

Dementia Services Development Centre
Department of Applied Social Science
Faculty of Human Sciences
University of Stirling

**Meeting the Needs of People with Alcohol
Related Brain Damage: A Literature
Review on the Existing and
Recommended Service Provision and
Models of Care**

Rhoda MacRae and Sylvia Cox

This literature review was commissioned by the
Scottish Executive Substance Misuse Division
to contribute to the work of the expert group on
Alcohol Related Brain Damage

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1 Executive Summary

1. ARBD is non-progressive if abstinence is maintained - No more alcohol means no more damage.
2. The damage sustained ranges from mild to very severe.
3. ARBD is best seen as a spectrum of disorders, merging into each other and overlapping
4. ARBD is not the same as having an intellectual disability or having dementia.
5. There are over 640 confirmed cases of ARBD in Argyll and Clyde and Greater Glasgow. This is likely to be an under-estimation as many cases will not have been identified, diagnosed or being treated as such.
6. Early identification and appropriate intervention can promote optimum recovery.
7. Specialised and standardised screening tools and assessment procedures need to be developed.
8. The needs of people with ARBD may be more akin to people with acquired brain injury than those with dementia.
9. Awareness, information and training is needed for a range of groups: carers of, and people with ARBD, staff in first point of contact settings and staff involved in the care of those with ARBD.
10. Alcohol specialists working in general settings are effective in raising awareness of alcohol misuse, facilitating referral and providing immediate support for those who have problematic alcohol use.
11. Alcohol specialists should have a role in the assessment and subsequent management of alcohol related issues wherever the person with ARBD is accommodated.
12. Guidance on the use of thiamine and community detoxification should be developed.
13. Full needs assessments should only be done after 3 months of abstinence.
14. Social work should be involved in joint planning and assessment.
15. Joint data sets should be developed to facilitate co-ordination and co-operation as well as to allow for more accurate estimations of prevalence.
16. Assessment should be done by multi-disciplinary teams with specialist knowledge of rehabilitation, on-going assessment and the particular needs of those with ARBD such as psychiatrists and specialist practitioners.
17. The care planning and provision will vary in each area, however whatever the form of care, an identified ARBD team or person could co-ordinate, track, and support the person with ARBD through the assessment, rehabilitation and placement process as well as facilitate regular multi-disciplinary reviews.

18. In areas of high prevalence consideration should be given to developing a multi-disciplinary specialist rehabilitation unit. However, dedicated units only provide one element in the continuum of care. Other options that could provide assessment, support and rehabilitation in the medium term should be actively considered. The degree of recovery, functional ability and support required will not be clear for at least one year after detoxification.
19. Detoxification may not always be an option but this should not negate the need for alcohol management, nutrition, vitamin treatment and on-going needs assessment led by an identified person and or team.
20. Treating people with ARBD as dementia cases to avoid accommodation problems is likely to result in further deterioration.
21. Care homes in which a climate of specialism is prevailing enhances social functioning. Staff and people with ARBD in care homes benefit from having links with multi-disciplinary team members and specialist alcohol practitioners.

2 Characterising Alcohol-Related Brain Damage

Introduction and Background

Alcohol Related Brain damage (ARBD) is a term used to cover a spectrum of conditions and disorders: this includes alcohol related dementia, Korsakoff's syndrome, Wernicke's encephalopathy, alcohol related brain injury and alcohol amnesic syndrome. In other words, these are conditions which have been induced by chronic alcohol consumption resulting in some degree of brain damage.

The prevalence of alcohol related brain damage (ARBD) is thought to be increasing (Chiang, 2002) (Smith and Hillman, 1999) (Ramayya and Jauhar, 1997). This alongside the concerns raised by the Mental Welfare Commission about the increased use of guardianship for people with ARBD has prompted an increased interest in the needs of those with ARBD and raised questions about how people with ARBD are identified, assessed and provided for through current service provision (Jacques, 2000).

Aims of the Literature Review

- To try and ascertain the needs and characteristics of service users and carers
- To identify how these people are identified, assessed and provided for through current service provision
- To draw together examples of good practice and models of care that will inform the development of service provision for those with ARBD

The review begins by describing the literature reviewed. It then asks what is alcohol related brain damage?, and describes the common characteristics associated with the spectrum of ARBD conditions. The numbers of those with ARBD are then characterised, highlighting the complex, diverse and long-term care needs of this population group. The review then discusses the ways in which we can draw on existing examples of good practice, existing knowledge about models of care and care pathways to inform positively the way we can develop service provision for those with ARBD. Using an adapted version of 'Pathways of Care' current service provision for those with ARBD in Scotland is described (Appendix 1). The main elements are: Training, Information and awareness, Detoxification and specialist assessment; Rehabilitation and monitoring; Carers, crisis and on-going care.

The emergent information and recommendations from the literature are set out under headings that reflect the main elements of a care pathway. Each heading is divided into current position/provision and potential developments. The review rendered explicit some gaps in understanding and directions for future study; these are discussed. The conclusions discuss the findings and issues for consideration regarding the potential service developments for people with ARBD.

The Literature Reviewed

The literature review was tiered, comprising three kinds of searches:

- *Bibliographic database searches* such as Cinahl; webspirls; zetoc; NHS register; system for information of Grey literature; OVID; Medline; British Nursing Index; NISW and BUBL.

- *Specialised database searches* such as ageinfo; centre for alcohol research; alcohol problems database; ISD; database of good practice in community care; Alcohol Concern as well as specific journal searches such as Alcohol and Alcoholism, Health and Social Care in the Community, Clinical rehabilitation, Alcohol and Health Research.
- *Internet searches* on alzheimers and dementia organisations; dementia sites and centres in Norway, Canada, Australia and The Netherlands.

In addition there was a request for information to over 90 individuals who were potentially interested and or involved in research or the care of people with ARBD.

This produced over 100 publications, reports, editorials, studies and evaluations. Almost half of this literature was clinical in nature, often concerned with the neuropathology of the condition. A large proportion were concerned with the epidemiology, diagnostic criteria, prevalence and symptoms of the condition. Only a small number of studies could be found that directly discussed the assessment, rehabilitation and long term care of people with ARBD. Very few studies had an evaluative component. However, models of care in other similar yet different population groups have been evaluated. It maybe these studies can be drawn upon in conjunction with what the literature suggests in terms of meeting the specific needs of those with ARBD in order to inform future service provision development and provision.

What is Alcohol Related Brain Damage?

This review will use the term alcohol related brain damage to encompass Korsakoff's, Wernicke's encephalopathy, alcohol related dementia, alcohol amnesic syndrome, whilst drawing attention to any specific implications these differences may have in relation to the aims of the review. The various terms are at times used interchangeably reflecting the often hazy lines of distinction between the various conditions. Jacques and Stevenson suggest that ARBD is best seen as a spectrum of disorders, merging into each other and overlapping (2000).

Alcohol related brain damage is not the same as having an intellectual disability or having dementia (ARBIAS).

Alcohol related brain damage occurs when a person is thiamine deficit, this damage affects long and short term memory; secondary damage can cause frontal lobe dysfunction (Chiang, 2002).

There are clinical definitions, differences and commonalities between the various alcohol related brain damage disorders such as Wernicke's encephalopathy and Korsakoff's psychosis (Cutting, 1978) (Oslin et al. 1998) (Smith and Hillman, 1999) (Jacques and Stevenson, 2000). The distinguishing features of these various conditions do have implications for clinical diagnostic and treatment purposes, however a detailed discussion of these issues are beyond the scope of this literature review.

Common characteristics of an ARBD condition

There are a number of characteristics commonly associated with an ARBD condition. The following are drawn from various studies such as (Smith and Hillman, 1999) (Chiang, 2002) (ARBIAS) (Elleswei, 2000) (Jacques, 2000) (Lennane, 1986).

- Cognitive and memory problems such as:

Confusion about time and place
Impaired attention and concentration
Difficulty in processing new information (verbal and visual)
Inability to screen out irrelevant information
Confabulation, often as a means to fill in gaps in context and memory resulting in inaccurate accounts of recent events
Apathy, a loss of spontaneity, motivation and initiative
Depression and irritability

- Physical problems such as:

Ataxia - a gait disorder often resulting in poor balance
Damaged liver, stomach and pancreas
Possibility of traumatic brain injury reducing cognition further
Peripheral neuropathy – numbness, pins and needles, burning sensations or pain in hands, feet and legs

The damage sustained is a continuum ranging from mild to very severe (Jacques and Stevenson, 2000).

It is crucial to remember that impairment is not degenerative if abstinence from alcohol and good nutrition is maintained (Smith and Hillman, 1999).

It appears that intellectual function remains relatively intact, despite the impairments to recent memory. Social functioning can be maximised through rehabilitative intervention, although degrees of recovery vary.

Recovery outcome is thought to be split into quarters (Smith and Hillman, 1999).

25% making a complete recovery
25% making a significant recovery
25% making a slight recovery
25% making no recovery

The Prevalence of Alcohol-Related Brain Damage

It is suggested that ARBD accounts for 10% of the dementia population (Lishman, 1990), and 12.5% of dementias in under 65's (Harvey et al., 1998). There is evidence to suggest that prevalence is increasing (Jacques and Stevenson, 2000) (Kok, 1991) (McCreadie et al. 1991) (Ramayya and Jauhar, 1997) (Smith and Hillman, 1999), although estimates differ widely.

A general increase in alcohol use, a withdrawal of IV multi-vitamins and an increase in the awareness of the condition all appear to explain the increasing prevalence (Jacques, 2000).

It is worth remembering that some people who may have ARBD will not have had diagnosis confirmed. Moreover, the prevalence will vary not only between nation states but between geographical areas. The prevalence of ARBD is greater in areas with high alcohol related disease and in those who areas with high levels of socio-economic deprivation (Chiang, 2002).

Scottish Prevalence

Scotland has pockets of high socio-economic deprivation coupled with high alcohol related health problems, Greater Glasgow and Argyll and Clyde being such examples (Chiang, 2002).

Prevalence in both these areas and in Scotland more generally appears to be increasing (Ramayya and Jauhar, 1997) (Chiang, 2002; McCreadie et al. 1991) (Smith and Hillman, 1999).

Argyll and Clyde seems to have the most accurate estimation of prevalence. (Chiang, 2002) suggests 7 per 10,000, whilst a GP practice in Argyll and Clyde established a prevalence rate of 14.4 per 10,000 within a patient list of 4850. Male to female ratio was 6:1. Local differences in alcohol consumption and deprivation are likely to account for the variation in estimates.

This means that Argyll and Clyde have 293- 303 confirmed cases of ARBD with a further 40 suspected (Chiang, 2002). Greater Glasgow has 341 confirmed cases of ARBD (unknown, 2002)

These figures suggest that there are *at least 680* people with ARBD in Greater Glasgow and Argyll and Clyde. Due to their high levels of socio-economic deprivation and alcohol related problems, they may have higher prevalence than other less-deprived areas with lower levels of problematic alcohol use. These figures suggest that either Argyll and Clyde has a much higher prevalence of ARBD than Glasgow, and or people with ARBD have not been identified in Glasgow (Chiang, 2002). However there is no evidence to suggest that Greater Glasgow would have a lower prevalence of ARBD as it is more socio-economically deprived than Argyll and Clyde. This may suggest that many people in Glasgow have not yet been identified or accounted for. Current work on the prevalence of ARBD in homeless and primary care populations should elicit a more accurate picture in the very near future.

These studies nevertheless provide an approximate picture of the numbers of people with ARBD in these two areas. These figures make Harvey's (1998) estimation of 2000 people with ARBD in the UK appear conservative.

Characterising the Figures

Men appear to account for 75% of people with ARBD (Harper, 1983).

Elleswei suggests that only a minority with ARBD will be the stereotypical image of troublesome drunks, such as street drinkers (2000). Most will have worked for many years, many will have had or have partners and families. However, people with suspected ARBD are often socially-isolated, many have incurred social, financial, occupational, physical and forensic difficulties as a consequence of years of problematic drinking. It seems that by the time many people with ARBD come into touch with services their relatives and friends are no longer involved or in touch with them (Jacques, 2000). This often means that people with ARBD will rely extensively on the continuity of integrated health and social support services.

Womens' alcohol consumption is generally thought to be increasing (Plant and Haw, 2000). Although women appear to account for around a sixth of the ARBD population (Chiang, 2002), they have an earlier age of onset, often after a considerably shorter drinking history than men, 10 and 20 years respectively (Cutting, 1978). This means that the small number of women who are vulnerable to developing an ARBD condition are likely to do so much earlier than their male counterparts; it may also mean that we will see a rising population of women developing an ARBD condition.

The age range of those presenting with an ARBD condition varies in the literature. It would appear that ARBD can become apparent in people as early as the third decade of life (ARBIAS), through to the eighth decade. There is a relationship between issues of identification and age of presentation/identification. For example, the Acquired Brain Injury Service in Australia places great emphasis on early identification and intervention, this emphasis may then account for over half of their clients being between 35-54 years of age. In the UK and Scotland it would appear that most of those known to services are in their 50's (Elleswei, 2000) (Price et al. 1988) or between 60-64 years (Chiang, 2002).

Age of onset has particular implications for service provision. For example, early onset of ARBD in both men and women has been associated with poorer prognosis and recovery potential (ARBIAS). However, early identification and intervention can also mean the management and or cessation of drinking, with rehabilitation and specialised support services promoting the optimum degree of recovery.

Care staff in Scotland have described *subgroups within the ARBD population*, subgroups that reflect the quarter split in recovery outcomes reported in the literature (Jacques and Stevenson, 2000). These are people who have:

- A relatively recent onset and significant recovery over a few months
- A more chronic condition with gradual improvement over two years
- Those who have improved but are still significantly impaired
- Those who showed no signs of improvement

Care staff also mention that people affected by ARBD have different needs to those with other dementias; it may be that their needs are more akin to adults of similar ages with head injuries (Jacques and Anderson, 2002). This association is made in part due to the recognition that other dementias are progressive whereas ARBD is not (unless alcohol consumption continues). Moreover, those with ARBD require specialist rehabilitation interventions and support systems from a diverse range of service providers.¹

As we can see identification of ARBD is problematic at various levels. This has implications for subsequent diagnosis, treatment, assessment, monitoring and rehabilitation for those with ARBD.

The next section describes the information gathered on current service provision for those with ARBD in Scotland. The information synthesised here is in no way a complete and detailed account of every provider and every service potentially available to those with ARBD: this information is not known. The section does, however, give a general picture of nature of service provision in Scotland. There have been studies into aspects of service provision for those with ARBD and it is these that are called on predominately; they are augmented with information from care staff working in the field.

For an illustration of the diverse nature of the condition and the range of services that may be required please see Appendix 2 where case examples are described

The format has been adapted from 'pathways of care: the main elements' (Appendix 1). Care pathways and person-centred approaches to care are models of care that include not only the immediate clinical diagnostic and assessment elements of care but also those required to respond to longer-term non-acute conditions. It encompasses the main elements in the spectrum of care, and is designed to facilitate thinking about how we can develop, adapt and extend existing service provision to meet the needs of those with complex, changing and long-term care needs.

Each section is divided into two parts: current service provision and potential ways we can meet the needs of those with ARBD. The structure throws into relief the areas of service provision ripe for development, the ways we can draw on our existing knowledge, and the principles of best practice in health and social care more generally to inform future service development.

3 Meeting the needs of those with ARBD: the main elements

Introduction

The exact nature of current service provision for those with ARBD in Scotland is not known. What we do know is that the type of support people receive within the different local authority and health board areas varies widely. As mentioned before, the epidemiological profile of ARBD indicates that there are population pockets. In other words we find some areas, often those with high levels of alcohol related problems and socio-economic deprivation, with significant numbers of people with ARBD, whilst in others the prevalence appears much lower. Additionally, many people with ARBD may not be identified and diagnosed as such; they may be in touch with services but this may not be being managed explicitly or regarded as an ARBD-related health or social care issue. This situation is likely to be compounded as ARBD may co-exist alongside mental health problems and often occurs under the age of 65 years.

ARBD is often an invisible disability – it often goes unrecognised until there is a change to daily routine (ARBIAS). This means it is difficult to estimate not only the prevalence of ARBD but also the kind of services those people with ARBD are currently receiving. This limits the information we can gather on the current service provision to those people who have a confirmed ARBD condition. Alcohol Related Brain Damage as stated at the outset is a term that encompasses a spectrum of conditions. The terminology we use to describe and define also raises issues over identification, establishing prevalence, establishing what the current service provision is as well as how to provide appropriate and adequate service provision. In other words the terminology we use impacts not only on our ability to identify and assess the numbers with ARBD but also the way in which we perceive their needs.

Training, Information and Awareness

Current Position

Training, information and awareness appear to be important for three main groups; People with an ARBD condition and their carers, health and social care staff who are potentially the first point of contact such as GPs, A&E staff and social work staff, and staff directly involved in the care of people with ARBD. It was beyond the scope of the review to determine how much awareness, information and training on alcohol related conditions and ARBD specifically is currently available to these groups. However we do know that basic awareness of alcohol related issues is generally lacking in primary care staff (Plant and Haw, 2000) (Anderson et al., 1999).

Alcohol Concern and some dementia organisations do provide some information about the condition but we have not become aware of any specific ARBD information leaflets designed for the public, health and social care staff or care staff working with those who have ARBD.

Information on ARBD screening tools, vitamin prescribing and referral options for primary care staff is lacking (Chiang, 2002).

Within specialised care home environments, staff also report a lack of training. Staff working in care home settings felt that their ability to do adequate assessments was impeded by a lack of background information, a lack of assessment tools and a lack of knowledge about the specifics of assessing and rehabilitating those with ARBD. Staff were often unaware of

other homes who had people with ARBD or who specialised in such care (Jacques and Anderson, 2002), constraining the scope for exchanging information and peer support.

Potential Developments

Basic information and increased awareness is seen as important given that people with ARBD are often first encountered in general hospital settings or in squalor at home (Smith and Hillman, 1999). A&E, police and general hospitals are also typical points of first contact for those with ARBD (Elleswei, 2000). It is likely that those with ARBD may be referred to services such as Gastroenterology for alcohol related health problems, or depending on the situation and presenting condition, to old age psychiatry, community psychiatric nurses (CPNs), social work teams, alcohol agencies or community dementia teams.

The literature suggests that staff in general hospital settings, primary care settings as well as those community teams are likely to encounter people with an ARBD condition; these staff need basic alcohol awareness training, information on ARBD screening tools, information and guidance on Vitamin prescribing and referral options (Chiang, 2002).

Alcohol specialists working in general settings have been shown to be useful for detecting, referring, counselling and preventing further alcohol related problems. They can be involved in the prevention and management of alcohol use, in raising awareness about alcohol related conditions, facilitating referral and providing immediate support for those who have problematic alcohol use (Chiang, 2002) (Anderson et al., 1999) (Hillman et al., 2001). A number of studies suggest active consideration be given to investing in this type of link service.

Care staff who have a role in the monitoring, rehabilitation and on-going care of people with ARBD need information on identification and assessment procedures. They also need training on the practical techniques that will assist people with ARBD to maximise their potential through improving memory, communication skills, diet, dealing with challenging behaviour and managing alcohol. Information such as this is provided by one such service in Australia (ARBIAS). They produce a number of information packs for case workers, carers, families, other professionals and people with ARBI (Alcohol Related Brain Injury). These have detailed information about the condition of ARBI, how to identify, assess and diagnose ARBI as well as guidelines for case managers. They also detail practical ways to help people with ARBI: strategies for improving memory, challenging behaviour, anger management, sleeping problems, balanced diet, communication skills and planning for change.

ARBIAS appear to be unique in that they also provide information for people with ARBD and their carers. They produce a guide for people with mild to moderate thinking difficulties, and information for carers on how best to support people to live in their own homes.

Staff have also asked for a special interest network to be set up in order to facilitate the cross-fertilisation of ideas and approaches in caring for those with ARBD.

Active consideration should be given to developing a variety of awareness, information and training aids. They may go some way to raising awareness of ARBD, facilitate early identification and address some of the information and training needs reported by care staff.

Detoxification and Specialised Assessment

Current Provision

There appear to be few home or out-patient detoxification services, with in-patient detoxification being inappropriate for some and lacking for others (Chiang, 2002). Concern was expressed about the lack of detoxification facilities and a reluctance to use IV/IM Thiamine in the community (Chiang, 2002). There was inadequate follow up and continued support for those detoxified (Chiang, 2002) (Plant and Haw, 2000).

The Specialist seven-bedded hospital unit designed for people with ARBD in Argyll and Clyde has a waiting list. It provides services for a large catchment area, which has implications for involving family and friends in rehabilitation. It is occupied by people from Argyll and Clyde and Greater Glasgow, though it has been suggested that capacity could be maintained by people solely from the Argyll and Clyde area and a similar facility will be required in Renfrew (Chiang, 2002).

(Chiang, 2002) suggested that the specialised unit could be extended to provide less intensive support locally for those able to move on. Moreover, any further development of services should take into account the needs of women (Chiang, 2002). There have been developments regarding co-ordinated working amongst the Social work teams, CPNs and voluntary services providing home support. Staff have reported that this is a good example of practice but requires expanding and more resources.

The Salvation Army also run a specialised unit for people with substance misuse problems. They currently use a screening and assessment tool that has been developed by the University of Kent, and offer specialised services for those with ARBD. (We were unable to get more detailed information on this service and development at the time of writing).

Greater Glasgow is proposing the development of existing services and the commissioning of new services to address the needs of those with ARBD. It is considering negotiating for designated beds to allow a six week in-patient stay, during which time people would be diagnosed and undergo detoxification as required.

In a survey of care homes that have specialist registration and or provision for people with ARBD most assessments were generic, although some units were attempting to develop specific assessment tools which they were doing in isolation (Jacques and Stevenson, 2000)

Staff in care homes reported problems with missing or delayed biographical information; it hampered assessment, intervention and co-ordination of care (Jacques and Anderson, 2002). Staff indicated that there may be a reluctance to undertake full and on-going assessments due to the problematic nature of an ARBD condition and the lack of suitable service provision options for people with a confirmed ARBD diagnosis.

Developing Provision

The literature points out that detoxification may not always be an option but this should not negate the need for alcohol management (working towards abstinence), nutrition, vitamin treatment and on-going needs assessment led by an identified person and or team.

Guidance on the use of thiamine and community detoxification should be developed (Chiang, 2002). Further consideration should be given to thiamine treatment in the community and to home and community detoxification.

Full needs assessments should only be done after three months of abstinence (Jacques and Stevenson, 2000). Assessments and tests done immediately after detoxification will produce misleading and pessimistic results.

Social work should be involved in joint planning and assessment (Chiang, 2002). Joint data sets should be developed to facilitate co-ordination and co-operation as well as to allow for more accurate estimations of prevalence (Chiang, 2002).

Assessment should be done by multi-disciplinary teams with specialist knowledge of rehabilitation, on-going assessment and the particular needs of those with ARBD such as psychiatrists and specialist practitioners (Jacques and Anderson, 2002) (Smith and Hillman, 1999) (Chiang, 2002).

Regular multi-disciplinary assessment is seen to be crucial for a number of reasons.

- To ascertain level, pace and areas of recovery
- To implement rehabilitation
- To decrease the possibility of inappropriate accommodation placements and inadequate reviews (as found by the Mental Welfare Commission)
- To address individual needs

Psychiatric, cognitive and functional assessment should be done every three months for up to one year (Smith and Hillman, 1999) and on-going for up to two years (Bruce and Ritson, 1998) (Jacques and Stevenson, 2000). Assessment procedures, whether inadequate or adequate, will have implications for prognosis, subsequent rehabilitation and appropriate accommodation placements for people with ARBD (Smith and Hillman, 1999).

An example of a case management service for people with ARBD is ARBIAS. They are commissioned by the Australian government to provide case management services and an assessment unit for people with an acquired brain injury in the state of Victoria. The Acquired Brain Injury Assessment Unit carries out neurological and neuropsychological assessments. They urge caution about relying solely on mini-mental state examinations (MMSE) as these are likely only to detect severe Alcohol Related Brain Injury (ARBI). Their Outreach Case Management services co-ordinate assessment, service planning, monitoring and advocacy which is provided in each region within the state.

Monitoring and Rehabilitation

Introduction

Although assessment and rehabilitation are under two separate headings, they are not meant to be thought of as two distinct phases in care rather than two aspects of a continuum.

Monitoring and rehabilitation encompasses a number of elements in the care pathway. It includes providing flexible care packages that support the person to maintain independence. For those that require a more supported environment, supported accommodation options may be more appropriate. In either case social and cultural stimulation to assist people continue everyday activities through day hospitals, day centres, evening care will be vital elements in maximising recovery and well-being. Of course there will be people who have a more severe impairment, those who show little or only slight signs of recovery that will require 24 hour care over a long period of time. On-going care, homes for life and palliative care will be taken up more fully in the next section, but whatever the service provision, the pathway of care will require to be monitored and reviewed by a lead team and or person.

It was beyond the scope of this review to investigate and report on the ways in which people with ARBD are currently monitored and rehabilitated by health and social care services in Scotland. We have little information about people who are cared for outside of hospital or care home settings although do have some information about monitoring and evaluation processes that take place in and around specialised care homes and hospital settings.

Current Position

Argyll and Clyde have developed services for people with ARBD. They currently provide support for people with ARBD through a range of regional and local services; from dedicated specialist units within a hospital (Inverclyde) to getting some help with shopping. The neuro-rehabilitation team provide services across the region, whereas other services are offered through local authorities. For example, Inverclyde supports a number of people with ARBD through its alcohol services, group and one to one counselling services and supported living. Renfrewshire and West Dumbarton offer home-based services, including a 'tuck in' service, laundry, personal hygiene, shopping, medication, meal preparation (Chiang, 2002).

Argyll and Clyde overall appears to be supporting around a third of their ARBD population in their own homes. The extent and nature of community support and provision elsewhere in Scotland could not be determined by this review. It would appear however, that many people diagnosed with ARBD are placed in some form of residential accommodation, most often care homes, (some of whom have specialist registration) and long term psychiatric wards. Therefore, most of what is described below is mainly in relation to how people with ARBD are monitored and rehabilitated in care home or in-patient facilities.

The Mental Welfare Commission raised concerns about the inappropriate placement and inadequate review of people with ARBD (Jacques, 2000). The placement of people in inappropriate care home settings relates, at least in part, to the lack of specialised and standardised assessment protocols and procedures (Jacques, 2000). People with ARBD in the Greater Glasgow area are often accommodated in nursing homes outside their Health board area because there is no provision in the community capable of meeting their long term care needs (unknown, 2002). (Although this situation is currently being addressed). The lack of move-on accommodation means many remain in psychiatric beds, with their progress unmonitored.

A number of care homes have specialist registration and or alcohol policies. Specific registration encouraged a climate of specialism, it promoted specialised assessment and rehabilitation (Jacques and Anderson, 2002) (Chiang, 2002). Specialised units and homes with mental health nurse reported fewer problems.

All specialised units within care homes surveyed by Jacques and Anderson reported a significant number of residents who had improved to a greater or lesser extent, again stressing the pivotal place of on-going assessment in care planning. However, medical and specialist reports were rarely made available to care home staff; having only sketchy details of the person impeded the re-assessment, rehabilitation and long-term care plans/needs for those with ARBD (Jacques and Anderson, 2002).

(Jacques and Anderson, 2002) found some individual examples of active rehabilitation towards lesser levels of care and independent living. Factors that appeared to facilitate success were:

- Alcohol abstinence
- A rehabilitation approach to activities of daily living, occupation etc.
- Active family involvement

Realistic choices and opportunities for those with ARBD to move to community living were constrained (Jacques and Anderson, 2002). A few individuals with ARBD had been discharged, one or two had returned (reason not apparent) but in most cases staff had no knowledge of the outcome of discharge.

However, having specialist registration, such as providing for those under 65 years only, often means that residents have to move on the basis of their age and not the basis of their needs (Jacques and Anderson, 2002). ARBD can occur at any age; arbitrary age thresholds negate the principle and practice of on-going care.

Care homes with specialist registration had differing alcohol policies; they varied from abstinence being a condition of stay to having the freedom to drink or not. Workshops with staff indicate that there can be conflict in maintaining alcohol free policies, this was in part related to the perception that the damage had already been done.

The geography of homes often meant reduced access to alcohol; although abstinence is desired, constrained access has implications for future management of drinking and rehabilitation into the community (Jacques and Anderson, 2002).

Only a quarter of the units in the survey had links with specialist (voluntary) alcohol services – those that did benefited from advice and positive educative approaches to alcohol management (Jacques and Anderson, 2002).

Lack of support for wider activities outside specialist units was common. This led to depression and deterioration in social functioning in ARBD residents, was compounded by no clear alcohol policy (Chiang, 2002).

Greater Glasgow are considering the commissioning of two 'core and cluster' units with ten beds each, two of which will be respite. Length of stay would be six months. They are also considering the development of two specialised day care facilities, with an outreach support team.

Developing Provision

Some studies have examined the rehabilitation outcomes of people with ARBD who have been placed in dedicated hospital in-patient units (Blansjaar et al. 1992) (Ganzevles et al. 1994) (Price et al. 1988) (Lennane, 1986). These studies alongside those that have investigated the care of people with ARBD have identified some rehabilitative principles and examples of good practice that can be drawn on.

The outcomes of 104 people with ARBD participating in a 12 week rehabilitation programme situated in a dedicated hospital in-patient unit were evaluated (Lennane, 1986). The programme involved regular routines of self care, work and leisure in an alcohol-free setting, memory therapies and AA meetings. Psychiatric symptoms such as depression and paranoia were also addressed. At two years after discharge 51% of the residents had been re-settled in supervised boarding houses, none managed to live entirely independently but

had remained there one to two years after leaving the rehabilitation unit. 32% were lost and could not be followed-up, 10% remained in or returned to hospital and 5% were dead.

Blansjaar followed up those people who had been accommodated in a specialist hospital unit, who had improved social functioning and who were discharged into their own homes (1992). They found that over half relapsed into alcohol consumption, discontinued medical treatment and neglected self-care, however, it is not clear whether those discharged received any kind of follow-up support (Blansjaar et al., 1992).

Follow-up support on discharge was the subject of the next study. (Price et al., 1988) compared those who received some form of discharge support and those who did not. Their findings are clear:

‘discharging patients with ARBD back into the community without any special provision regarding placement or rehabilitation is hazardous, a substantial number will die within a short period’

What these studies show is that hospital-based specialist units that provide structured rehabilitation and support on discharge can substantially improve the social functioning, health and recovery outcomes of people with ARBD. They also show that those accommodated in long-stay non-specialist accommodation had greater degrees of social deterioration than those who received encouragement to live independently within supported accommodation (Ganzevles et al. 1994) (Price et al., 1988).

Specific ARBD rehabilitative principles emerge from the literature:

- The promotion of participation in alcohol free socialising activities: these are exemplified in the work of ARBIAS who provide in-house activities to residential accommodation projects via recreational workers. Activities include, card and board games, walking groups, art and crafts, discussion groups, ten pin bowling, fishing, dancing, bingo, gardening and golf, as well as various social outings to the beach, shopping centres, swimming and theatre
- Structured personal hygiene routines, memory work and interventions that maximise the activities of daily living. Standards for assessment, re-assessment, medical management, alcohol management, memory impairment, residence and legal issues are suggested by Jacques and Anderson (2002)
- Specialist alcohol practitioners can advise on the day to day management of this aspect of care (Smith and Hillman, 1999). They have a role in the assessment of risk of relapse into drinking and subsequent management of alcohol related issues wherever the person with ARBD is accommodated. Rehabilitation should aim towards a structured alcohol free life (Chiang, 2002)
- The presence of a social and family network is seen as crucial in the process of rehabilitating those with ARBD to independent living (Jacques and Anderson, 2002)

The relatively intensive short-term nature of rehabilitation programmes provided by dedicated hospital units provide a significant but not exclusive element of care. As we have seen it is likely to take at least one year of abstinence and structured rehabilitative interventions to maximise and fully assess recovery. If abstinence can be maintained normal life expectancy is probable – long-term support or placement needs is then an important consideration. Placements and type of on-going care should be determined only after at

least 12 months of multi-disciplinary assessment. This means we need to look at a range of accommodation and rehabilitation options.

Carers, Crisis and On-going Care

Current Provision

Many people with ARBD seem to receive on-going care through care homes. Some of these will have specialist registration and or a dedicated unit/wing within the home. Some of these homes make mention of involving family and friends, providing rehabilitation interventions specific to ARBD and making active attempts to promote a return to independent but supported living.

Long term, respite and crisis care is provided in some areas by a range of voluntary organisations. These include, Turning Point Scotland, The Salvation Army, Penumbra, Crossroads and the Church of Scotland. The service provision depends on local health and social care commissioning policies. Health trusts and local councils may also provide services, usually within existing mainstream services such as hospital wards or care homes or sometimes in specialist dementia services. It is likely that existing dementia organisations such as Alzheimers Scotland, Action on Dementia may also provide support services in various forms to people with ARBD.

Developing Provision

Various supported accommodation options have been developed to provide for other similar but different population groups with complex and long-term care needs; such as those with acquired brain injury, learning disabilities, mental health problems and dementia. Supported housing schemes vary from specialist units attached to care homes², specialist units with a small number of residents sharing communal facilities such as Domus care, shared houses, a variety of sheltered or supported accommodation and supported living in ordinary houses. Small scale domestic units in dementia care have been discussed in the literature (Marshall, 1993) (Fahrenfort, 1997) (Murphy et al., 1994). These studies tell us something about the particular features that impact on quality of care in a positive way.

The main elements are: multi-disciplinary assessment, staff leadership and management, staff training, good practices in care planning and good building design (Schofield et al., 1995). These elements in combination with small scale domestic environments appear to facilitate quality on-going care for those with complex and long-term care needs. These types of care and the principles that underpin them could be adapted for meeting the needs of those with ARBD who require significant support over the medium and long term.

All care plan reviews should consider options for a return to independent but supported living, or less sheltered accommodation depending on level of improvement (Jacques and Stevenson, 2000). If independent living is not possible support in the community for adults with incapacity, provisions of guardianship and the Mental Health Act may need to be considered.

Accommodation options are always likely to be constrained. Independent but supported living is unlikely to be a viable option for some people and in these situations there should be attempts made to place those with ARBD together either in dedicated units within care homes, or in homes that specialise in the care of those with ARBD, who have alcohol policies and special registration (Chiang, 2002). Some people with ARBD will have high

² Small group living in a domestic style environment

dependency and or palliative care needs. ARBIAS provides a 'Slow to recover programme' for a small and generally younger group who have complex and high dependency needs. Palliative care in dementia could also be used to inform service developments.

The field of dementia care and acquired brain injury offers us some general principles in terms of assessment tools, care pathways, and person-centred approaches to care (Naidoo and Bullock, 2001) (Cunningham et al., 1998). These are models of care that can not only provide the immediate clinical diagnostic and assessment elements of care but also those that respond to longer term, not acute conditions. Some service developments that follow many or all of the general principles of person-centred and care pathway approaches to care have been evaluated.

These are often specialist multi-disciplinary community teams. Their focus tends to be to augment existing service provision by providing and/or facilitating early diagnosis, joint working to co-ordinate service provision, prevention of admission and support after discharge. (see appendix three). Most have an identified lead practitioner to co-ordinate referrals and help navigate the person through their care pathway. These are models of care that can be drawn upon to inform service development for people with ARBD.

4 Conclusions

Identification

Identifying an ARBD condition is problematic. It can be an 'invisible disability', masked by other associated problems such as depression or dementia, or just not recognised as a specific condition. Awareness needs to be raised amongst health and social care staff; staff in typical 'first point of contact settings' such as A&E and general practice need information on how to recognise an ARBD condition as well as information about the referral routes/options in their area. Information packs for carers, families, people with ARBD, case workers and other health and social care staff should be produced.

Identification can be more problematic through a lack of clarity in terminology. This review has discussed ARBD as a spectrum of conditions, whilst acknowledging that the different clinical diagnostic categories impact on the way we classify, assess and treat people. Although these various diagnostic criteria are required to make appropriate clinical interventions, there may be merit in having a standardised catch all term. It may enable further identification: those with an ARBD condition could be included in the health and social care statistics, which in turn would enable us to have a more accurate estimation of prevalence and need.

Identification is also hampered by a lack of standardised and specialised screening tools and assessment procedures. Many people with ARBD will not have confirmed diagnoses; they may be in touch with services but not be being treated as someone with an ARBD condition. Moreover, a lack of specialised assessment tools impedes staff from maximising recovery potential and preventing further damage. ARBD needs to be recognised as a preventable condition; a condition that can have significant degrees of recovery given the appropriate interventions and support.

Building Bridges

The concept of rehabilitation may be a way of building bridges between diagnostic classifications and service structures that often tend to segregate people according to their impairment or age. It seems a worthwhile exercise to highlight the shared similarities that exist between those with ARBD and other groups of people who have cognitive impairments and communication difficulties.

A person's age affects the way they are responded to by health and social care services. Whilst accepting the real world implications of these divisions we also need to recognise that the nature of an ARBD condition crosses these boundaries. People with this condition are likely to make repeated demands on services such as A&E, the police, general medicine and long stay wards. Early identification and intervention may reduce some of these demands.

We need to find ways of overcoming segregated service delivery, even in areas where specialist teams/units operate. For example Adult psychiatry services commonly see people with mental health and alcohol problems but will not generally see people with cognitive impairment. People with ARBD do not fit neatly into any existing category of care, they 'fall through the net' at multiple points in the care pathway. This seems to be related to a lack of information, a lack of specialist knowledge, a lack of agreed local care pathways and segregated service provision systems. We have limited information on how health and social care systems respond to ARBD, it is rarely mentioned specifically (occasionally as a dementia sub-group) in joint care plans, local strategies or national policies for mental health, alcohol or older people.

These divisions do not serve the needs of people with complex conditions such as ARBD, moreover they are likely to compound the 'falling through the net' scenario. A compartmentalised and inflexible system of service provision mitigates against service providers providing integrated, person-centred health and social care. ARBD needs to be recognised as a complex condition, four of the common characteristics cognitive impairment, chronic alcohol use, apathy and depression cross over existing boundaries.

The solution to complexity is often to create a specialist resource that can provide the range of expertise required. However, dedicated units are only one element in the continuum of care, which could provide a significant element of service provision in areas of high prevalence, though such facilities for low prevalence and or rural areas are unlikely to be a viable option. Moreover, if specialist services do evolve, part of their role will be to enhance and support mainstream services such as home care workers, general practitioners and primary care services – as well as providing their specialist services such as diagnosis, specialist assessment, managing challenging behaviour, alcohol detoxification, treatment and rehabilitation. This is likely to mean that existing services will be required to adapt or extend their service in order to meet the needs of people with ARBD.

The service models and examples of good practice described in appendix one seem to go some way to preventing inter-agency tensions that inevitably occur when trying to provide a range of services to people with complex and long term care needs.

The models of care and examples of good practice described tend to have particular features:

- A focus on augmenting existing service provision by providing and or facilitating an integrated response to early diagnosis and assessment
- Joint working to co-ordinate service provision, forward and contingency planning in care plans to help prevent admission and give support on discharge
- An identified lead practitioner to co-ordinate referrals and help navigate the person through their care pathway

These are models of care that can be drawn upon to inform service development for people with ARBD.

Examples of good practice in service provision specifically for people with ARBD can be seen in the work of ARBIAS and the services in Argyll and Clyde. Although the philosophy and system of care are very different, both examples have an identified team and or person is involved in managing the local care pathways of clients. Both services draw on a multi-disciplinary approach to assessment and rehabilitation. Both services are constrained by a lack of move-on/supported accommodation and support options, and Chiang notes that although the Argyll and Clyde service is a good example of practice it needs to be extended to provide local community-based support services (2002). ARBIAS explicitly operates a case management service, facilitating access to as well as directly providing services from the point of identification and assessment through to on-going care.

What these models of care and examples of good practice suggest is that a multi-disciplinary case management approach promotes a more person-centred approach to care. Having an identified lead person (rural/low prevalence) and or team (urban/high prevalence) may prevent people 'falling through the net'.

Bridging Gaps and Addressing Concerns

The relatively intensive short-term nature of rehabilitation programmes provided by dedicated hospital units provide a significant but not exclusive element of care. As we have seen it is likely to take at least one year of abstinence and structured rehabilitative interventions to maximise and fully assess recovery. If abstinence can be maintained normal life expectancy is probable – long term support or placement needs are then an important considerations. Placements and type of on-going care should be determined only after at least 12 months of multi-disciplinary assessment. This means we need to look at a range of accommodation and rehabilitation options. There is a need to bridge the gap between detoxification and or intensive assessment and decisions about long term support and accommodation needs.

Various supported accommodation options have been used for other similar but different population groups such as those with acquired brain injury, learning disabilities, mental health problems and dementia. Small-scale domestic environments with the desired elements of multi-disciplinary assessment, staff leadership and management, staff training, good practices in care planning and good building design appears to facilitate quality on-going care for those with complex and long-term care needs. These types of care and the principles that underpin them could be adapted for meeting the needs of those with ARBD who require significant support over the medium and long term.

This review was in part prompted by the concerns raised by the Mental Welfare Commission. If we are to go some way to addressing the problems of inappropriate placement and inadequate review, identification and assessment procedures will need to be clarified. People with ARBD need to be cared for as such; placing people with ARBD in generalised long term care settings will result in their social functioning deteriorating. Staff training is a crucial component of meeting the needs of people with ARBD that are currently accommodated throughout care homes in Scotland.

Providing adequate community support, through case management-type models of care may prevent crisis admissions and facilitate continuity of care. Having an identified person and or team may facilitate the monitoring, co-ordinating and reviewing the care pathways of people with ARBD. ARBD is a condition that demands flexible health and social care services and collaborative working. It challenges existing systems of care, though developments in pooled health and social care give some cause for encouragement. Meeting the needs of people with Alcohol Related Brain Damage requires us to take a whole systems approach, to move beyond disciplinary and service divisions, otherwise people with ARBD will continue to ‘fall through the net’ or remain in inappropriate care facilities with their situation unmonitored.

5 Key Findings and Issues for Consideration

ARBD is non-progressive if abstinence is maintained - No more alcohol means no more damage.

The damage sustained ranges from mild to very severe.

ARBD is best seen as a spectrum of disorders, merging into each other and overlapping

ARBD is not the same as having an intellectual disability or having dementia.

There are over 640 confirmed cases of ARBD in Argyll and Clyde and Greater Glasgow. This is likely to be an under estimation as many cases will not have been identified, diagnosed or being treated as such.

Early identification and appropriate intervention can promote optimum recovery

Specialised and standardised screening tools and assessment procedures need to be developed

The needs of people with ARBD may be more akin to people with acquired brain injury than those with dementia.

Awareness, information and training is needed for a range of groups: carers of and people with ARBD, staff in first point of contact settings and staff involved in the care of those with ARBD.

Alcohol specialists working in general settings could raise awareness of alcohol misuse, facilitate referral and provide immediate support for those who have problematic alcohol use.

Alcohol specialists should have a role in the assessment of risk of relapse into drinking and subsequent management of alcohol related issues wherever the person with ARBD is accommodated.

Guidance on the use of thiamine and community detoxification should be developed.

Full needs assessments should only be done after 3 months of abstinence (Jacques and Stevenson, 2000).

Social work should be involved in joint planning and assessment.

Joint data sets should be developed to facilitate co-ordination and co-operation as well as to allow for more accurate estimations of prevalence.

Assessment should be done by multi-disciplinary teams with specialist knowledge of rehabilitation, on-going assessment and the particular needs of those with ARBD such as psychiatrists and specialist practitioners.

The care planning and provision will vary in each area, however whatever the form of care an identified ARBD team or person could co-ordinate, track, and support the person with ARBD through the assessment, rehabilitation and placement process as well as facilitate regular multi-disciplinary reviews.

In areas of high prevalence consideration should be given to developing a multi-disciplinary specialist rehabilitation unit. However dedicated hospital units provide only one element in the continuum of care. We need to look at other options that could provide assessment, support and rehabilitation in the medium term. The degree of recovery, functional ability and support required will not be clear for at least one year after detoxification.

Detoxification may not always be an option but this should not negate the need for alcohol management (working towards abstinence), nutrition, vitamin treatment and on-going needs assessment led by an identified person and or team.

Treating those with ARBD as dementia cases to avoid accommodation problems is likely to result in further deterioration.

Care homes in which a climate of specialism is prevailing enhances social functioning, staff and people with ARBD in care homes benefit from having links with the care co-ordinator/lead person/multi-disciplinary team and specialist practitioners.

6 Future Studies

Further work is needed to identify numbers and needs in different localities. People with ARBD, many of whom will not have a suspected or confirmed diagnosis, will be located in many different settings. There will need to be clarification on terminology and how we classify the condition, which will help in identifying numbers. It may be a worthwhile exercise to try to identify the number of people with suspected and/or confirmed ARBD, and how local services provide for this population group to highlight the potential points in the system where more effective interventions might be made.

Appendix 1 - Pathways of Care: The Main Elements

(Scottish Needs Assessment Programme on Dementia, forthcoming)

<p>Information and awareness of care staff and the public to dementia Provide readily accessible information in range of formats and locations. Sessions could be commissioned from health education, primary health care, voluntary organisations, local authorities or colleges.</p>
<p>Health promotion and prevention Link with campaigns re. heart/strokes, and promote recognition of memory problems</p>
<p>Team development Establish teams for assessment, diagnosis and care management with old age psychiatrist, social worker, occupational therapist, psychologist, medical staff (includes geriatrician and general practitioner), and psychiatric nurse.</p>
<p>Specialist assessment and diagnosis Identify those who actually have a treatable cause of mental impairment, establish a differential diagnosis (e.g. Alzheimer's or vascular), treat concomitant medical (e.g. heart problems) and psychiatric disorders, identify the needs of carers and people with dementia, provide information and advice</p>
<p>Maintaining Independence Provide flexible, individualised care packages, which combine support to maintain independence with personal care, domestic help, shopping, cleaning, preparation of meals and practical help. Available also during evenings, week-end and overnight</p>
<p>Crisis response services Provide for people with challenging behaviour, for very complex combinations of medical and psychiatric care, and for sudden breakdowns in their support network</p>
<p>Intensive care and therapy Provide for people with challenging behaviour (e.g. agitation, hitting or yelling), and for people with very complex combinations of medical and psychiatric care, Provide short term services, in small care settings</p>
<p>Rehabilitation and monitoring of functioning For people with deteriorated functioning or who have the potential for improvement, for people who would benefit from a drug review or with depression and dementia, monitoring through carer and staff communication</p>
<p>Housing For those needing a safer & more supported environment including extra care housing use of technology for communication, monitoring and safety</p>
<p>Carer support Includes education, counselling, training, and respite, with flexible hours of operation (e.g. evening, weekend), availability at short notice, appropriate transport arrangements, in small, homely, domestic settings or at home</p>
<p>Social and cultural stimulation Support, especially in the early stages, to assist people continue everyday activities Provide day opportunities at home, in day hospitals, day centres, and evening care.</p>
<p>Ongoing care Provide homes for life, to maximise functioning and independence, ensure quality of life, and prevent excess disability. Needs small, homely, domestic environments with carer involvement, and with a compensating design, and which are culturally appropriate</p>
<p>Palliative care - Provide for end stages of dementia or dying of other causes</p>
<p>Care coordination and care management services Staff needed to coordinate and manage services for people with dementia and their carers, acting on a remit and to a plan formulated by a dementia team, and seeking the perspective of the carer and person with dementia.</p>

Appendix 2 - Case Examples

To highlight the diverse nature and character of an ARBD condition, case examples synthesised from real case examples described in the literature.

Jim is 52, he has worked in construction much of his life; drinking alcohol has been part of Jim's life for many years: drinking after work with his mates and social drinking at the weekend. He can't say exactly how much he drank each day but at a guess at 6 pints on weekdays and more at the weekend. For many years this did not appear to affect his work and nobody considered his drinking to be problematic. Jim then moved house and there were some changes in his duties at work, which generated some anxiety and mood changes in him. He found planning and organising increasingly difficult and distressing. Jim began to let friendships slide, bills were left unpaid and he had begun to lose weight. On a visit to his GP his depressed and agitated state as well as his lack of ability to recall and recount for recent events prompted a referral to a psychiatrist.

Davy is 60, unemployed for 4 years, and prior to that he worked for the council cleansing department for 15 years. Daily drinking has been a feature of Davy's life for many years. He occasionally has heavy binges, which have resulted in involvement with the local police and tension in the family. After becoming unemployed Davy's wife began to notice that Davy was sometimes confused and forgetful. He continued to drink daily and was becoming increasingly irritable and withdrawn. Davy did not come home one afternoon and two days later his wife was called to the local A&E department. Davy was in a toxic confusional state. A&E staff referred him to the alcohol team and he was assessed and admitted to hospital for detoxification. After 6 weeks Davy was discharged, and missed follow-up appointments with his CPN and alcohol worker.

These examples show how difficult ARBD can be to identify. The first point of contact with services varies and of course these examples do not tell us what happened after Jim was seen by the psychiatrist, or what happened to Davy after he disengaged with service providers. The likely scenarios are worth considering. What kinds of health and social care support are Jim and Davy likely to need to maximise their recovery potential, prevent further damage and maintain their independence? What services are they likely to receive at the moment? What services would be likely to meet their needs? How can we bridge the gaps between the two?

Appendix 3 - Models of Care: Examples of Service Provision and Good Practice that Can be Drawn On

- The Joint Dementia Initiative provides support to people with dementia in their own homes. Much of these services are provided by volunteers in partnership with paid staff from Falkirk, Stirling and Clackmannanshire councils. It includes, respite, day care, group work and individual support.
- The Coordination of Assessment and Resources in Dementia (C.A.R.D) in Glasgow facilitate the co-ordination of community care for people with dementia and their carers through the dementia care co-ordinator. The Dementia care co-ordinator is jointly managed by health and social services to co-ordinate the local care pathways of those identified and assessed (O'Neill, 2002).
- The Connections service for people with acquired brain injury provides flexible support to enable people to live in ordinary housing instead of hospital or supported accommodation and to develop community links (Cunningham et al., 1998).
- Acquired Brain Injury Services (ARBIAS) provide a specialised case management service to people with acquired brain injuries; they specialise in alcohol and substance-related brain injury. The case management service is aimed to assess and secure basic needs, it involves outreach assessment, service linkage, monitoring of service provision and advocacy. They provide a community access recreation project; recreation workers are employed to deliver to social and cultural stimulation activities to care homes and supported accommodation units that accommodate people with ARBD. They produce over 20 kinds of information leaflets for case workers, carers of and people with ARBD.
- SCOPE 2000 is a residential care resource, which provides a spectrum of care from post acute to rehabilitation and on-going care to people who have difficulties adjusting to hostels or unsupported communal living. Their clients have a range of mental health problems, though they specialise in 'Korskov's and dual diagnosis'. They offer a client centred approach, in which care provision is developed around the client's on-going and changing needs. A range of therapeutic, recreational, social, cultural activities and facilities are available. They also offer guidance to carers supporting people at home.

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