO	4	4	1	9
Community CTO	1		1	
Welfare Power of Attorney	3	1	4	
Guardianship	29	24	6	59
CPSA Guardianship Order	0	1	0	1
Guardianship (proposed)	1	2	1	4

made due to the lack of choice in an area and it is very difficult when families or social workers have to choose the least unsuitable option.

#### Practice example: guardianship without specialist ABI assessment

*The local authority made an application for guardianship for Mr S who had had a brain injury some years previously, but was currently in a general psychiatric admission ward. The ward consultant was pressing for him to be discharged as he felt they had nothing to offer him. The day after the guardianship was granted the social worker took him to a local care home that had experience of coping with people with brain injury, but no specialist expertise. The placement broke down on the first day because of Mr S's violence towards other residents and staff. Mr S was not used to having to conform to communal rules, as he had been mostly free to come and go from the psychiatric hospital. While developing the care plan there had been no ABI assessment to look at Mr S's functioning and to outline what could be expected of him in terms of controlling his behaviour, or what approach the care staff should take. Mr S had to return*

*to the hospital. Although the consultant did not believe detention was warranted, guardianship could not be used to ensure Mr S stayed in hospital, and he was detained under the Mental Health (Care & Treatment (Scotland) Act 2003. The admission allowed for an assessment of his cognitive functioning to assist the social worker develop a care plan which had some chance of success.*

During our visits we also saw some very good examples of innovative care arrangements underpinned by guardianship. The following case shows how guardianship powers were formulated to apply to a specific situation to enable a man to live at home.

#### Practice example: using guardianships powers creatively

*We met Mr T in his home where he had lived with his wife for 25 years. He used to have a skilled job in industry but had retired early on health grounds. His wife was still working for the time being. He had had a stroke just over two years ago and when in hospital ARBD was diagnosed. He called this his first 'wake up call'. He was discharged when medically fit but soon after went on a binge. His*

*behaviour during the binge threatened his marriage. This he called his 'second wake up call'. He was referred to the mental health service and guardianship was proposed because of memory loss and cognitive impairment. The effect of ARBD was such that he could not remember the risk that alcohol posed to his welfare and could not establish new routines in his local neighbourhood. Mr T told us that he felt humiliated by the guardianship but realised it was the only way to get home and the alternative did not bear thinking about. A guardianship power was framed to give support workers the power to prevent him accessing alcohol. The social worker and community nurse worked with him to identify the risky times and support workers were employed to support him at those very specific times, namely, from 3pm each afternoon until 6pm when his wife returned from work. One year later he said he had come to appreciate rather than resent the company of the care workers. Both he and his wife were positive about the local authority social worker who was his day to day guardian. It is relevant here that this care package was put together by a social worker and community nurse who were not specialist ARBD workers but were alert to the issues.*

We were surprised to find some cases where the care home was unaware that a person in their care was on guardianship. We also found a number of cases where the local authority had not identified anyone either to exercise the day to day responsibility of the guardian, (where the court had appointed the Chief Social Work Officer as guardian) or to take on the supervision of a private guardian. In these cases we contacted the local

authorities involved to ask them to allocate social workers for these statutory responsibilities.

In some cases we felt that formal measures should be considered because someone was being restricted on a regular basis without formal authority.

#### Practice example: de facto detention

*Mr U had been admitted to hospital following a fall, probably whilst intoxicated. We heard that he repeatedly tried to abscond, but could not actually get away because of mobility problems. He was a voluntary patient and was adamant that he wanted to go home. We advised that formal measures should be considered to provide legal authority for detaining him.*

Mr U was clearly objecting to the restrictions and, in our opinion, was being deprived of liberty without right of appeal. A person in hospital on a voluntary basis who experiences restrictions amounting to deprivation of liberty can use section 291 of the 2003 Act to challenge their situation. Formal detention or guardianship gives a legal basis to restrictions and these measures give the person a means to appeal against them.

We met one man in a care home, on a guardianship order under the Criminal Procedure (Scotland) Act 1995, section 58, sections (1) and (6). Where the offence is one punishable by imprisonment the court can make a guardianship order, if satisfied that the person has a mental disorder, on evidence of two medical practitioners and 'there is an authority or person willing to receive that person into guardianship'. For this man this was a sound disposal,

especially as the brain injury had contributed to the offending behaviour.

### What we found – consent to treatment

Many of the people we met had complex health problems and were on various medications for physical and mental health problems. Some people were able to give informed consent but many were unable to do so. In many cases it was not clear that an assessment of capacity had been carried out. A number of people were assumed to have capacity because they were compliant with their medication. In a significant number of cases we found there were no section 47 certificates and a lack of knowledge amongst care home staff about AWI requirements. Other care home staff had experienced some GP reluctance around completing section 47 certificates.

### Practice example: lack of clarity over consent

*We found that Mr V had a number of drugs prescribed. He had little understanding of what they were for, and was not particularly interested. However he clearly said he wanted to stop taking them, but was frequently persuaded by the staff administering them to accept them. He had been in the care home for one year on an informal basis and was talking about being ready to go home. However he was placed in the home on a permanent basis and there were no plans for him to go home. We wrote to the GP suggesting a re-assessment of his ability to give informed consent and alerted the care home staff to this issue.*

### What we found – financial measures

Helping to manage a person's money can provide an important safeguard against

disorganisation, neglect and exploitation. Controlling expenditure can also serve to limit someone's access to alcohol. Some people are happy to accept help and many relatives, carers and social care workers provide help on an informal basis. If someone is unwilling to accept help but lacks capacity to understand the implications of their poor money management, the following measures can be considered:

- if relatives already have a financial power of attorney<sup>11</sup> they can take on this role;
- the Department of Work and Pensions has a procedure whereby someone can apply for 'appointeeship' to collect and manage the person's benefits;
- a care home can use Part 4 of AWI to manage residents' funds; or
- if the person lacks capacity to appoint an attorney, an application to be a financial guardian can be made.

For further information on these measures see our 'Money Matters'<sup>12</sup> guidance.

We found all of these measures in use amongst the people we saw. We found that for most people there were measures in place to help with money management. Service providers frequently used appointeeship to allow support workers to access someone's money to help them with domestic and social

<sup>11</sup> Powers of Attorney have to be granted when the person is capable of understanding this action but only come into force when the person loses capacity.

<sup>12</sup> Money Matters: <http://mwscot.org.uk/web/files/publication/money-matters-2.pdf>

## Measures used to help manage a person's money

Legal context	ABI	ARBD	Both	All
AWI part 4	2	4	0	6
Financial Power of Attorney	3	1	3	7
Financial guardianship	18	7	1	26
DWP appointeeship	25	42	9	76

activities. People living in care homes need money for day to day expenditure and many homes managed money under part 4 AWI or acted as corporate appointees.

### Practice example: the benefit of good money management

*Ms W was living in a supported tenancy following a long period in hospital. She was happy to move into the tenancy and accepting of support, however she was unaware of the real risks to her health and wellbeing of returning to drink. The social work department accepted responsibility for her finances under appointeeship and by regulating her access to money managed to ensure she budgeted for food and bills first. The risk of financial exploitation by an unscrupulous friend ceased and she no longer resorted to begging. She is now experiencing a quality of life that would not have been thought possible 12 months ago.*

### Key issues raised by managers of specialist services living arrangements

We met with 31 managers of services providing for people with ABI and ARBD. Some were set up as specialist services and some were specialists by experience. We asked their views about the strengths of their service and the difficulties they encountered providing

care for people with post acute ABI or ARBD. It was not our aim, however, to undertake a comprehensive review of specialist services.

The points below are the main issues arising from our discussions with these services and care providers.

- ABI teams reported missed opportunities in taking advantage of a person's optimum readiness for rehabilitation because of the inflexibility of care planning and funding procedures, or the time taken to progress guardianship applications.
- The availability of ABI and ARBD training is very limited, mostly being in-house learning by experience. Care homes which had access to ABI and ARBD teams, such as the ARBD team in Glasgow and West Dunbartonshire ABI team, had useful input from them.
- Many of the managers described the lack of 'step down facilities' as a major problem. At a stage when someone was able to move on, there was little opportunity to do so because there was no suitable accommodation, or no support service to provide ongoing care.
- The opportunity for people to have trial

placements in the community is limited if they do not have their own accommodation.

- The managers of some services felt that more people were living permanently in care homes than was necessary.
- Where ARBD is suspected it can be difficult to get the necessary six week period of abstinence before a neuro-psychological assessment can be done. To make this possible a person will require focussed support at home, or commitment from hospital ward staff to discourage access to alcohol. ARBD teams or hospital alcohol liaison nurses can facilitate this.
- A number of managers described difficult interfaces with both addiction and mental health services. ARBD or ABI teams can help to improve communication between these services and those we met had negotiated clear service protocols in their area. Increased knowledge of each other's roles, criteria and referral routes enhances coordination between services.

### Summary and conclusions

It is clear that ABI or ARBD teams provide invaluable expertise in their catchment areas. Good specialist assessments are fundamental to underpin good care plans. These specialist teams also worked with non-specialist care providers to enhance the care they provided for people with ABI or ARBD, especially if difficulties arose.

We were not confident that care managers, care home staff and/or guardians are alert to the likelihood of longer term improvement for people with ARBD or ABI. Where they

were, we found they often had difficulty accessing specialist re-assessment.

We found that access to specialist expertise was limited to a few areas across the country. The lack of timely diagnosis for ARBD and timely individually focussed provision, for both post acute ABI and ARBD, can lead to windows of opportunity being missed.

The choice for many people, whether made by themselves or others acting on their behalf, was often between being cared for in non-specialist settings, or in a specialist facility some distance from their locality.

We did find in a few areas that people had care packages tailored to suit their specific needs. We found some care managers recognised the problem and were willing to set up creative care arrangements, even in the absence of a specialist service.

We visited some people in innovative ARBD projects which provided individually responsive care while recognising the boundaries each individual might need.

Once their problems were diagnosed the improvement in quality of life was evident for many people, especially individuals with ARBD, who had experienced years of disruption and social difficulty.

For some people a care home placement was the optimum arrangement. While most care homes provided adequate care, those who used focussed activity plans to help people maintain and extend their skills and keep in touch with friends and families, provided the best care.

Specialist providers were more able to meet the complex needs of this group of people than

# We were not confident that care managers, care home staff and/or guardians are alert to the likelihood of longer term improvement for people with ABI or ARBD.

homes with no specialist experience. Generally they were more aware of the legislative framework than non-specialists. The specialist care providers had developed effective links with alcohol and mental health services.

We heard of work currently going on in NHS boards and local authorities to look at their provision for ARBD and to set out care pathways, but it is at different stages and there is no national coordination.

The ABI Managed Clinical Network has made good progress by looking at care and rehabilitation in the health service. They flagged up the need to extend this to social care, recognising the different phases of need for people with ABI.

## Recommendations

**We make a number of recommendations arising from this exercise looking at the care of people with ABI and ARBD. Some relate to national strategic issues and some to local service provision. It is important to remember that appropriate care is not necessarily more expensive than inappropriate care. Timely assessment can lead to focussed support which may prevent the need for long term care.**

### Recommendations for the Scottish Government

- In line with their own expectation the Managed Clinical Network for ABI should be supported to evolve into a Managed Care Network, incorporating social care and ongoing health care beyond the initial stage.
- An equivalent national Managed Care Network for ARBD should be established to coordinate and enhance the efforts of

health and social care services, learning from best practice in the field.

### Recommendations for NHS boards and local authorities

- NHS boards and local authorities should ensure that specialist assessments, including assessment of capacity, should be obtained:
  - for people with ABI at the stage of discharge from clinical care when care plans are being made; and
  - for people with ARBD, when it is first diagnosed.
- NHS boards and local authorities should ensure they commission a range of resources in their area to meet the very varied but very specific needs of people with ABI and ARBD.
- Multidisciplinary care planning should be the standard with a robust review process, such as CPA, for ongoing care at least until the person is settled. Coordination facilitates the integration of input from different agencies.

### Recommendations for service providers

- Service managers should ensure that individually focussed activity plans are implemented for people in their care.
- Services should provide information and support for relatives.
- Services should provide training on legal frameworks to ensure frontline workers are aware of the rights and safeguards for people whose capacity may be impaired by ABI or ARBD.

## Appendix

Table 1 Profile of people visited by diagnosis and age, gender and location

	ABI	ARBD	Both	All
<b>All people</b>	<b>64</b>	<b>72</b>	<b>23</b>	<b>159</b>
<b>Age group</b>				
Up to 24	1	0	0	<b>1</b>
25-34	14	0	0	<b>14</b>
35-44	14	5	1	<b>20</b>
45-54	23	21	6	<b>50</b>
55-64	11	38	15	<b>64</b>
65+	1	8	1	<b>10</b>
<b>Gender</b>				
Male	48	44	18	<b>110</b>
Female	16	28	5	<b>49</b>
<b>Current setting</b>				
Care home	47	64	16	<b>128</b>
Hospital	15	3	4	<b>22</b>
Own home	2	6	3	<b>11</b>



Table 2 ABI: time since incident

Time since incident	Age groups					Total
	up to 24	25-34	35-44	45-54	Over 55	
Less than 1 year	1	1	0	1	2	5
From 1 up to 3	0	0	4	6	2	12
From 3 up to 5	0	6	1	6	2	15
From 6 to 10	0	5	6	3	2	16
Over 10	0	1	3	8	4	16
<b>Total</b>	<b>1</b>	<b>13</b>	<b>14</b>	<b>24</b>	<b>12</b>	<b>64</b>

Table 3 People we saw in hospitals

	ABI	ARBD	Both	Total
Athol Unit, Pitlochry Hospital	1			
IPCU Gartnavel		1		
Central Scotland Brain Injury Rehabilitation Unit, Murdostoun Castle	7			
Dunnottar Ward, Royal Cornhill Hospital, Aberdeen		3		
Graham Anderson House, Glasgow	3			
Ayrshire Central	1			
Robert Ferguson Unit, Royal Edinburgh Hospital	5		1	
<b>Total</b>	<b>17</b>	<b>4</b>	<b>1</b>	<b>22</b>

Table 4 The people we saw in care home settings by NHS board area

NHS board	No. of homes	Specialist homes	Number of people seen by diagnosis			
			ABI	ARBD	Both	All
Ayrshire & Arran	2	2	6	1		7
Fife	2	0	4	7	2	13
Forth Valley	2	1		2		2
Grampian	6	3	5	3	1	9
Greater Glasgow & Clyde	15	15	11	29	4	44
Highland	4	2	5	6	3	14
Lanarkshire	5	5	5	14	3	22
Lothian	3	3	4	1	2	7
Tayside	3	2	7	2	1	10
<b>Grand Total</b>	<b>42</b>	<b>33</b>	<b>47</b>	<b>65</b>	<b>16</b>	<b>128</b>





Thistle House  
91 Haymarket Terrace  
Edinburgh  
EH12 5HE

Tel: 0131 313 8777

Fax: 0131 313 8778

Service user and carer  
freephone: 0800 389 6809

[enquiries@mwscot.org.uk](mailto:enquiries@mwscot.org.uk)

[www.mwscot.org.uk](http://www.mwscot.org.uk)

August 2010