



UNIVERSITY OF
STIRLING

A Fuller Life

Report of the Expert Group on

Alcohol Related Brain Damage



SCOTTISH EXECUTIVE



Dementia Services
Development Trust



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The Scottish Executive commissioned the Expert Group.

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Glossary

Affective disorder	A mental health condition where disturbances of mood or emotional state are major features.
Alcohol and Drug Action Team	Multi agency partnership responsible for local alcohol problems and drug strategies. Its membership varies according to local needs and circumstances but will generally include representatives from the health service, local authority and voluntary sector, housing, the business community, drinks industry and trade, and the police.
Alcoholic dementia/alcohol related dementia	A full definition is given in Appendix C.
Alcohol problems	This refers to a whole spectrum of harm (actual or potential) to work, relationships, social position, physical or mental health. The amounts of alcohol involved will vary from individual to individual and over time.
Cognitive deficits	A loss in abilities related to knowledge, thinking and memory.
Community Health Partnerships (CHPs)	Are intended to evolve from Local Health Care Co-operatives (LHCCs). CHPs will build on the best practice of LHCCs and have a more consistent and central role in delivering health outcomes and patient benefits for local people. They will co-ordinate the planning, development and provision of NHS services and will create and strengthen local networks and partnerships with hospital and specialist practitioners and teams to deliver integrated health services.
Degenerative condition	A disease or disorder with a continuous and deteriorating progression.
Delirium tremens	A severe manifestation of alcohol withdrawal. Symptoms may include tremors, insomnia, nausea, hallucinations and confusion.
Dementia	A variety of illnesses and conditions which result in a global impairment of brain function and a decline in intellectual functioning, personality changes and behaviour problems.
Epidemiology	The branch of research/medicine that deals with the study of the causes, distribution and control of disease in populations.

Harm reduction	An addiction care policy based on the premise that reducing the amount of alcohol or drugs used by individuals may be a more effective strategy than the promotion of complete abstinence.
Harmful drinking	(Referring to adults) levels of drinking at which physical or psychological harm is already occurring.
Joint Future	The joint planning, assessment and provision of future services by different agencies to provide integrated care for individuals in Scotland.
Korsakoff's psychosis	A full definition is given in Appendix C.
Managed Clinical Networks	Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high-quality, clinically-effective services throughout Scotland.
Person-centred care	Care that respects the person as an individual and is arranged according to their needs.
Single Shared Assessment	A person-centred streamlined assessment led by a single professional with other specialist involvement as appropriate. The results should be acceptable to all professionals in social work, health and housing.
Socio-economic deprivation	A state of observable and demonstrable disadvantage relative to the local community or the wider society or nation to which an individual, family or group belongs.
Wernicke's encephalopathy	A full definition is given in Appendix C.

Executive Summary

There is concern that the needs of people with alcohol related brain damage (ARBD) and their carers are not being well met by current service provision across Scotland.

The Expert Group was set up by the Scottish Executive to achieve better understanding of the issues and problems involved, and to advise on how they can be addressed.

The Scottish Executive's *Plan for Action on alcohol problems* (2002) and *Alcohol Problems Support and Treatment Services Framework* (2002) provide the policy context for the work of the Expert Group.

The approach of the Expert Group is based on the recognition of the importance of listening to users and carers, and of looking holistically at individuals, populations and service systems.

Available information on incidence and prevalence of ARBD in local populations in Scotland is inadequate, but there are signs of an overall increase and of changing patterns of gender and age distribution.

There is evidence of a concentration of ARBD in areas of high socio-economic deprivation such as Greater Glasgow and the Argyll and Clyde area. ARBD is associated with poor nutrition and a range of physical and mental health problems.

Early identification of ARBD is important, and difficult. The diversity, complexity and fluctuation of individual needs mean that people with ARBD require a person-centred approach.

Early diagnosis and vitamin supplementation is important, especially for people whose ARBD results from Wernicke-Korsakoff's Syndrome.

The harmful effects of long-term excessive alcohol consumption, the potential for recovery and the crucial role of abstinence need to be better understood.

Stigma attaches to ARBD as a result of its triple association with alcohol, mental health problems and dementia, and this needs to be addressed at an individual, institutional and societal level.

There are ethical dilemmas in balancing an individual's right to autonomy with an acceptable level of protection for themselves and others.

The development of information, advice and health promotion services is of key importance in changing attitudes and practice in relation to people with ARBD.

Assessment of an individual's longer-term needs is possible only after a period of abstinence, and may take up to two years. It is important to avoid premature and inappropriate placement decisions, and to consider community living options.

Single, shared and comprehensive assessment is central to the provision of better health and social care for people with ARBD. Assessment must be ongoing and subject to continuous monitoring and review.

People with ARBD need both general health and social care services, access to specialised services and dedicated hospital beds. Service outcomes depend on individual characteristics and circumstances and, crucially, on where people with ARBD are first identified.

There are significant variations in the availability and nature of service provision both nationally and within local areas. Disjointed information about services reflects a lack of co-ordination between services, and a fracturing of care pathways for people with ARBD.

Appropriate sharing of information about individuals, between different professionals and agencies, is important but may be problematic.

Whole system approaches should characterise all levels of service planning and provision.

Inherent tensions exist, and need to be constructively resolved, between the need for high quality specialised clinical care on the one hand, and an approach based on community living on the other.

The provision of suitable housing or of an appropriate residential placement are of key importance.

Support is needed for family and other carers who play a vital role, especially in preventing social isolation and in helping their relative to achieve continued abstinence.

Achieving integrated and effective services involves both maximising existing resources and identifying new ones.

People with ARBD should receive the 'integrated spectrum of care' for which local Alcohol and Drug Action Teams are made responsible in the Scottish Executive's *Plan for Action on alcohol problems*.

The Joint Future approach to service planning and delivery is vitally important for improved provision for people with ARBD.

It should be noted that the needs of people with ARBD must be identified within Tiers 1-3 as well as Tier 4 of the *Alcohol Problems Support and Treatment Services Framework*.

Recommendations

There are many suggestions for action and improvement throughout the report. We have limited the number of formal recommendations in the hope that the report will provide a focus for action.

Health promotion and prevention

1. The Scottish Executive and Alcohol and Drug Action Teams should undertake work to increase public and professional awareness of ARBD, as part of more general work to raise awareness and promote mental health and well-being. This activity should highlight risk factors for ARBD such as poor nutrition, sustained heavy drinking, co-existing head injury, and the association with deprivation. It should also recognise high-risk groups such as homeless people, prisoners, older people, young people, women and people with co-existing mental or physical health conditions, and highlight the potential for recovery or improvement.

Challenging stigma and discrimination

2. The Scottish Executive should include work to challenge stigma and discrimination associated with ARBD through the ‘see me’ national anti-stigma campaign. This should target all sections of society with a view to increasing awareness and changing attitudes.

Improving information

3. Information and Statistics Division (ISD Scotland) should support local providers and planners in improving information for assessing need, planning and providing services for people with ARBD. This should link with current work to improve mental health information.

Planning and delivering better services

4. People with ARBD are likely to have needs that continually cross the boundaries between mental health services including dementia, acquired brain injury, alcohol problems and services for older people. Alcohol and Drug Action Teams, mental health services, acquired brain injury services, older people’s services and local health and social care partnerships, including the voluntary sector and other agencies, should work jointly and across professional and service boundaries to ensure appropriate and integrated service provision at local level for this group.
5. Each Community Health Partnership, Alcohol and Drug Action Team and local mental health service should be aware of those practitioners with expertise in relation to people with ARBD and their families. They may be attached to the Alcohol and Drug Action Team, community care team or mental health team depending on local care and clinical network protocols. These individuals should co-ordinate arrangements and provide advice on treatment and management and take the lead in reviewing current pathways, identifying opportunities to improve/redesign and involving all stakeholders, including people with ARBD and carers.

6. Planners and commissioners should develop, implement and monitor relevant local protocols between addiction, neuropsychology, rehabilitation, psychiatry, children, family and older people's services and primary care/local authority partners, and agree care pathways and appropriate referral and assessment arrangements. Local protocols should cover the use of vitamin supplementation.
7. Planners, commissioners and providers should ensure that people with ARBD and their carers and advocates are involved in developing and improving services.
8. Alcohol and Drug Action Teams should include action on service provision for people with ARBD in their Alcohol Action Plans. Specific services for people with ARBD are identified within Tier 4 of the Alcohol Problems Support and Treatment Services Framework but the needs of people with ARBD and those at risk of developing ARBD should be also be addressed in Tiers 1-3. Chapter 6 of this report identifies where the needs of people with ARBD can be built into service planning and local action at each Tier level.
9. The Scottish Executive should consider setting up a specialist network for service providers to promote quality service provision and exchange information about good practice.

Training

10. People with ARBD are likely to come into contact with a range of services including housing and homelessness services, the criminal justice system, social work services, primary care teams, hospitals, mental health and alcohol services/agencies. Appropriate staff training within these services, in identification of ARBD, its assessment and management will allow opportunities for early interventions to be maximised. Training should cover detoxification, care management, legal and risk issues, local care pathways and service options, service review and carer support, and should highlight the potential for recovery and rehabilitation.
11. Appropriate training providers should expand their provision of training for people involved in the care and management of people with ARBD.

Service standards

12. The Care Commission should consider the issues raised in this report in relation to the care and personal plans of people with ARBD residing in care homes, supported accommodation and hostels.
13. NHS Quality Improvement Scotland should consider the development of specific standards for the care of people with ARBD.

Evaluation and research

14. The Scottish Executive should commission the development of guidelines for monitoring and evaluation of services and interventions. As far as possible, people with ARBD should be involved in this work.
15. The research community should improve the evidence base in relation to epidemiology and population needs assessment, early identification, rehabilitation, community living and care home provision.

Preface

There is a significant stigma attached to both cognitive impairment and brain damage whatever the cause, but even more so when this appears to have been caused by drug or alcohol problems. Terms such as Korsakoff's and ARBD may have their place in professional discourse, but are often felt to be stigmatising by individuals. For instance we do not refer to smoking related lung cancer or road accident related brain damage. The Expert Group is aware of a plethora of terms used to refer to conditions which imply brain damage due to alcohol. This term is used by the Scottish Executive in its policy documents and in the remit for this group. The group raised this issue during the consultation process but no other acceptable term emerged and thus it is used in this report.

Chapter 1 Introduction

Key Points

- Concern that the needs of people with alcohol related brain damage (ARBD) and their carers are not being well met by current service provision across Scotland.
- The Expert Group was set up by Scottish Executive to achieve better understanding of the issues and problems involved, and advise on how they can be addressed.
- The Scottish Executive's Plan for Action on alcohol problems (2002) and Alcohol Problems Support and Treatment Services Framework (2002) provide the policy context for the work of the Expert Group.
- The approach of the Expert Group is based on recognition of the importance of listening to users and carers, and of looking holistically at individuals, populations and service systems.

1 The Context

- 1.1 For several years there has been concern that the needs of people with brain impairment related to alcohol misuse are not being adequately met by current service provision and organisation in Scotland (SNAP 2000). The SNAP report published in 2000 produced a needs assessment of people with Huntington's disease, Acquired Brain Injury and Early Onset Dementia. The Chief Medical Officer has recently identified key areas to be addressed for these groups following a review of progress since the publication of the report.
- 1.2 There are overlaps between the fields of alcohol problems, acquired brain injury (ABI) mental health and dementia. This report views the Alcohol and Drug Action Teams and their planning partners as having a lead role with regard to ARBD. However consultation confirmed that it is essential that those responsible for joint planning of services throughout the life course for ABI, mental health and dementia should ensure that the intersecting needs of those with ARBD are taken into account within the joint planning and commissioning of health, social care and housing resources. This will depend on the varying population needs and resources in different local communities.
- 1.3 This level of overlapping needs, corresponding confusion about health and social care responsibilities at different levels and lack of progress in addressing needs of people with varying degrees of ARBD was confirmed by the public consultation that preceded the publication of the Scottish Executive's Plan for Action on alcohol problems (2002).

- 1.4 The Plan recognised that individuals and services with responsibility for planning, commissioning and providing better services for people with ARBD confront a series of complex and interrelated issues. It stated that:

"...the Executive will set up an expert group to review models and approaches to providing services for people with alcohol related brain damage..."

- 1.5 Alcohol related brain damage (ARBD) refers to the effects of changes to the structure and function of the brain resulting from long term consumption of alcohol. There is no single cause of ARBD, which usually results from a combination of factors. These include the toxic effects of alcohol on brain cells, vitamin and nutritional deficiencies, head injury and disturbances to the blood supply to the brain.

2 Key Issues

2.1 Attitudes, Awareness and Misconceptions about ARBD

- 2.1.1 Alcohol occupies a complicated place in Scottish culture. It plays a part in most people's lives, and is viewed favourably by many sections of society. Even excess drinking is often tolerated until some consequent behaviour becomes unacceptable. At this point the person concerned may be perceived as undeserving, meriting exclusion and beyond help.
- 2.1.2 In relation to ARBD there is, in society in general and amongst some professionals, an apparent lack of awareness of the potentially damaging consequences of prolonged excessive drinking. On the other hand, there is often an unjustified pessimism about the possibility of rehabilitation or recovery for those who suffer them.
- 2.1.3 Such attitudes and perspectives may affect individuals in organisations responsible for screening, identification, service provision and service planning, because they are reluctant to make what feel like value judgements about someone else's drinking.
- 2.1.4 They also influence the way health and social care systems respond to people with ARBD: a group whose needs are not easily identified, who are often regarded as having 'brought the problem on themselves' and who may not have the capacity to understand the damage caused by their continuing to drink.
- 2.1.5 As a result it becomes less likely that the complications of alcohol problems will be detected or appropriately addressed until they are severe. Their impact then, both on service resources and on the lives of the people concerned, will inevitably be much greater.

2.2 Local Needs Assessment at Population Level

- 2.2.1 The number of people with ARBD is expected to increase, as a result of population trends and changing patterns of alcohol consumption. Current legislative and policy changes in relation to housing and homelessness will also lead people who are homeless to become more visible, and this too will have an impact on services.

- 2.2.2 Though prevalence figures are at present available for only a few areas in Scotland there is evidence that the condition is under-diagnosed in many local populations (Chiang, 2002).

2.3 Identification and Intervention

- 2.3.1 ARBD is often an invisible condition. This is due in part to the difficulty of distinguishing ARBD from other causes of brain damage, such as head injury or incipient dementia. It also, however, reflects the diversity of those affected and the fact that many of them are hidden in the community, or are living in inappropriate health or social care facilities.
- 2.3.2 There are legal and ethical issues, both at a policy level and for practitioners, about how to balance the rights of individuals with the need for intervention where there may be risk, for the individual themselves or others.

2.4 Diversity of Those Affected by ARBD

- 2.4.1 People affected by ARBD are a diverse group in terms of age, gender, lifestyle, family structure, social networks, drinking history, age of onset of ARBD, the presence of other mental health problems, physical or learning disabilities, neurological or medical conditions, employment history, cultural and spiritual background.
- 2.4.2 The point of entry to services for people with ARBD may be largely a matter of chance, but often determines their subsequent care pathway.
- 2.4.3 These factors influence the way services view and respond to an individual with ARBD. This was confirmed by the consultation with service users and carers carried out to inform the work of the Expert Group (Consultation & Involvement Trust Scotland, April 2003).
- 2.4.4 Individual characteristics and circumstances result in some people with ARBD becoming socially excluded, whilst the problems of progressive brain damage due to alcohol are often tolerated and masked.

2.5 Complex and Fluctuating Needs of People with ARBD

- 2.5.1 The needs of people with ARBD span the boundaries between many services and professional disciplines: primary, secondary and tertiary health care, social care, mental health, dementia, including early onset dementia, acquired brain injury, neurological conditions as well as alcohol problems.
- 2.5.2 An individual's needs will change and fluctuate, requiring ongoing assessment, monitoring and review.
- 2.5.3 They will depend crucially on detoxification and subsequent maintenance of abstinence.

2.6 Lack of Integration in Service Systems and Organisation

- 2.6.1 Policy makers and planners are unclear where ARBD fits within different organisational and financial systems, and what service models are effective, or outcome measures appropriate.

- 2.6.2 This results in a fragmentation of systems and services, and different definitions and understandings of the conditions and diagnoses involved.
- 2.6.3 Existing service boundaries have tended to result in provision for people with ARBD being compartmentalised in either health or social care services. People may remain inappropriately in a particular type of service, e.g. addiction, acquired brain injury, mental health or dementia.

3 Policy and Practice Background

- 3.1 Practitioners and service providers were aware of these issues for some time. Recent policy developments have led to some targeted changes in services for people with ARBD. They have included reducing the number of long stay beds in hospitals, more emphasis on care in the community, better identification of specific emerging populations such as people who are homeless and roofless or living in hostel accommodation, and more emphasis on responsible and integrated mental health services.
- 3.2 The Scottish Executive's Plan for Action on alcohol problems sets out the aim for the provision of support and treatment services as:
 - “To provide equitable, accessible and inclusive services to address the needs of those who experience problems with alcohol and those affected by others' alcohol problems” (par. 5.1).
- 3.3 The Plan acknowledges that there are gaps in current provision, and disparities in treatment and support services, for people with alcohol problems across Scotland.
- 3.4 It highlights particular concerns about how to respond effectively to the needs of people with ARBD and requires local Alcohol and Drug Action Teams to publish three-year local action plans.
- 3.5 The Alcohol Problems Support and Treatment Services Framework provides guidance on the support and treatment elements of these local action plans. It adopts a four-tier structure, covering services for the whole community through to services for people with highly specialised needs.
- 3.6 Specific services for people with ARBD are identified within Tier 4 i.e. services for people with highly specialised needs. The Alcohol Problems Support and Treatment Services Framework recognises, though somewhat in passing, that the needs of people with ARBD, or at risk of developing ARBD, should be considered at all tiers of the system.
- 3.7 The Alcohol Problems Support and Treatment Services Framework emphasises the importance of Alcohol and Drug Action Teams and their constituent agencies incorporating current knowledge about effective service provision and good practice in their planning and commissioning.
- 3.8 The Expert Group on ARBD, set up under the terms of the Plan for Action on alcohol problems is seen as contributing to this process.

4 The Expert Group

4.1 Terms of reference

These were set by the Scottish Executive:

- To advise on establishing numbers and characteristics of people in local areas across Scotland.
- To identify and advise on good models of service.
- To provide guidance on how to promote the planning and delivery of such services, within the context of the Alcohol Problems Support and Treatment Services Framework, and the Joint Future Group initiatives etc.
- To promote quality services through effective monitoring and evaluation.

4.2 Objectives

More detailed objectives were agreed by the Expert Group:

- To achieve a good understanding of the problems faced by service users and their carers, and thus to identify and describe the range of needs.
- To achieve a good understanding of those who provide services, and thus to identify and describe these services.
- To identify current knowledge on establishing the numbers and characteristics of people with ARBD, and highlight the difficulties of ascertainment.
- To review available information on the range of service provision in the UK and in other relevant countries.
- To identify the ways in which services currently respond at different levels or tiers of service.
- To make proposals on a spectrum of quality service models to meet health, social care and housing needs for the population addressed.
- To take into account the different service delivery problems in urban/suburban/rural and remote areas and their implications for both specialist and mainstream services.
- To provide guidance on the planning and delivery of such services, including training programmes.
- To address issues of effective monitoring and evaluation of services.
- To involve a range of other stakeholders in the process of discussion, with a view to seeking consensus as to the way forward.
- To produce a report for wider consultation.

4.3 Approach

The approach of the Expert Group is underpinned by the service principles set out in The Plan for Action on alcohol problems (2002):

- Confidentiality
- Accessibility
- Ongoing rather than time limited
- Holistic - encompassing the context and causes of alcohol problems

- Understanding and supportive, with a non-judgmental attitude
- Taking a positive approach
- Tailored to the needs of the individual
- Joined up across agencies and other services
- Designed with input from service users, carers and communities and
- Addressing the needs of other family members

4.4 Perspectives

The following perspectives drove the work of the Expert Group:

- Ordinary lives
- Choice and control
- A whole person approach
- A life span perspective
- Integrated services - health/social work and housing
- Spectrum of services
- Quality of life

4.5 Ways of Working

- A literature review focusing on identifying the needs of people with ARBD (MacRae and Cox, 2003) was carried out before the first meeting. This included discussion on population needs assessment.
- A previous small study of long-term care provision (Jacques and Anderson, 2002), and work by the Mental Welfare Commission and the Dementia Services Development Centre on guardianship for people with ARBD, also contributed to the knowledge base.
- The Expert Group created opportunities for networking with a range of groups and individuals through conferences, workshops and personal contacts.
- The Expert Group gathered information on services and care pathways for individuals with ARBD from a wide variety of sources including consultations with professionals, and experiences of members of the Expert Group.
- A service questionnaire was sent out to over 60 services, in the UK and internationally, to further inform the deliberation of the Expert Group.
- Of particular value was the consultation with service users and carers, funded by the Scottish Executive and carried out by Consultation and Involvement Trust, Scotland (April 2003). One of the first actions of the Expert Group had been to discuss and agree the method of user and carer consultation to ensure that the voices of service users and carers informed the understanding of the group and any recommendations it might make.
- By taking a developmental approach to its work and by involving a wide range of professionals, planners, commissioners, service providers and service users the Expert Group reached a broad consensus about perceived problems and possible solutions.

4.6 Boundaries

- The Expert Group agreed that it was important to address both the shared and specific needs of people of all ages.

- A separate working group considered the needs of those with co-occurring substance misuse and mental health problems (Scottish Executive 2003).

5 The Report

5.1 Aim

- The aim of the report is to address the problems and issues identified in the terms of reference set out by the Scottish Executive.
- The report identifies key areas of action, makes recommendations and calls attention to areas where further research and evaluation are needed. Wherever possible the report draws on research evidence and emerging needs assessment work in local areas.
- It should be noted that the report is not a summary of research. Those interested in the research background are referred to the associated literature review (MacRae and Cox, 2003) and consultation with users and carers (Consultation & Involvement Trust Scotland, April 2003).

5.2 Target Audience

- The report is addressed primarily to those responsible for planning and commissioning services to assess local requirements and identify gaps in services.
- The report is also addressed to service providers in the statutory, voluntary and independent sectors who wish to provide better for, and encourage others to consider the needs of, people with ARBD.
- An equally important aim, however, is to ensure that the report is accessible to a wider audience of front-line staff who may come into contact with people with, or at risk of ARBD, service users and carers. A glossary of terms is included (see page v).

5.3 Structure of Report

Chapter 2 describes what is meant by ARBD; the importance, and difficulty, of early identification; ethical issues raised for policy and practice; problems in establishing incidence and prevalence; and the epidemiological information available, and not available, for local populations and Scotland as a whole.

Chapter 3 outlines the principles of a person-centred approach to understanding individual need; the effects of stigma associated with ARBD; the variety and complexity of the social and health care needs individuals have at different stages of the assessment process; and the importance of access to both general and ARBD specific services.

Chapter 4 stresses the role and importance of information, advice and health promotion; the many factors that influence outcomes for an individual including where they are first identified; the diversity of service responses they may encounter; and the appropriate sharing of relevant information between service providers.

Chapter 5 explores in detail the components and stages of an individual's care pathway; gives practice examples from a variety of settings across the UK; and underlines the importance of whole-system thinking, single shared assessment and housing provision in the community.

Chapter 6 summarises the Expert Group's views about how to achieve better services for people with ARBD and their carers within current service arrangements, practice models and policy frameworks; describes the legislative structure for regulating quality and standards for people with ARBD in residential care homes; and discusses training needs and provision.

Chapter 7 sets out the Expert Group's conclusions.

Chapter 2 - ARBD in Scotland

Key Points

- The harmful effects of long-term excessive alcohol consumption, the potential for recovery and the crucial role of abstinence need to be better understood.
- There are ethical dilemmas in balancing an individual's right to autonomy with an acceptable level of protection for themselves and others.
- Early identification of ARBD is important, and difficult.
- Available information on incidence and prevalence of ARBD in local populations in Scotland is inadequate, but there are signs of an overall increase and of changing patterns of gender and age distribution.
- There is evidence of a concentration of ARBD in areas of high socio-economic deprivation such as those within Greater Glasgow and the Argyll and Clyde areas.

1 What is ARBD?

- 1.1 This report uses the term Alcohol Related Brain Damage (ARBD) to refer to the effects of changes to the structure and function of the brain resulting from long term consumption of alcohol. There is no single cause of ARBD, which usually results from a combination of factors. These include the toxic effects of alcohol on brain cells, vitamin and nutritional deficiencies, head injury and disturbances to the blood supply to the brain. ARBD encompasses a range of conditions characterised by impaired mental function such as Wernicke-Korsakoff's syndrome, alcohol related dementia., alcoholic dementia and alcohol amnesic syndrome. As Jacques and Stevenson (2000) suggest, ARBD is best seen as a spectrum of disorders, which merge and overlap with each other (see Appendix C for clinical descriptions.)
- 1.2 The common characteristics of ARBD are disorders of cognitive functions, which interfere with the individual's ability to lead an independent life. Cognitive functions, which are impaired, may include memory, attention, planning, judgement and processing new information. In addition, change of personality and behaviour are commonly associated with ARBD. Thus the affected individual may be apathetic, unmotivated and neglectful of personal care or disinhibited and impulsive. Chapter 3 of this report describes health needs in more detail.
- 1.3 Long term excessive consumption of alcohol has a harmful effect on almost all organs in the body. Those particularly affected include the brain and the gastro-intestinal system. The effect of protracted excessive consumption on the brain varies from person to person. The reasons for this are not yet clear, but theories include the style of alcohol consumption - binge versus chronic consumption - and differences in individual susceptibility.

- 1.4 Excessive consumption of alcohol may also have a more generalised effect on the whole brain; causing shrinkage, visible via scanning, and a clinical picture that more resembles dementia. This picture is more common in women, and carries a better prognosis for cognitive recovery as long as abstinence from alcohol can be ensured (Smith & Hillman, 1999).
- 1.5 There are many unanswered questions about the genesis of ARBD, about prevention and about treatment once the condition is established.

2 The Crucial Role of Abstinence

- 2.1 What is clear is that once the diagnosis is made, in whatever setting, abstinence from alcohol in the long term is essential to optimise cognitive recovery. People with ARBD, their carers and all agencies involved in assessment, care planning and service provision of this condition must be aware of this.
- 2.2 Once the condition is established, minor amounts of alcohol could cause significant worsening of cognitive functions and delay effective rehabilitation. This has important implications for service planning and provision, and for carers, care staff and professionals.
- 2.3 People with ARBD frequently continue to have a compulsion to drink, even if very severely affected. This can be the most crucial issue in deciding eventual placement for a person with ARBD. Thus a mild to moderately affected individual may, after assessment, be considered unsuitable for supported living in the community due to his perceived lack of judgement about the risk of deterioration should he drink.
- 2.4 This issue contains an inherent ethical dilemma. Once a patient has made some cognitive recovery a judgement needs to be made about whether he or she is competent to make the decision whether or not to drink and risk a catastrophic worsening of their condition.

3 ARBD - Capacity and Ethical Issues

- 3.1 The tensions that exist in society between protecting a vulnerable individual's well-being, and protecting that individual's rights, are most clearly exposed by people with ARBD. A person who retains capacity has the right to make their own decisions, even where the outcome leads to significant risk. A person whose capacity is significantly impaired can expect to be protected by someone else from the risks resulting from their impaired capacity for decision-making. Between these two poles there are many grey areas, which cause distress for individuals and families and challenge professional skills.
- 3.2 The Adults with Incapacity (Scotland) Act 2000 is a major piece of legislation that makes provision for managing the property, financial and personal welfare of adults who are incapable by reason of 'mental disorder' or inability to communicate. The term 'incapacity' is used as a legal and medical term. ARBD, as does dementia in general, comes under the umbrella of 'mental disorder'.

- 3.3 Incapacity is not, however, an all or nothing concept. For interventions to be authorised under this Act there must be a specific correlation between the power sought and the nature of the adult's incapacity.
- 3.4 The Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Scotland) 1984 Act provide the major means in Scottish civil law for overriding an adult's wishes in respect of treatment and care. The Mental Health (Treatment and Care Scotland) Act will replace the current Mental Health Act within the next two years. For more detail on this legislation see Appendix A.
- 3.5 There are, as already noted, particular ethical issues related to society's view of alcohol and people who drink. The extent to which someone (not being diagnosed with ARBD) who is dependent on alcohol makes a competent decision to continue drinking is a matter of debate. Many people would not view drinkers who continue to drink harmfully as having sound judgement before the onset of ARBD.
- 3.6 As long as an individual retains some capacity to change their drinking behaviour it is not acceptable for the state, or anyone else, to intervene compulsorily to prevent even a reasonably predictable downward spiral. Ironically, once damage leading to cognitive impairment has been done to the brain, proactive intervention can be legally sanctioned; proactive intervention may then be possible.

4 Risk and ARBD

- 4.1 Society appears more prepared to tolerate risk for people with cognitive impairment due to ARBD than for people with other types of dementia. This may reflect a lack of care, and a belief that people with ARBD have brought their problems on themselves. Many people with ARBD are homeless. Many others lead inactive and unfulfilled lives in care homes. Care providers have to balance risk and independence for people with ARBD.
- 4.2 If less restrictive care arrangements are considered by multidisciplinary reviews it may be difficult for the individual with ARBD to remain abstinent. Powers under Adults with Incapacity (Scotland) Act 2000 can be obtained to control access to alcohol and these may be important in underpinning a care plan deemed essential to protect an individual, but practitioners are often reluctant to apply for these and they can only be enforced with continual supervision.

5 Good Practice

- 5.1 The principles underpinning the Adults with Incapacity Scotland Act require a relatively sophisticated analysis of the nature and effect of incapacity, so that compulsory measures are only instigated for areas directly affected by the impairment, and only when no other avenue could provide protection.
- 5.2 Regular reviews should be supported by re-assessments to capitalise on any improvements resulting from abstinence, good nutrition and effective rehabilitative programmes. Care arrangements should then be altered accordingly.

- 5.3 The concept of reciprocity should always be respected: that if someone's freedom to decide for themselves is removed, there is an ethical responsibility to ensure that any imposed care is appropriate.
- 5.4 The issues in working with integrity with people with ARBD are no different from other practice dilemmas: staff need to be aware of their own values, beliefs and prejudices. They should be willing to engage openly with service users without discrimination, find the time to listen to the person's own view and be willing to respond to awkward questions. Providing clear information about ARBD and available treatment approaches is also important.
- 5.5 There is need for a multidisciplinary commitment to sharing skills, knowledge and practical approaches. The dilemma of balancing the individual's wish for autonomy against an acceptable level of protection needs to be made explicit.
- 5.6 There is increasing recognition of the need for advocacy services, and these are especially relevant for people with cognitive impairment and communication problems. It is important that advocacy services are made available to people with ARBD, particularly when decisions are made about planning for their treatment and care and arrangements for accommodation, support and rehabilitation.

6 Understanding the Natural History of the Condition

- 6.1 Identifying people with ARBD and planning services for them is made difficult by the wide range of individual patterns and outcomes.
- 6.2 People with ARBD present in one of the following phases, which impact on their assessment and the effectiveness of interventions:
- relatively recent onset and a rapid recovery (over a few months) to a level where a lesser level of care/support may be appropriate
 - a perhaps more chronic condition and a slow gradual improvement over two or more years
 - those who show no signs of improvement at all
 - those who are at the end of their improvement and still significantly impaired.
- 6.3 Mistakenly seeing ARBD as a static or degenerative condition may prevent care planners from providing activities that would retain or extend the person's capabilities.
- 6.4 Smith and Hillman (1999) note that the recovery outcome is split into quarters: 25% make a complete recovery, 25% making significant recovery, 25% making slight recovery and 25% making no recovery. Recovery is measured in terms of improved cognitive functioning, physical ability and quality of life. It is important to emphasise, therefore, that 75% of this group of people will have the chance of some recovery if they are identified at an early stage and appropriate intervention offered.
- 6.5 It is, however, difficult to predict outcomes and recommend appropriate placement of an individual in the early stages of assessment due to uncertainty about the extent of recovery that may occur.

- 6.6 Identifying this population and providing effective interventions is difficult. (MacRae and Cox 2003). Doing so depends on the capacity of services to undertake initial and ongoing assessment, the availability of skills and expertise to carry out treatment and rehabilitation and, finally, factors relating to the particular individual such as transience, continued alcohol intake and the motivation to engage and respond to treatment. Further discussion on these points can be found in Chapter 4.

7 Establishing the Needs of Populations

- 7.1 Very little epidemiological work has been done in relation to ARBD. Major studies of dementia in younger people have usually relied either on medical case note reviews or on a two-stage screening process as part of a larger population study. The second of these approaches has not been adopted with ARBD, but some smaller studies based on case note review have been undertaken. Research suggests that ARBD accounts for 10% of the dementia population (Lishman, 1990), and for 12.5% of dementias in people under 65 (Harvey et al, 1998). The peak age of those with ARBD is between 50 and 60 years of age. Work by the ISD in producing local alcohol profiles and further work by ISD on hospital admission codes should provide more accurate information in Scotland.
- 7.2 There is some evidence to suggest that the prevalence of ARBD could be increasing (Jacques and Stevenson, 2000; Smith and Hillman, 1999) although estimates differ widely. A general increase in alcohol use, changes in treatment and increased awareness of the condition could explain the current figures.
- 7.3 Prevalence rates are likely to vary not only internationally, and between Scotland and England, but also between Scottish regions. It seems likely that the prevalence of ARBD is greater in areas with a high level of alcohol-related health problems, and in those with high levels of socio-economic deprivation. (Ramayya and Jauhar 1997)

8 Identifying People with ARBD in Local Populations

- 8.1 Identifying individuals who may be in need of a more detailed assessment for possible ARBD in local populations is problematic. There are dangers in some individuals being designated with ARBD before a period of abstinence has taken place. Equally there are dangers in missing individuals who may have the condition and would benefit from further assessment. Screening of individuals is difficult and much more work needs to be done with regard to epidemiology and population needs assessment.

Alcohol Related Brain Damage Screening Tools

There does not appear to be a standard screening tool for alcohol related brain damage. This is a complex area and there are various forms of ARBD and individuals can display different symptoms. Diagnosis of people with dementia is difficult as noted below on Korsakoff's syndrome for example.

There have been a number of research studies which have used a combination of screening tools. For example some studies have used an alcohol screening tool such as CAGE alongside cognitive impairment tests such as the Cognitive Abilities Screening Instrument.

The Mini Mental State Examination (MMSE) is the most commonly used test for complaints of memory problems or when a diagnosis of dementia is being considered. This has also been used alongside alcohol screening tools to investigate the relationship between dementia and alcohol in research.

Many alcohol screening devices have been designed with younger respondents in mind and have lower sensitivity among older people. AUDIT, for example, is not considered suitable for use with older people and other instruments, CAGE and MASTG have been suggested as more suitable for this population group (Dawe et al 2002).

In the Argyll & Clyde NHS Board area a case study approach to case finding (not screening) for a population study targeted health and social care providers. It described key characteristics of cognitive functioning and alcohol history of an individual with ARBD and asked whether service providers recognised these in their particular population. This process acted as a high level filter of a larger population and reduced the overall assessment capacity required to identify the patient group.

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Unpublished thesis

- 8.2 Studies relying on medical case notes are often problematic, and especially so for people with ARBD. As already seen, people with ARBD may be identified at different stages of the condition, in all age groups and in a wide range of settings. These include acute medical services, psychiatric hospitals, addiction services, the homeless population, nursing homes, supported accommodation and community settings, in each of which information will be recorded in a different and often incompatible way.
- 8.3 In addition, individuals may come to the attention of one service through a number of others (housing, local social work, employment or benefits services, primary care, voluntary organisations and criminal justice agencies, for example); and this may happen as a result of their social circumstances, or of behaviour due to their drinking or cognitive impairment.

- 8.4 Diagnosis of ARBD is difficult, as already noted, especially in an individual who continues to drink. It may require the exclusion of other disorders or co-existing conditions. Often only a 'clinical suspicion' of ARBD will be found. A confirmed diagnosis only becomes possible following detoxification and thorough assessment.

9 Prevalence and Incidence of ARBD

- 9.1 Without accurate diagnosis and assessment it is not possible to conduct epidemiological studies of the incidence and prevalence of ARBD.
- 9.2 Scotland has pockets of high socio-economic deprivation, coupled with high alcohol-related health problems, such as those within Greater Glasgow and Argyll and Clyde.
- 9.3 Prevalence of ARBD in both these areas, and in Scotland more generally, appears to be increasing. In Argyll and Clyde, which is thought to have the most accurate prevalence figures, Chiang (2002) suggests 7 per 10,000. A GP practice in Inverclyde established a prevalence rate of 14.4 per 10,000, male to female ratio 6:1, within a patient list of 4850.
- 9.4 Local differences in alcohol consumption and levels of deprivation are likely to account for some variation in estimates. The studies establish that Argyll and Clyde have 293-303 confirmed cases of ARBD (population base - 1999, 425,600), with a further 40 suspected. Greater Glasgow has 341 confirmed cases of ARBD (population base - 1999, 906,000).
- 9.5 The figures suggest either that Argyll and Clyde has a much higher prevalence rate of ARBD than Glasgow, or that people with ARBD have not been effectively identified in Glasgow (a more socio-economically deprived area than Argyll and Clyde). Ongoing work on the prevalence of ARBD in homeless and primary care populations in Glasgow should provide a more accurate picture in the near future. However, it should be noted that socio-economic deprivation may exist in rural and remote areas, though it is sometimes harder to identify
- 9.6 Due to their high levels of socio-economic deprivation and alcohol-related problems, these areas may have higher prevalence rates than other less deprived areas where there are lower levels of problematic alcohol use.
- 9.7 The current, imperfect understanding of the prevalence of ARBD in Scotland is that there has been an overall increase in recent years. Smith and Flannigan (2000) note that ARBD admissions to psychiatric hospitals increased sharply between the 1970s and the 1980s but have since stabilised. There is a suggestion that there is a diagnostic under-reporting due in part to the wide variety of placements where individuals may be living.
- 9.8 It is necessary to increase staff awareness of the possibility of ARBD in these settings, in order to establish incidence and prevalence in particular areas. This in turn will improve access to services for the individual.
- 9.9 More research is needed to address the problem of population assessment for people with ARBD (Harvey et al 1998); and epidemiological studies of alcohol use, and of social conditions related to alcohol, need to be conducted with ARBD in mind.

- 9.10 The general trend is that the prevalence of ARBD is increasingly recognised in certain areas of Scotland, particularly in those characterised by multiple deprivation. But ARBD affects individuals in all strands of society. In some cases families conceal their relative's problems; and awareness of the difficulties that may be attributable to ARBD is low among some front line workers in health and social services. ARBD must, therefore, be regarded as a largely undetected or hidden disorder that requires specific epidemiological study.

10 Issues Regarding Sub-populations

- 10.1 Although at present 75% of the reported ARBD population are men (Harper, 1983), increasing numbers of women are coming into contact with services. Overall in Scotland it also appears that the age of presentation to services is lower than it used to be. The increasing proportion of women, and the lower age at presentation, probably reflects changes in alcohol use in the Scottish population over the past 20 to 30 years.
- 10.2 The female population requires special consideration owing to their increasing number, the evidence of damage at an early age and the high levels of reported histories of sexual abuse by women attending addiction services.
- 10.3 Women's 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 and it is often after a considerably shorter drinking history than men (10 and 20 years respectively (Cutting, 1978).
- 10.4 This means that the small number of women who are vulnerable to developing an ARBD condition are likely to do so earlier than their male counterparts; it may also mean that we will see a rise in the number of women developing ARBD. It is not clear whether women develop ARBD at a younger age than men or whether these cases result from changing patterns of drinking among women.
- 10.5 Services should also note the increased presentation of men at a younger age. Assessment and ongoing care will have to take account of the needs of this younger client group. According to the literature ARBD can become apparent in people from their twenties to their nineties (Chiang, 2002).
- 10.6 There is a relationship between the effectiveness of approaches to identification and age of presentation. For example, the Alcohol Related Brain Injury Service in Australia (ARBIAS) places great emphasis on early identification and intervention, and this emphasis may account for the fact that over half of their clients are between 35-54 years of age. In the UK, and in Scotland, it is estimated that most of the people with ARBD who are known to services are in their fifties (Elleswei, 2000, Price et al, 1988) or between 60-64 years (Chiang, 2002).
- 10.7 Within sub-populations such as people with learning disabilities, older people and members of ethnic minority groups, homeless people or those in the criminal justice system, there may be distinctive patterns of ARBD prevalence and incidence.
- 10.8 The number, characteristics and distribution of people with ARBD are also likely to differ in populations in rural, urban and sub-urban areas.

Chapter 3 - Understanding Individual Needs

Key Points

- Due to the diversity, complexity and fluctuation of individual needs people with ARBD require a person-centred approach.
- Stigma attaches to ARBD as a result of its triple association with alcohol, mental health problems and dementia; and this needs to be addressed at an individual, institutional and societal level.
- Accurate assessment of an individual's longer-term needs is possible only after a period of abstinence, and may take up to two years.
- It is important to avoid premature and inappropriate placement decisions, and to consider community living options.
- ARBD is associated with poor nutrition and a range of physical and mental health problems.
- Early diagnosis and vitamin supplementation is important, especially for people whose ARBD results from Wernicke-Korsakoff's Syndrome.
- People with ARBD need both general health and social care services, and access to specialised services and dedicated hospital beds.

1 Towards Person-centred Services

- 1.1 People with ARBD have a range of individual needs, social and medical, and it is important that these are comprehensively assessed and due consideration is given to both.
- 1.2 Increasingly health and social care practice is moving towards person-centred solutions for people with disabilities. In the mental health field a range of services enable many people to lead independent and fulfilling lives in the community. In many other areas too, rehabilitation now takes place in the community; and the principle of community living - that services should be delivered in someone's home or a homely environment - is well established.
- 1.3 People with ARBD have often been seen as a difficult group to support in their own homes owing to the variety and complexity of their social and medical needs, and the range of possible or perceived risks. This has sometimes led to people being placed and remaining in age-inappropriate residential facilities.

2 Principles of Person-centred Support

2.1 The principles underpinning person-centred services include:

- Dignity
- Respect
- Choice
- Participation
- Interventions in the best interests of the individual
- Home based support or the least restrictive alternative
- Holistic approach to care packages

3 People with ARBD in Society

- 3.1 Following initial diagnosis and detoxification from alcohol, the person with ARBD is likely to require help with the social management of their situation. Abstaining from alcohol and continuing to take Thiamine as a precaution is the only clinical treatment that can reverse the effects of ARBD. Social needs should not, however, be viewed in isolation from the need an individual may have for ongoing medical treatment.
- 3.2 It is clear that the time frame within which a person with ARBD is referred to community-based services is crucial in the development of effective support services. It is important to make a distinction between someone recently diagnosed, and someone who has either had insidious onset of ARBD, or has been institutionalised for a number of years - usually in care homes or hospital.
- 3.3 There is evidence that there is a two-year window for recovery after an initial diagnosis of ARBD, and that it is unwise to make long-term decisions too early in the process.
- 3.4 People with ARBD may have difficulty in gaining access to services due to stigma, anti-social behaviour (if still drinking), previous debts, poor budgeting skills, inability to maintain/develop social relationships and other factors. Social exclusion, characterised by inadequate social support and family disintegration as well as poor nutrition (Chick, 1996, Health Bulletin), may thus be associated with the presence of ARBD. It may also complicate the services' ability to prevent, assess and manage resulting problems.

Case Study

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 six pints on weekdays and more on 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. These changes generated some anxiety and mood changes in Jim. 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.

The names and details of the case studies
have been changed to preserve confidentiality.

4 Stigma and ARBD

- 4.1 There is anecdotal evidence of people with ARBD facing stigma within services, either through exclusion from them or from being 'bounced' between services.
- 4.2 People with ARBD face three levels of stigmatisation - associated with alcohol, mental health problems and dementia - yet do not fit clearly in any one of these groups.
- 4.3 Stigma occurs at different levels: individual, institutional and societal.
- 4.4 Systematic stigma within the NHS towards people with alcohol-related problems leads some services to reject people with alcohol problems on the basis that it is 'not our problem'. This attitude extends to people with ARBD and often, by association, to their families too.
- 4.5 The Scottish Executive in its Plan for Action on alcohol problems (2002) has set out short- and long-term aims to address attitudes, behaviours and outcomes related to alcohol problems in general. Some of these initiatives could also be used directly to deal with stigma and ARBD.
- 4.6 National campaigns could help to change unhelpful perceptions of, and attitudes to, alcohol in Scotland. The complexity of ARBD makes the issues around stigma particularly important for services and professionals working with people with ARBD.

5 Social Care and Support

The following factors affect the social needs of people with ARBD:

5.1 Stages Within the Assessment Process

- 5.1.1 The needs of an individual with ARBD will change as they move through an assessment and rehabilitation process, and on to some form of continuing care. A full assessment is likely to take at least one year of abstinence and structured rehabilitative interventions. (Smith and Hillman 1999)
- 5.1.2 During the assessment and rehabilitation period the individual has social needs, but the primary focus will usually be on medical needs since rehabilitation often takes place within a hospital.
- 5.1.3 It may be, however, that by addressing the social needs less intrusive care options can be found, such as community detoxification with ongoing support from non-specialist home support workers.

Case Study

Grace was 37 on her first admission to psychiatric hospital, referred by her GP with severe depression. Grace described low energy levels and paranoid thoughts; becoming severely agitated when faced with decisions or responsibilities. She lived alone in a one bedroom rented flat. She went home with arrangements in place for a home help two days a week and day hospital support (referral to the addictions team or counselling for alcohol problems not suggested). She continued to drink, was rarely in for the home help and did not attend day hospital. Follow up was not assertive and services lost contact.

A year later Grace broke her wrist after a fall. She weighed only five stones, and was clearly unable to provide even basic care for herself. When she refused hospital admission emergency, short-term legal action was taken. Following a diagnosis of ARBD a full assessment concluded that she was incapable of living independently. Her home was in a state of squalor. Following a decision to apply for a guardianship order the court appointed a safeguarder to represent her interests. Grace then went to a nursing home that specialised in the care of people with ARBD. She stayed there for seven months, built up her weight and health generally and began to control her drinking.

She returned to her renovated home, still subject to guardianship, after six months, with a support plan which included: day hospital five mornings per week, home help on Tuesday and Saturday and regular visits by CPN, health visitor and social worker on alternate weekday afternoons.

After six months the order was discharged and the intensity of support reduced. A few weeks later a further crisis occurred resulting in hospital admission. Plans are in now place for a longer period of rehabilitation in a care home with the long-term aim of supported housing. Following a supported detoxification programme her self care skills are improving and she now has supervised visits from her children.

5.2 Follow-up Support

- 5.2.1 Follow-up support is crucial when an individual moves on to long-term care, whether in their own home or in supported accommodation.
- 5.2.2 The involvement of both health and social care staff is important at this stage, so that continued joint assessment and support can be provided following discharge from hospital after detoxification. Social workers are often involved at the point of discharge in arranging accommodation and care in the community.

Case Study

Davy is 60. He has been unemployed for four years, 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; these have resulted in involvement with the local police and tension in the family. After Davy became unemployed, Davy's wife began to notice that he 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 six weeks Davy was discharged. He missed follow up appointments with his CPN and alcohol worker.

5.3 Degree of Brain Damage

- 5.3.1 An individual's longer-term needs will be dependent on the degree of brain damage they have sustained, and it is only possible to assess this accurately after a period of up to one year after cessation of drinking.
- 5.3.2 The brain damage may be slight, and its effect on cognitive functioning almost negligible following the rehabilitation period. Such individuals may require continuing support to maintain abstinence from alcohol, but may have few other needs in order to live a full life in their community.

Those with a significant degree of cognitive impairment will also need support to maintain abstinence, but may in addition need help with accommodation, aspects of their daily life, finance and social activities.

- 5.3.3 There will also be people who have a more severe impairment, and who show no, or only slight, signs of recovery. They will require 24-hour care over a long period of time.

5.4 Social Situation and Support

There are currently people in age-inappropriate settings, who have not received the support they needed to aid their rehabilitation. Many of these people could be supported to live independently in the community. Professional staff involved in assessment and care management need to have a fully informed understanding of the aetiology, pathology and likely outcomes of Korsakoff's syndrome and ARBD in order to make appropriate assessments and care plans in such cases.

5.5 Social Consequences of Problem Drinking

Many people with ARBD will have had a long history of problem drinking. In most cases this will have had a detrimental effect on their day-to-day lives. They may experience, or have experienced, periods of unemployment. They may be divorced or separated, and have lost contact with their family members and become socially isolated. Alcohol problems often also cause financial difficulties and temporary or insecure housing. Many people with ARBD are homeless.

5.6 Importance of Support Networks

- 5.6.1 The circumstances of their living situation will impact strongly on the social care needs of people with ARBD. In particular, the existence of a social and family network is seen as crucial in the process of rehabilitation to independent living (Jacques and Anderson, 2002).
- 5.6.2 Carers can provide vital support for an individual undergoing detoxification, and then striving to maintain continued abstinence. For the many people with ARBD who do not have families or carers, other sources of support to maintain abstinence and, therefore, their health must be found or provided.

Case Study

Lawrence (72) lives with his wife Jean. She describes him as a 'bully' and spoke of having experienced years of physical abuse prior to him becoming less mobile. He continues to be extremely demanding. She only leaves him alone for brief periods, but on numerous occasions he has phoned the police to report her missing. Jean provides good physical care and meals for her husband and keeps an immaculate home. Jean has difficulty standing up to her husband and buys him approximately three litres of spirits weekly. She fears that her husband will refuse respite care. Staff are concerned about her mental and physical health and believe she is at the end of her tether. She has no close family or friends. Specialist addiction service have set up a review to look at the needs and possible options for the couple.

5.7 Avoiding Inappropriate Placement

- 5.7.1 The Mental Welfare Commission has raised concerns about the inappropriate placement and inadequate review of people with ARBD (Jacques, 2000). People are often accommodated in care homes outside of their Health Board area because there is no provision in the community capable of meeting their long-term care needs.
- 5.7.2 The scarcity of move-on accommodation means many people with ARBD remain in psychiatric beds or unsuitable community settings, with their progress unmonitored. In these situations the social needs of the individual are neglected.
- 5.7.3 Some care homes, by contrast, have specialist registration and/or a dedicated unit within the home. They recognise the wider needs of the person with ARBD by involving family and friends, providing rehabilitation interventions specific to ARBD and actively promoting a return to independent, but supported, living. Mainstream care homes may also provide good standards of care if staff are trained and supported.

Case Study

Robert is a 58-year-old man who moved into a care home, mainly for older people, three months ago. For many years he had been a hostel dweller and rough sleeper. He described drinking heavily from the age of 17 onwards and drinking "continuously" when money was available. Robert described having been married with children but had no idea of the whereabouts of his family and has no contact with other family members.

His alcohol consumption in the home was a pint of cider daily. According to staff, alcohol and cigarettes were his main concern and he would approach staff several times a day for both. Smoking under supervision is only 'allowed' twice a day as he damages chairs and carpets and puts himself and others at risk. His mobility had improved, progressing from a wheelchair to a zimmer. He needs close supervision as he was recently found in the street trying to buy matches. Robert appears to have no difficulty finding his way around the home but will enter resident's bedrooms and staff areas and take cigarettes and soft drinks belonging to others. Robert is incontinent of urine and wears a catheter. He will occasionally pull it off and, when he does, appears oblivious and unconcerned that his clothes are wet. Staff describe Robert as being generally bright and cheerful though he calls everyone by the same name.

Although Robert needs some nursing care, staff think that he needs an environment that would provide more interest during the day and more opportunities to go out and about in the open air. He misses male company but finds little in common with the other male residents and there are few male staff.

5.8 Community Living for People with ARBD

5.8.1 Views differ on what constitutes community living. Some define it as any situation where people have, and can exercise, a series of rights. For others, it is based on more pragmatic interpretations such as access to resources and services. What both approaches have in common is agreement that community living should lead to a 'positive state' where people feel included and able to participate as active citizens.

5.8.2 Community living requires:

- A secure home/tenancy
- Available transport
- Meaningful daytime activity or employment
- Social network
- Access to medical services
- Leisure/recreation facilities
- A good diet
- Adequate level of income (from benefits or employment)

5.9 Components of Successful Community Living

There is emerging practice evidence that it is possible for people with ARBD to sustain a relatively high level of independent community living, but that this depends on the following factors:

- Abstinence from alcohol, or at least a carefully managed harm reduction programme
- Consistent support from staff with understanding/knowledge of ARBD
- Developing/redeveloping skills in daily living, developing/ maintaining routines
- Safe living environment (house may require some aids/adaptations)
- Good diet/nutrition
- Meaningful daytime activity
- Support from family and friends
- Activity-based rehabilitation strategies to improve memory and other cognitive impairment

5.10 Finding Appropriate Accommodation for Community Living

Most people with ARBD will, prior to diagnosis, have moved through a range of accommodation including hostels, hospital, rented flats, homelessness, bed and breakfast accommodation and so on. Many have a history of rent arrears and eviction. It can prove difficult to secure permanent accommodation for this group, as social landlords and local authorities often have allocation policies that preclude people with rent arrears or a history of evictions from becoming tenants in a secure tenancy. To overcome this problem, a number of voluntary agencies have negotiated management agreements with Housing Associations that enable them to nominate people for tenancies and so bypass the normal allocation process. In these cases the nominating agency undertakes to provide support and ensure rent payments. Other agencies have developed rent deposit schemes, where the agency pays a deposit on behalf of the client to secure accommodation from private landlords.

6 Health Care Needs of People with ARBD

6.1 Physical Causes of ARBD

- 6.1.1 Alcohol related brain damage is caused by a combination of Thiamine (vitamin B1) deficiency, general cerebral shrinking secondary to alcohol, and a consumption range of other insults to the brain including repeated head injury or assault.
- 6.1.2 Thiamine is an important vitamin for ensuring the steady supply of sugar to the brain. Metabolising alcohol increases the metabolic demand for Thiamine. Total body Thiamine is very vulnerable to depletion and in normal circumstances the body contains approximately ten days' supply. Alcohol dependence decreases the absorption of Thiamine from the gut, so oral treatment with vitamin supplementation or supplementation of foodstuffs or alcoholic drinks with Thiamine becomes ineffective. Repeated experiences of alcohol withdrawal, epileptiform seizures and delirium tremens all increase the metabolic demand for Thiamine.

6.2 Wernicke-Korsakoff's Syndrome

- 6.2.1 Wernicke-Korsakoff's Syndrome is one cause of ARBD. This is where a specific alcohol induced vitamin deficiency results in bleeding into parts of the brain resulting in damage to specific cognitive functions, including short-term memory. There is an acute phase (Wernicke's Encephalopathy) where, if the symptoms are recognised, urgent intravenous vitamin replacement will prevent the condition becoming established.
- 6.2.2 Although there is increasing recognition of Wernicke's Encephalopathy in emergency medical populations and policies to manage this in certain hospitals, the majority of episodes of Wernicke's Encephalopathy occur undetected in the community and, therefore, Korsakoff's Psychosis can develop either suddenly or insidiously over time. More detail is given in Appendix C.

6.3 Trends in Vitamin Supplementation

- 6.3.1 There is an established body of evidence on the value of intramuscular or intravenous high potency vitamin supplementation in those suffering from the acute phase of the Wernicke-Korsakoff's syndrome (Cook et al 1998). However, this condition rarely presents to treatment services in a classical form and a diagnosis may easily be missed unless staff are sensitised to the possibility by the existence of local guidelines.
- 6.3.2 There is some evidence that the withdrawal in 1991 of a form of a high potency vitamin, due to a serious adverse reaction, and the absence of any supplements to the market for a nine month period, may have contributed to increasing rates of ARBD, and in particular Korsakoff's Psychosis, in the east end of Glasgow (Ramayya & Jauhar, 1997).
- 6.3.3 A Committee on Safety of Medicines warning is attached to the current form of the high strength vitamins, which restricts their use to hospitals and areas where resuscitation facilities are available, such as health centres and day hospitals.

- 6.3.4 Research is required to establish whether increased rates of provision in those facilities, and A & E departments, of prophylactic intramuscular or intravenous vitamin supplementation may reduce the rates of alcohol related brain damage. A Cochrane Library Review is underway to examine the current literature on this topic. Most alcohol treatment units now use intramuscular or intravenous vitamins during the acute phase of detoxification to reduce the risk of Wernicke's Encephalopathy. The effectiveness of these interventions needs to be the subject of further research. An extract from the current SIGN Guidelines (2003) on the management of harmful drinking and alcohol dependencies in primary care is given in Appendix D.

6.4 Deprivation and Nutrition

- 6.4.1 ARBD is strongly associated with high levels of deprivation. Inverclyde, for example, is the most deprived area in Argyll & Clyde NHS Board area and has the highest prevalence of ARBD. There are also very high prevalence rates in the east end of Glasgow, which also has a high incidence of deprivation. General nutritional status is poor in alcohol-dependent people and this increases vulnerability to ARBD.
- 6.4.2 While reported per capita rates of consumption remain steady (not allowing for illicitly imported or other supplies not registered by Customs and Excise) there is evidence, as already noted, of increases in harmful levels of alcohol consumption in specific sub-groups, especially women and young people.
- 6.4.3 Excessive steady use of alcohol and binge drinking are both thought to be particularly damaging to the brain. A further worrying trend is that the relative cost of a unit of alcohol has been falling steadily. Nutrition, and vitamin B1 deficiency in particular, is very clearly related to ARBD as discussed above. This may be one of the reasons why alcohol damage, given comparable levels of intake, is much more pronounced in deprived areas.

6.5 General Medical Conditions Associated with ARBD

Alcohol, when taken to excess, can damage almost all systems in the body. There are a range of medical disorders that are strongly associated with regular excess use of alcohol. A comprehensive list of all such conditions is beyond the scope and remit of this document but some common examples are given in Appendix B. The diagnosis of these disorders is relevant for three principle reasons:

- The presence of such disorders should alert clinicians to the possible existence of ARBD
- The relationship to alcohol may afford the opportunity to institute preventative measures
- Those suspected of having ARBD should receive a medical examination to check for such conditions.

6.6 Accidental Injury

- 6.6.1 People with ARBD are at increased risk of death or injury from fire, drowning, suffocation, head injury from falls, assaults and road accidents (as driver or pedestrian). All these can result in brain injury compounding the difficulties of their ARBD. In addition, orthopaedic and other traumatic injuries occur more frequently in this group than in the general population. Follow-

up for the physical injury allows follow-up for the alcohol problem too and can result in a reduction in drinking up to a year later (Royal College of Physicians, 2001).

- 6.6.2 As with the medical conditions described above, health professionals treating people presenting with such injuries should always consider the need for alcohol advice to prevent further damage. In some cases screening for ARBD should be undertaken.

6.7 Mental Health Problems

- 6.7.1 People with ARBD may have a wide range of mental health problems including depression, anxiety, dementia and other severe mental disorders (Scottish Executive 2003). This is a complex area as these mental health problems may:

- Be instrumental in the individual developing an alcohol problem in the first place
- Occur as a consequence of their heavy drinking
- Be a direct consequence of the alcohol related brain damage itself

- 6.7.2 Individuals may also have had a number of psychiatric diagnoses prior to ARBD becoming established, such as schizophrenia or bipolar disorder. Associated psychological problems may include apathy, irritability, attention problems and difficulty coping with anything new.

6.8 Alcohol and Depression

Various studies have estimated that at least 13% of those with an alcohol disorder met criteria for an affective disorder. With respect to the risk of suicide, those with an alcohol problem have been estimated to be at 60-120 times greater risk than those without mental illness. Long-term alcohol use is associated with depressed mood, and in the majority of cases this will resolve entirely with continued abstinence from alcohol for 2-4 weeks (McIntosh and Ritson, 2001).

6.9 Multiple Substance Misuse

People with ARBD may have more than one substance misuse or addiction problem. The most frequent of these is tobacco dependence, but, increasingly, addiction services are seeing people dependent both on alcohol and on a range of other drugs, most commonly opiates and benzodiazepines. These multiple addictions also have a plethora of associated general medical conditions that may include hepatitis B or C or, in rare cases, HIV. Such individuals have extremely complex health care needs, and also the added complication that their cognitive deficits make it difficult for them to understand these and to present to services.

7 General Alcohol Services

- 7.1 Alcohol problem services in the UK are currently established in a fashion that meets the needs of those who recognise they have an alcohol problem, and are fit to make the conscious decision that they wish to address it. These services provide detoxification and psychological and medical interventions to prevent or minimise relapse. While some can provide appropriate detoxification facilities for people with ARBD, they do not adequately meet the needs of those with cognitive impairment.

8 The Need for Specialist Support and Services

- 8.1 Access to specialist alcohol assessment and treatment is extremely important. Teams working with people with ARBD should include, or have access to, individuals with expertise in cognitive assessment, especially neuropsychologists, occupational therapists and rehabilitation and general psychiatrists.
- 8.2 Access to specialist expertise is scarce. It may be appropriately and cost effectively used to support staff in mainstream service across the different service sectors as well as providing a direct service.
- 8.3 Dedicated psychiatric beds for rehabilitation and continuing care are needed for the sub-group of people with ARBD who have major behavioural or psychiatric difficulties.
- 8.4 There is a need for specialist psychiatric expertise in prescribing and monitoring psychotropic medication, since people with ARBD may be particularly vulnerable to side effects: GPs, service users, carers and service providers need to be aware of this possibility.
- 8.5 There is a need for education of carers, service users and all agencies about the impact of alcohol on those already with ARBD. This information should inform policy in the various care settings and there should be an emphasis on abstinence.
- 8.6 Given the different styles and modes of treatment for those already with established ARBD, it is important that detoxification services for them recognise their additional support needs.
- 8.7 Ongoing work on mental health and stigma should include people with ARBD.
- 8.8 Recommendations include the need for all staff to understand the common psychological and behavioural problems associated ARBD itself, and how to use basic behavioural techniques to maximise any new learning.

9 Different Needs

This chapter concludes with discussion on the range of both social and medical needs of people with ARBD. People with established ARBD have a range of health and social care needs. In order to assist in the process of planning for such a mix of needs, people with ARBD can be grouped in the following ways, which are drawn from research literature and the views of users, carers and staff.

Slow to Recover Group

- This group often includes people who have established brain damage, which may result in behaviour problems and low self-care ability. Such people respond to intervention, so long as this takes the form of a care programme that provides specialist intervention and support, and recognises that improvement will be slow.

- It usually requires specialist multi-professional treatment, care and support in a supportive care environment, often with 24-hour care, before perhaps moving on to supported accommodation. This will depend, in part, on the availability of family and home support
- Staff in these settings will continue to need access to specialist advice and support from addiction and psychiatric specialists.

Stopped Drinking and Accepts Intervention (may relapse/multiple relapse)

- Depending on age and family support and if there is an appropriate living situation, at home or in supported housing, this group may do well as long as those involved understand the need for ongoing rehabilitation and support.
- Providing alternative social and employment opportunities to replace drinking habits and prevent boredom is essential.
- There may be additional physical disabilities and illness, due to drink or other conditions e.g. epilepsy. There is a need for good primary care and general nursing support. If there are other mental health problems e.g. depression, support may need to be co-ordinated between mental health and primary care services.

Continue Drinking, Resistant to Intervention

- This is the group that is most likely to present at crisis point for services. If there is established brain damage, consideration should be given to the need for legal intervention regarding alcohol withdrawal and/or compulsory admission.
- Currently many people are excluded from services because of their problem drinking and anti social behaviour.
- This group may require different types of outreach and specialist approaches if a breakthrough is to occur.
- There is some evidence that even where no action is taken to provide assessment, care or support, family members, including young carers, may continue to struggle to provide appropriate support themselves. In such cases families and front line staff benefit from specialist advice and support from voluntary organisations and carers groups.
- It is likely that brain functioning will be progressively damaged if drinking continues and individuals will then be referred for care at a point of crisis.

Chapter 4 - Meeting Individual Needs

Key Points

- The development of information, advice and health promotion services is of key importance in changing attitudes and practice in relation to people with ARBD.
- Service outcomes will depend on individual characteristics and circumstances and, crucially, on where people with ARBD are first identified.
- There are significant variations in the availability and nature of service provision both nationally and within local areas.
- Disjointed information about services reflects a lack of co-ordination between services, and a fracturing of care pathways for people with ARBD.
- Appropriate sharing of information about individuals, between different professionals and agencies, is important but may be problematic.

1 Information, Advice and Health Promotion

- 1.1 Before discussing the care pathway and the services within it, it is important to emphasise the key importance of health promotion, and of providing information and advice both to those who may be affected by ARBD and those involved in commissioning, planning or providing relevant services.
- 1.2 Due to the increasing numbers of people with ARBD in Scotland it is essential to highlight the consequences of prolonged and heavy drinking, poor diet and the risk of ARBD.
- 1.3 In theory, ARBD is a wholly preventable disorder. Of those at risk of developing it, or who have developed it, a significant number have the potential to recover - substantially or completely - if ARBD is managed in an appropriate environment, ideally free of alcohol. This factor distinguishes it from most forms of dementia or brain injury, where recovery is unlikely, and makes early identification a priority.
- 1.4 There is little evidence currently of public health promotion in relation to ARBD, though this could be a relatively simple but effective way of addressing some of the issues.
- 1.5 Information about ARBD should be disseminated to all relevant professionals and service providers across Scotland to help ensure early identification of the condition, and enable appropriate services to be delivered. Current programmes of health promotion on healthy drinking and healthy ageing should also encompass ARBD as an issue.

- 1.6 Information on identification is needed so that a wide range of service providers, from the criminal justice system to health and social care services, can know when and how to seek specialist help where necessary. This is particularly important for people working in front line services.
- 1.7 Many people with ARBD are identified within hospitals when undergoing treatment for other conditions and it is particularly important for hospital staff to have training in the identification of ARBD.
- 1.8 Detoxification or other appropriate interventions can then be provided at the earliest opportunity. Early intervention will slow down the progress of the condition, reduce the impact of the brain damage and improve the chance of recovery.
- 1.9 Service staff currently rely on a range of professionals for information and advice; usually medical and psychiatric consultants, but also specialist voluntary organisations and alcohol services that offer counselling and support.
- 1.10 Advice on treatment and management of ARBD is needed by people providing services once the condition has been identified.

Information and Awareness

The Alcohol Liaison Service at the Royal Infirmary of Edinburgh was developed when it was found that early detection and minimal intervention for alcohol problems could considerably reduce longer-term harm. (Learmouth and Leslie 2003) The service provides minimal interventions for people in the hospital who are found to have alcohol related problems. These interventions include screening, assessment and providing advice and information to the patients. Another aspect of this service is that the nurses provide training and information on minimal intervention to other health professionals. The training has a central aim of encouraging ward nurses to enquire routinely about alcohol consumption thus enabling them to appropriately refer these patients. In the case of individuals with ARBD appropriate referrals are key.

2 Factors that Influence Outcomes

- 2.1 ARBD is often a hidden condition until a crisis occurs. An individual's needs may then be categorised and packaged in a way that makes sense for service systems, but not necessarily to the person with ARBD, or to those that care for and support them.
- 2.2 Service responses often depend on the following factors:
 - **Current living arrangements:** for example hospital, acute or long stay, home alone or with partner/carer, homeless/roofless, care home (specialist/mainstream, with nursing care or without), criminal justice system.

- ***Phase of ARBD***: people with ARBD present at different phases of the condition. Depending on where and to whom people present, this will impact on the effectiveness of their assessment and thus the success of subsequent interventions.
- ***Other physical or mental health conditions or disabilities***: such as traumatic brain damage due to other causes (falls, for example), stroke, vascular dementia or fronto-temporal dementia, liver disease, nutritional problems, epilepsy, mental health problems, learning disability, physical or sensory disability.
- ***Past and present alcohol use***: for example, drinking/not drinking, previous attempts at withdrawal or management at home or in hospital, number of relapses, ability to recognise and accept problem with alcohol, age of onset of drinking problems, wish to continue drinking, previous acute episode of Wernicke-Korsakoff's Syndrome.
- ***Age, gender, language/ethnic background/culture***: these factors may affect the range of service options available, ease of access to services, recognition of problems and type of specialist or specialist service. For example, some community teams focus only on under 65s; old age psychiatrists tend to take referrals of those in older age groups; care homes may be restricted on basis of age.
- ***Legal status***: an individual's current, or previous, legal status will have a bearing on the ability of services to intervene and may affect the types of service provided (see Appendix A).
- ***Family responsibilities and support***: the family support available to an individual will also affect the type and level of services available to them; but this may be missing for an individual with ARBD, due to their previous alcohol histories. Responsibilities for the care of children or other dependents will also influence needs and outcomes.

3 The Journey of Care for an Individual with ARBD

- 3.1 Information on the journey of care experienced by people with ARBD in Scotland is patchy. Needs assessment work in the areas covered by the Greater Glasgow and the Argyll and Clyde Health Boards and in Edinburgh City is beginning to build up a more comprehensive picture, but further work is needed in most areas of Scotland.
- 3.2 As already noted, collating information and tracking individuals with ARBD as they access different health and social care services is extremely difficult.
- 3.3 Elleswei (2000) suggests that only a minority of those with ARBD will fit the stereotypical image of troublesome drunks, such as street drinkers. Most will have worked for many years; a number will have had, or have, partners and families.
- 3.4 Many, however, will have social, financial, occupational, physical and medical difficulties as a consequence of their alcohol history. Relatives and friends are often no longer involved or in touch with them (Jacques, 2000). This means that people with ARBD are very dependent on the availability and continuity that can only be provided by integrated health and social support services.

4 Care Pathways

- 4.1 There are wide variations across Scotland in the way that individuals with ARBD seek help and access services. Figure 1, on page 35, represents the different pathways that may be followed by individuals.
- 4.2 Within local provision, too, there are variations in both assessment and ongoing response. Amongst factors that account for these variations are:
- Differences in knowledge, awareness and attitudes of front line staff
 - Extent of co-operation and continuity between different professionals and different services
 - Level of agreement between agencies on protocols and assessment tools
 - Degree of consensus about eligibility for specialist services for people with ARBD
- 4.3 The views of service users are important in the planning and development of effective services. In practice, involving people with ARBD may prove challenging because of their transience, manner and behaviour, and the fact that some will previously have had negative experiences of services.
- 4.4 It is very important, however, for services to 'adhere' to such individuals and offer appropriate choice and support; and this is a point particularly reinforced in the user consultation conducted to inform this report (Consultation & Involvement Trust Scotland, April 2003).
- 4.5 Available research and practice evidence suggests that a key worker/support worker is needed, to provide continuity of support and outreach and ensure that the rehabilitation process is sustained.
- 4.6 Co-ordinated assessment procedures and services are important: to minimise time spent, to reduce repetition, to maintain participation and to maximise the quality of information and care.
- 4.7 Sharing information between agencies is crucial for the delivery of effective care, but access to previous health and social care records may be hindered or prevented by agency and professional policies on confidentiality.
- 4.8 In some settings existing information is patchy or unavailable, and some information provided by individuals themselves may not be reliable for assessment purposes.

Case Study

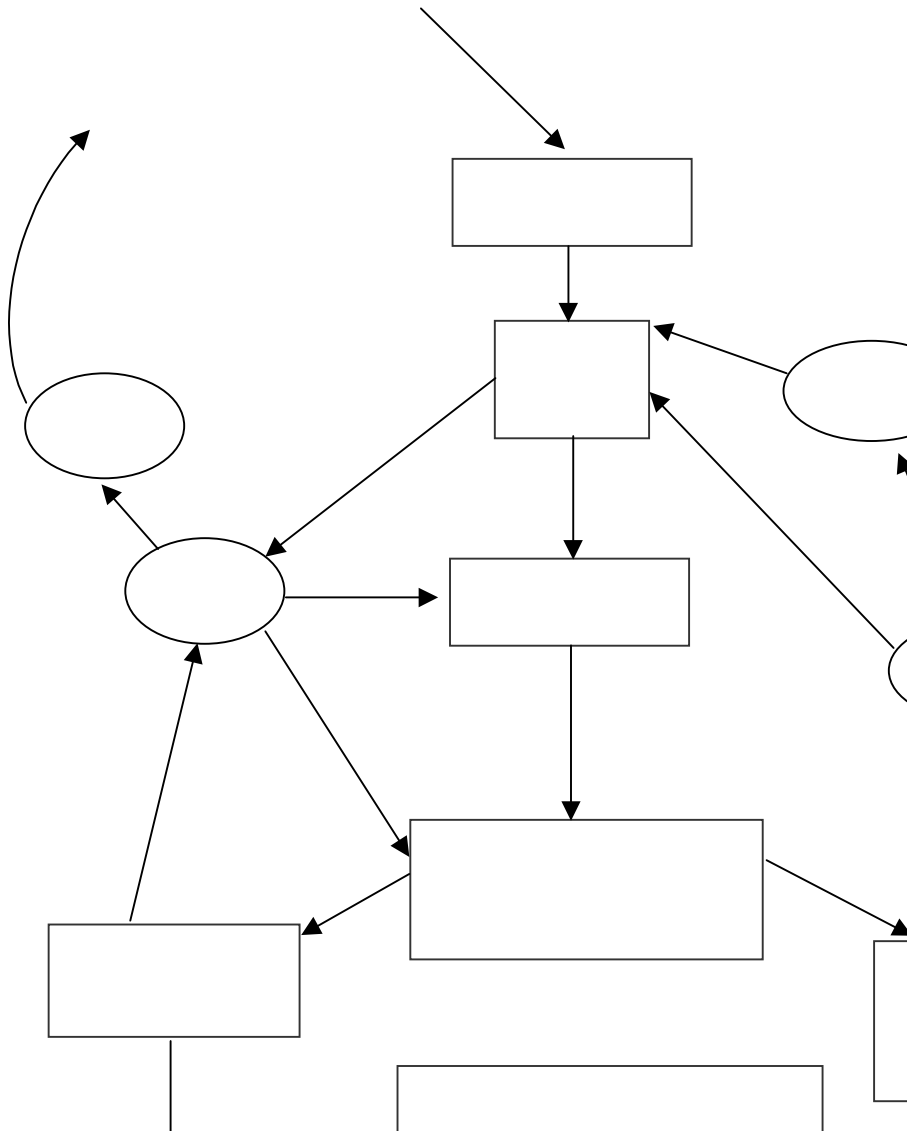
Paul had a well-paid administrative post and enjoyed a good standard of living. He married young but his marriage broke down after a few years when his wife left him. Now in his early 30's, Paul began to drink heavily. His drinking reached the level, at its height, of two bottles of whisky every day. More and more days were missed from work, debts began to spiral, and Paul became more reclusive. Eventually he was retired on health grounds, was declared bankrupt and lost everything. A relative found him one day, unconscious on the floor of his flat and after an emergency admission to hospital a Wernicke's crisis was quickly diagnosed.

Paul incurred quite severe brain damage as a result of the initial Wernicke's crisis. His short-term memory was severely affected, balance and co-ordination were poor, and anxiety and depression became increasingly worse. After almost a year in hospitals, Paul was admitted to a nursing home at the age of 45. All the other residents were in their 80's and 90's. The depression and anxiety worsened dramatically, he became very withdrawn and disengaged from everything around him.

Social work staff, GP and care staff at the nursing home were not optimistic about Paul's chances of independent living, but an independent advocacy agency and a voluntary agency were involved through a family friend and a rehabilitation plan began to take shape.

The first couple of years were very hard for Paul, but a few years on, Paul is living a full and independent life. He is no longer anxious or depressed, and, with his support package, manages extremely well. His cognitive skills and short-term memory have improved dramatically and continue to do so. The voluntary agency provides a support package of over 30 hours per week and there is a consistent level of support (home help, support workers and friends). Paul is committed to remaining abstinent and has a great resolve to better his own quality of life.

Figure 1 Care Pathways



Chapter 5 - Matching Services to Needs

Key Points

- Whole system approaches should characterise all levels of service planning and provision.
- Single shared and comprehensive assessment is central to the provision of better health and social care for people with ARBD.
- Assessment must be ongoing and subject to continuous monitoring and review.
- The provision of suitable housing or of an appropriate residential placement is of key importance.
- Support is needed for family and other carers who play a vital role, especially in preventing social isolation and in helping their relative to achieve continued abstinence.

1 Individual Care Pathways

1.1 The following section sets out the service elements that need to be in place in order to respond appropriately to the needs of people with ARBD and their carers/supporters. They have been arranged to represent the pathway an individual with ARBD might take through services, from initial identification through to longer-term care. The service elements have been drawn from research, identified good practice examples and expert views from the field. The services described illustrate a range of responses to the needs of people with ARBD in different areas.

1.2 Essential elements of an effective service response:

- Crisis response
- Detoxification, managed alcohol withdrawal/treatment
- Assessment, care management, care planning and co-ordination
- Rehabilitation programmes
- Ongoing care, support and treatment
- Carer support, for family and direct care staff

1.2.1 The way these elements are planned, commissioned and provided and funded will vary across Scotland and depend on:

- Levels of assessed needs
- The urban/rural nature of the area
- The services currently available
- The degree of integration, and arrangements for partnership working between health, social work services and housing, voluntary organisations and independent sector organisations.
- Use of funding streams e.g. supporting people

- 1.2.2 It is vital that those involved in planning and commissioning services take a whole system approach. In the absence of long-term places, and support or access to specialist advice, it is likely that some parts of the system will cease to provide care for people with ARBD.

2 Crisis Response

- 2.1 Crisis response can take many forms. It depends to a large extent on where the individual asks for, or is referred for, help. Common settings are accident and emergency departments or general hospital wards, to which individuals may be admitted for some other reason but are then found to have ARBD. Others may be identified by GPs or social workers, the criminal justice system, homeless hostels or specialist alcohol centres.
- 2.1.1 Initial responses in any of these settings may, but often do not, lead on to appropriate medical treatments and a structured care pathway.

Crisis Response for Homeless People

The Summer Street Project in Aberdeen provides support and a drop-in service to adult homeless people, just under 10% of whom are people with ARBD. Outreach workers may refer individuals for residential detoxification and treatment for alcohol problems and also assist them, following detoxification, to maintain their own tenancies in the community. People often self-refer to this service.

- 2.2 Services offer different responses to people with ARBD. Some have no specific expertise in dealing with the problems of ARBD and their response is accordingly limited. Where an individual is identified tends, at present, to govern what follow-on services they receive. Professional and service responses also depend on the individual with ARBD, most crucially on whether they abstain from drinking or undergo managed alcohol withdrawal. Some people, however, will not be offered these options, or may refuse or fail to complete the process.
- 2.3 It is important to note that many people with ARBD do not undergo detoxification and continue drinking. They may still be offered support but, because many services operate a 'no alcohol' policy, this will be limited in extent. If an individual is in hospital, where they are prevented from drinking alcohol during their stay, they are more likely to undergo detoxification.

3 Detoxification and Managed Alcohol Withdrawal

- 3.1 Detoxification services are central to treatment once ARBD has been identified. Detoxification most commonly takes place in a hospital setting, but community and ambulatory detoxification may be more appropriate for some individuals. Successful community detoxification, however, is only possible with good social support. Those who already have some degree of cognitive impairment require additional help during detoxification, and residential detoxification options are usually more appropriate.

- 3.2 There is a lack of information about the problems of detoxification for people with ARBD and this is an area where more research is needed. There is agreement, however, that alongside detoxification and withdrawal, nutrition issues should be addressed, and vitamins and appropriate medication given to help with recovery.

4 Assessment and Care Management Co-ordination

- 4.1 A number of assessment tools are available to assist the clinical/multidisciplinary team in establishing a diagnosis of ARBD and its severity, and in determining individual needs.
- 4.2 Jacques and Anderson (2002) suggest a standard approach to assessment for people in longer-term care in hospital, care homes, and supported accommodation, which does not cover the acute treatment of ARBD. Initial diagnosis would be confirmed by the co-ordinated use of a range of physical and cognitive function tests as well as subjective and objective assessment of alcohol use.
- 4.3 The need for single shared assessment systems and integrated care planning for people with ARBD has already been stressed. Diagnosis of ARBD is the first step in the assessment process (see Chapter 3).
- 4.4 One problem for people with ARBD is, as previously noted, that they enter services by many different routes and end up with a different range of professionals and services according to their point of entry. A number of other factors make the assessment of people with ARBD problematic:
- It may take place at different levels and within different service systems such as hospital teams, age-related agencies or condition-related services (for example: dementia, brain injury or alcohol services).
 - It may be prolonged owing to the slow recovery process, and individuals may find it difficult to maintain their engagement.
 - Continued alcohol intake will render many formal assessments invalid, because true cognitive function will be impaired.
 - Many people with ARBD have co-existing physical or mental health problems.
 - Due to the impact on cognitive functioning it may be difficult to gain informed consent for the assessment process.
 - It may also be difficult to gain accurate information from the individual.
 - The gathering of information from different agencies is important but may be difficult because of different systems and confidentiality policies.
- 4.5 A multidisciplinary approach to assessment is required across health and social care agencies. This should include:
- Assessment of physical health and nutritional state
 - Psychiatric assessment
 - Neuro-psychological assessment of attention, concentration, memory, perception, problem-solving, vocabulary and information processing

- Assessment of physical functioning
 - Assessment of social needs
- 4.6 The multidisciplinary and multi-agency team/network involved should be co-ordinated to reduce duplication and repetition, and also to manage the process of assessment so that the individual is not overwhelmed. Staff involved need to develop skills and expertise in using a range of assessment methods.
- 4.7 Care planning and co-ordination arises from the assessment process and it is important to have an integrated service approach to it. People with ARBD need a range of services crossing traditional boundaries between medical and social care. Local planning partners need to ensure that these joint approaches are in place, and that a local service co-ordinator for people with ARBD is identified in each Alcohol and Drug Action Team area.

Care Management and Assessment

Inverclyde Alcohol Services (IAS), part of Inverclyde Social Work and Housing Services, provide care management for people with alcohol problems, about 20% of whom are people with ARBD. The services link with local projects to provide a comprehensive care package. IAS employs alcohol specialists and a dual diagnosis worker who undertake assessment and link with the Community Mental Health Team which in turn liaises with relevant social work departments as required. IAS also links with the local NHS Trust, with which they carry out single shared assessments, and the Gryffe Unit (see section on Rehabilitation), which provides medical intervention for people with alcohol problems. Referrals work both ways, with the Gryffe Unit, the local Community Mental Health Team and psychiatric services referring individuals to IAS and vice versa. Clients undergo an initial assessment, followed by assessment over a four-week period, which is reviewed every 12 weeks. The staff do not have a specific assessment tool for ARBD but it is usually recognised during the initial assessment. Clients maintain contact with the centre for as long as they need to.

- 4.8 Effective monitoring and review is crucial as recovery and rehabilitation of ARBD may be long-term. The commonly accepted view is that monitoring and review should continue for a period of between one to two years from detoxification. Individual needs will vary (Smith and Hillman 1999; Bruce and Ritson 1998; Jacques and Stevenson 2000).
- 4.9 Individuals with ARBD may be inappropriately placed within long-term care units despite good recovery from ARBD. It would sometimes be possible for such people to return to homes in the community but - unless the assessment process is still ongoing - they may get stuck in inappropriate, and unnecessary, long-term residential care with high opportunity costs.
- 4.10 Provision should also be made for those who choose to continue to drink. There may be limited alternative placements, and individuals may exercise their choice by disengaging. Particular skills are required for engaging with this challenging group of people.

5 Rehabilitation Care

- 5.1 Rehabilitation is an essential part of the care pathway. It may not be possible to arrive at an accurate assessment of an individual's needs and capacity for improvement during the two years following initial detoxification. This is a factor that it is important for those involved in planning, commissioning and providing services for people with ARBD to bear in mind.

Residential Rehabilitation

The Arbennig Unit in Colwyn Bay in Wales has 12 beds in six-bedded units for people under 65 who have ARBD. It offers a residential programme for assessment and rehabilitation lasting for up to two years. The staff provide counselling, social care and physical rehabilitation. There is a focus on life skills to enable the individual to return to the community or to reach their optimum level of recovery. The unit has six flats within the same building where people with ARBD can live during rehabilitation because current options for long-term care are limited and do not provide appropriate care for people with ARBD.

- 5.2 During the rehabilitation period the individual with ARBD may require psychological, nutritional, medical and social care. Support to maintain abstinence is likely to be a key element together with nutritional support. Medical care by GP or consultant should be ongoing, and address other medical conditions caused by the long-term alcohol problem. Social support may be necessary both short and long-term. In the short term the individual may need support with personal care due to cognitive deficits. As the individual recovers this may change, but it is likely that during the rehabilitation period the individual will need continued social support with housing, finance and self-care.

6 Ongoing Care, Support and Treatment

- 6.1 Many people with ARBD require medical, psychiatric or psychological treatment and interventions following detoxification, sometimes as a result of their previous alcohol history or medical problems related to their drinking (see Chapter 3). Working through a single shared assessment, it should be possible for people with ARBD to have all such needs met in a coordinated manner.

Medical and Psychiatric Support

The Gryffe Unit at Ravenscraig Hospital provides in-patient and day-patient detoxification and rehabilitation for individuals with alcohol dependence. For people with ARBD and marked cognitive impairment an in-patient detoxification followed by a period of in-patient rehabilitation lasting up to eight weeks is offered. More severely damaged patients may be admitted under general psychiatry. Rehabilitation includes medical, psychiatric and psychological programmes to prevent relapse and provide ongoing support for individuals. People stay in contact with the unit for varying lengths of time with individual care packages designed according to clinical need. Individuals who remain abstinent may continue as out-patients for several years. The unit works closely with the Inverclyde Alcohol Services (see section on Assessment) and so is able to provide a multi-agency approach through single shared assessment.

- 6.2 Community programmes such as day activities, or other individual support programmes providing leisure activities or employment for people with ARBD, are not common. Where they exist, they are mainly provided by services for people with younger onset dementia or by community mental health services.
- 6.3 Alzheimer Scotland - Action on Dementia Glasgow Younger Person's Project provides services for people with ARBD within its day care and home support services. Some specialist residential units, such as the Arbennig Unit, provide support with leisure activities and work related activities as part of a rehabilitation programme. Inverclyde Alcohol Services also provide ongoing support for people living in the community and have a drop-in centre.

Day and Home Care

Alzheimer Scotland - Action on Dementia Glasgow Younger Person's Project run day care and home care services that are used by people with ARBD. Home care tends to be more popular with people with ARBD as they are often younger than the other day care clients. Home support enables people with ARBD to maintain their own tenancies and helps with rehabilitation and integration into the local community. Home support workers help people with ARBD to undertake courses to help regain life skills such as cooking and social activities such as going to the cinema. The service tries to match the age of the client and the support worker, and if two clients have similar interests a 'buddy group' of clients and support workers may do things together. The service does not have any specific policies regarding alcohol but staff try to help individuals reduce their intake or abstain from alcohol. The service has a counsellor for the clients and their carers. Alzheimer Scotland - Action on Dementia have an open referral system and so the Younger Person's Project can get referrals from a variety of sources. This means that the individuals may be at different stages in the care pathway when they are referred to the service. The staff liaise with other services such as the local Alcohol and Drug Action Team to ensure each client gets a comprehensive care package. Most clients live in the community but the service has also provided home support and day care for people with ARBD in nursing homes.

- 6.4 The ongoing needs of individuals with ARBD living in the community depend on their existing support networks and the level of their cognitive impairment. Individuals with minimal cognitive impairment may still require ongoing support to maintain abstinence from alcohol, or with other aspects of their lives. Those with a greater degree of cognitive impairment may require more intensive support services such as day care, and home care to assist with housing, daily living and self care. Non-specialist home care services may, however, be reluctant to provide such care, particularly if there has been a history of alcohol problems and behaviour that challenges services.

Day Opportunities

The Differently the Same project of Turning Point Scotland in Glasgow provides day opportunities for people under 65 with dementia and includes people with ARBD. The service provides support and advice for individuals through their diagnosis and beyond. The day opportunities provide support with education, leisure and employment. Support workers may help with transport or accompany a client to a college class or on a leisure outing. Staff also help individuals find and sustain employment, often on a voluntary basis. The staff work one to one with the clients unless there is a group of clients with similar interests for example in art. The service does not have a strict alcohol policy but supports clients to abstain from alcohol. Support workers also work with people with ARBD living in care homes, who are often younger than the other residents and benefit from undertaking community activities.

- 6.5 Housing support for people with ARBD is key but can be highly problematic. People with ARBD often have poor financial histories and may find it difficult to get a tenancy. They may also be at risk living in the community, and in need of substantial support to make it possible. Penumbra provide home support services for people with ARBD living in their own homes, and organisations such as Loretto Housing provide some specialist community accommodation for people with ARBD. Several other organisations see this as an effective way forward and are also planning, or building, specialist accommodation, and the provision of person-centred support.

Housing and Home Care Support

Penumbra provides a range of services for people with mental health problems across Scotland including housing and tenancy support services. In Edinburgh and Aberdeen there are specialist services for people with ARBD. Following referral from either health or social work services, support plans are agreed with referrer and clients. If required, people are offered support in finding accommodation and securing a tenancy. Support to enable people to remain abstinent or reduce alcohol consumption, recovering or coping with memory difficulties and other aspects of daily living are provided in people's own homes. Penumbra staff believe that many individuals with ARBD can maintain their own tenancies in the community with the right support packages. In some cases people have been supported to move out of residential/nursing homes and into houses in the community where they are supported by Penumbra staff along with input from community nurses and home carers. A number of service users with ARBD have recovered significantly and benefit from a multi-agency approach. Regular reviews and assessments are key to ensuring that the service is responsive to changing needs. Good risk assessment is important as is a positive attitude to considered risk taking.

- 6.6 Community living can help to integrate people with ARBD in a local community and thus contribute to reducing the stigma they may feel. Appropriate housing may also provide an opportunity for the individual with ARBD to move on in their life. The local authority medical advisor on housing may play a key role in the inter-agency collaboration necessary to provide this.

Supported Accommodation

Loretto Housing provides supported accommodation for four people with ARBD within flats in Glasgow. Each individual has their own tenancy and the flats are situated in the same street. The service provides support workers who call in on the individuals during the day and have a sleepover service at night. The staff provide support with daily living skills such as budgeting, meals, personal care, household tasks, shopping and social events. Most of the individuals lived in long-term hospital care before moving into the flats. The service does not have a strict alcohol policy and, as the people with ARBD are living in their own tenancies, they may continue to drink. The staff manage the clients' alcohol intake through budgeting and monitor it carefully. As a result there have been few problems related to alcohol. The clients have their own social workers and CPNs who continue to manage their care needs. The levels of support appear to be appropriate for people with ARBD.

- 6.7 As already seen, people with ARBD are vulnerable to losing their homes and it is clear that many people with ARBD are homeless or roofless. Unless they come to the notice of alcohol or ARBD services because of a particular incident or crisis - such as a fall, an accident, challenging behaviour or an acute medical emergency - people in this group are unlikely to have their ARBD identified or their needs appropriately met. Many of these individuals will, however, be in contact with services for adult homeless people.

Services for Homeless/Roofless People with ARBD

One project of the Glasgow Simon Community provides residential services for adult homeless men with addiction problems. Around 15-30% of their users are people with ARBD. They provide a short-term residential programme, which tries to deal with the addiction issues for each individual through a person-centred approach. They liaise with local mental health services for specialist input and may refer individuals for supported accommodation or provide support with tenancies.

- 6.8 Many people with ARBD are to be found within specialist or mainstream care homes. Such homes have different registrations such as adults and older people. Few are specifically for people with ARBD, but a growing number have small specialist units within them sometimes referred to as 'Korsakoff's units'.
- 6.9 It seems that, once admitted to care homes, individuals are unlikely to move on to more independent living in the community. This is despite evidence of the potential for rehabilitation, improved mental and physical capacity and cessation or management of alcohol problems.
- 6.10 Care homes are often struggling to provide optimum care and rehabilitation for people with ARBD with little assistance from local specialist teams.
- 6.11 There are indications that increasing numbers of people, mainly but not entirely male, in their 40s, 50s and 60s are being admitted to homes that cater primarily for a much older age group. Such individuals may not have an accurate diagnosis, and may well be considered as having dementia. This may mean they do not receive appropriate support with alcohol related issues.
- 6.12 Some homes refuse admission for individuals with ARBD because alcohol problems are involved. Care homes specialising in frail older people, or older people with mental health problems, may be more likely to identify people with ARBD and seek specialist help to provide care. Some such homes have become expert over time due to the level of ARBD referrals.

Specialist Unit Within a Care Home

Langcraigs residential home in Dumbarton has a specialist unit for people with Korsakoff's with six beds. The unit is self-contained and gives the residents opportunities to undertake simple household tasks such as making tea. The unit has been open for six years and has four residents who have remained at the home long term. These residents are in general younger than those in other parts of the home and relate better with the staff than with other residents. Other residents with ARBD have stayed in the unit for shorter periods of time. Those for whom the unit is found unsuitable return to long-term psychiatric care in hospital. The unit does not prohibit alcohol but the staff find that the residents tend not to return to previous drinking habits.

- 6.13 Specialist units are usually for medium term rehabilitation of one to two years, and individuals are then moved on to supported accommodation or another nursing home dependent on their assessed need. Other specialist units offer long-term care.

Specialist Residential Care

KorCare at Scope 2000 is a privately owned registered care home in Devon caring for people with mental disorder or 'dual diagnosis' and specialising in people with Korsakoff's. The home is registered for 26 residents and around 75% of their residents are people with ARBD. There are no age limits but the home rarely has residents in their 20s and 30s. Scope 2000 provide long-term care with an emphasis on needs-led care. Clients are supported through a programme of recreational and therapeutic activities supplemented by visiting staff including work involvement and life skills. The home has a dry policy and a monetary management joint agreement which decreases the ongoing management problems with the residents. The home does not employ alcohol specialists but staff liaise with Alcoholics Anonymous, consultant psychiatrists, NHS Drug and Alcohol teams and use websites to gain information. Staff at the home provide advice for people with ARBD living in the community. The home gets referrals from all over the UK and has had enquiries from the USA and Ireland. Residents move from the home in the case of severe physical deterioration or at their request, usually to a nursing home or a unit in another area. The staff stress the importance of therapeutic activities, good nutrition, structure and routine for people with ARBD.

7 Support for Family and Direct Care Staff

- 7.1 Support for carers is vital. People with ARBD may have a continued compulsion to drink, and carers have a crucial role in helping maintain abstinence.
- 7.2 Carer support is particularly important for individuals who are left with permanent cognitive damage and who require long-term care.

- 7.3 Carers need to be given information and helped to understand ARBD, and the progression and symptoms of the condition, in order to maintain their support for the individual with ARBD and to reduce the associated sense of stigma.
- 7.4 Abstinence from alcohol may lead to improved relationships between the person with ARBD and family carers.
- 7.5 Although many people have lost contact with their families, other people's families, including former partners, may be forceful advocates and sources of support.
- 7.6 There are suggestions that services work well where they promote family support.
- 7.7 Organisations providing support to carers of people with ARBD appear to be lacking. It is important that services for people with ARBD, GP Practices and carers' organisations review their approach to support for this group of carers.
- 7.8 Family carers have the right to seek assessment of their own needs as part of the single shared assessment process for community care services.
- 7.9 The needs of children within families where there is a person with ARBD should be addressed by relevant agencies.

Chapter 6 Planning and Delivering Better Services

Key Points

- Achieving integrated and effective services involves both maximising existing resources and identifying new ones.
- People with ARBD should receive the 'integrated spectrum of care' for which local Alcohol and Drug Action Teams are made responsible in the Scottish Executive's Plan for Action on alcohol problems.
- The Joint Future approach to service planning and delivery is vitally important for improved provision for people with ARBD.
- Inherent tensions exist, and need to be constructively resolved, between the need for high quality specialised clinical care on the one hand, and an approach based on community living on the other.
- The combined contributions of the 'Tiers of Service' approach and a chronic problems model may provide a framework within which this can be usefully explored.
- It should be noted that the needs of people with ARBD must be identified within Tiers 1 - 3 as well as Tier 4 of Alcohol Problems Support and Treatment Services Framework.

1 Effectiveness

- 1.1 The essential elements that need to be in place to provide a full spectrum of treatment and support services were identified in Chapter 5. Planning and providing services that meet the health and social care needs of people with ARBD should be informed by approaches that move beyond professional and service boundaries and divisions. Otherwise people with ARBD will continue to 'fall through the net' or remain in inappropriate health or care facilities with no prospect of review or opportunities for rehabilitation. Even people with significant levels of brain damage can be supported in the community if there is sufficient choice in the models of housing and support services available. Current policy directions provide the climate for implementing a more integrated approach.
- 1.2 People with established ARBD may be appropriately helped through the process of single shared assessment and good managed clinical and care networks, providing that the appropriate services are in place in the community and in the supported accommodation and care home sector.

- 1.3 The Expert Group is convinced that there is potential for better use and redesign of existing staff and resources to achieve this end. However, those with responsibility for budgets should recognise that it will require considerable effort and some additional resource input if repeated admissions to, and delayed discharges from, high cost services such as A&E and medical/surgical wards are to be avoided by better prevention and rehabilitation services.

2 Redesigning Services

- 2.1 The local planning partners should ensure that there is sufficient capacity (knowledge, expertise and resources) to initiate the redesign of services and ensure recognition of the needs of people with ARBD, within alcohol treatment and support, mental health including dementia, acquired brain injury and older people services.
- 2.2 The Expert Group is convinced that the involvement of service users and their carers and advocates at all levels of developing and improving services is essential. A user and carer consultation process has informed the preparation of this report. Local planning partners and service providers should similarly seek to involve service users and carers by using all, or parts, of the consultation process designed by Consultation & Involvement Trust Scotland, and those being developed by other research and development bodies.

3 Joint Working

- 3.1 The Alcohol Problems Support and Treatment Services Framework clearly locates the responsibility for addressing the needs of people with ARBD with Alcohol and Drug Action Teams (or in many areas, local Alcohol and Drug Action Teams) to provide an 'integrated spectrum of care for individuals with alcohol problems, their carers and families'. People with ARBD have a right to this spectrum of care.
- 3.2 The Alcohol Problems Support and Treatment Services Framework highlights the importance of joint working by, and within, Alcohol and Drug Action Teams - especially with bodies which co-ordinate other local strategies under the 'broad community planning umbrella'. These will include organisations responsible for local health plans, joint health improvement plans, mental health, community care, criminal justice, community safety and homelessness strategies, social inclusion partnerships, statutory and voluntary equality bodies and service providers.

Inverclyde Alcohol Service

The Inverclyde Alcohol Service (AIS), described in chapter 5, provides a good example of joint working. In a project established in March 2003, supported community housing is provided for people with ARBD. Initial partnership working for this project involved Cloch Housing Association, Communities Scotland, Inverclyde Council Social Work and Housing Service, Inverclyde Alcohol Service and specialist architects. The IAS now acts as a referral point for tenants who are given housing support from voluntary sector partners SAMH. Intensive support was provided initially from both SAMH and IAS. The development of the services was monitored via the Mental Health Strategy Group. Through IAS, the tenants may link with other groups as described in Chapter 5.

- 3.3 That joint working is the key to delivering better services for people with ARBD is confirmed by the experiences of service users and carers and the views of staff, planners and providers of services in all sectors. The establishment of Community Health Partnerships should facilitate this joint working.

4 Joint Future Approach

- 4.1 The Expert Group considers that the Joint Future approach, especially single shared assessment and local care partnerships, is the key to planning and providing better and more effective services for people with ARBD and their carers.
- 4.2 The Health Department Letter on Widening of Joint Future to all Community Care Groups, for action 2004-05 onwards, provides an opportunity to apply the approach to people with ARBD across all age groups. The Joint Future approach depends on joint responses from the NHS and local partners. As we have seen in earlier chapters, people with ARBD need the kinds of responses identified in research, and in policy guidance on assessment and care planning within the single shared assessment process:
- Sharing information and single shared assessment producing better care plans and outcomes
 - Faster and better assessment
 - Local partnership working preventing unnecessary admission, and facilitating discharge to and from hospital
 - Better access to more integrated services such as intensive home support
 - Addressing issues of risk management and legal safeguards where appropriate (as in mental health services)
- 4.3 There are, however, major challenges in ensuring high quality clinical advice, support and treatment whilst supporting an approach whose aim is community living rather than continued or frequent use of hospital care. With regard to the health components of the Alcohol Problems Support and Treatment Services Framework, the White Paper Partnership for Care NHS Scotland (2003) sets out its commitment to the redesign of services, in close consultation with primary health care staff and Community Health Partnerships.
- 4.4 The White Paper proposes an integrated system so that primary care in partnership with social care will be able to provide a generic and holistic approach to care. The white paper draws attention to the needs of those with chronic health conditions. In some respects people with established brain damage due to alcohol problems or other types of acquired brain injury are more akin to those with chronic conditions such as diabetes or heart disease, or dementia.

5 Chronic Problems Model

- 5.1 People with ARBD, or those susceptible to ARBD, have a chronic alcohol dependence problem as well as a chronic problem with incipient or established brain damage. The latter may or may not be progressive, depending on whether alcohol consumption continues and the presence of other conditions such as progressive dementia.

- 5.2 An individual's chronic health and social care problems may result in acute episodes. Responding to these necessitates a close relation between primary health and social care networks, and speedy access to specialist advice and support. The purpose will be to maintain the person in the community, including care homes and supported housing, but also to assist in making decisions about the need for hospital treatment when necessary.
- 5.3 We suggest that the most effective way forward is to adopt a chronic problems model, especially when considering people with established or suspected brain damage accessing services in Tiers 2, 3 and 4. Key features of the chronic problems model are set out below.
- 5.4 In order to support primary care and local authority partners, the Expert Group stresses the importance of managed clinical networks and managed care networks, characterised by joint approaches to diagnosis and assessment, and speedy access to expert advice and support at all stages of the individual's pathway.

5.5 Features of a Chronic Problem Model Include:

- User and carer empowerment
- Expertise transferred to user and carer as much as possible (in the case of ARBD this may also include the person's advocate, or support worker)
- Joint assessment, resourcing and management under the joint future banner
- A local flag in general practice where the service user is registered
- A worker(s) with specialist knowledge/expertise at Local Health Care Cooperative/Community Health Partnership level - depending on population base - servicing a number of GP practices/ health and social work community teams.

5.6 The Specialist Worker Role May Encompass Tasks Such as:

- Support of primary care/community care staff at local level
 - Regular review of identified users with carer and care partners
 - Continuing contact with individual and carer
 - Working with local voluntary organisation which may act as the service user's advocate
 - Liaison with partner organisations with an agreed input
 - Recognition of when a specialist input or service is needed
 - Indicating to care partners when a crisis is brewing
 - Knowing first steps to take in the event of a crisis
 - Managed care network available to supplement local expertise on the premise that care should always be provided as close to home as possible and that local workers should be supported and 'up-skilled' by the managed care network.
- 5.7 The skills and activities of specialist worker(s) will assist local planning partners in agreeing how services should be integrated at local levels, in order to get the right balance between specialist assessment and treatment services, and providing services closer to people's homes.

6 Tiers of Service Approach

- 6.1 The Alcohol Problems Support and Treatment Services Framework adopts a 'Tiers of Service' approach within which to identify the needs of people with alcohol problems and the ways in which services can respond. People with ARBD are not specifically mentioned in Tiers 1-3 of the Alcohol Problems Support and Treatment Services Framework, though it is vital that their needs are addressed when the spectrum of service responses is planned. Unmet need at this stage may result in much heavier demands on services later on, and a heavier impact on the lives of people with ARBD. These may include, for example, repeated crisis admissions to hospital and delayed discharges.

The following sections do not repeat the content of the Alcohol Problems Support and Treatment Services Framework. Our aim here is to draw attention to the particular parts of the Alcohol Problems Support and Treatment Services Framework where the needs of people with ARBD can be built into service planning and local action.

6.2 *Tier 1: Services for the Whole Community*

- 6.2.1 Advice and information about the risks of ARBD associated with hazardous drinking and alcohol problems should be built in to all aspects of advice, information and support networks and agencies, including education, work places and community groups. Health promotion and prevention is a priority for all age groups but especially for younger people and those approaching older age.
- 6.2.2 Information on ARBD in user-friendly formats should be directed to the various health and care settings and professionals such as GPs and health centres, housing and benefits services, care homes, day centres, voluntary organisations, help-lines, A&E and other acute hospital settings including continuing care and rehabilitation.

6.3 *Tier 2: Local Services that Identify and Respond to People with ARBD*

- 6.3.1 Members of primary health care teams, local authority social work and housing services and staff in relevant voluntary sector agencies should acknowledge that their remit extends to their clients' alcohol problems, especially if this is associated with suspected brain damage and ability to self-care, and/or if other family members or the community are at risk.
- 6.3.2 Opportunities for detoxification and assessment should be pursued. Brief interventions as advocated in the Alcohol Problems Support and Treatment Services Framework may not be effective with people with ARBD.
- 6.3.3 Practical support is needed for families and carers, including befriending, respite care, home care, and ensuring that those involved understand the impact of ARBD on day-to-day living and the need to manage alcohol.
- 6.3.4 Counselling services may be appropriate for some people with ARBD. Services providing such counselling and support need to be aware of the impact of ARBD. Both individual and group counselling and support may be helpful.

- 6.3.5 Employers should be helped to understand the implications of ARBD, and know where to go to access help and support. If a person can no longer continue in employment, support is needed to ensure that income/pension rights are planned carefully, otherwise they may risk losing not only job but also home and family.
- 6.3.6 A single shared assessment process is likely to result in a faster gateway to services. Staff with responsibility for assessing people with ARBD or at risk of ARBD (lead assessors may be located in statutory or voluntary agencies) should have awareness of ARBD and be familiar with local arrangements for access to specialist advice and service input. This is especially important in order to ensure detoxification if the person is still drinking. Sharing information, but respecting confidentiality, is a major concern for those with ARBD in view of their vulnerability and the stigma that may attach to their condition.

6.4 Tier 3: Services for People with More Complex Needs

- 6.4.1 Specialist advice and support for services in statutory, voluntary and locally commissioned services is an essential component of the chronic problems approach. Effective links are needed between mainstream service providers in all sectors (including care homes, supported housing and people in mainstream housing support services and homeless services) and specialist support. Such specialist support may be provided within primary care/community care or by outreach from specialist centres based in hospitals or other types of specialist resource centre (Tier 4).
- 6.4.2 People with ARBD are likely to have needs that continually cross the boundaries between mental health, alcohol problems, acquired brain injury and community care. Community Health Partnerships and local authorities should have available one or more practitioners with knowledge and expertise on needs and best practice in relation to people with ARBD and their families. They may be attached to the local Alcohol and Drug Action Team/Community Care Team/Mental Health Team depending on local care and clinical network protocols.
- 6.4.3 A lead practitioner for this area of work should be identified, although day-to-day management may fall to members of different teams. In this way continuity and consistency should be ensured. This is consistent with the concepts of managed care networks and managed clinical networks.
- 6.4.4 Such practitioners, in collaboration with others, provide:
- Specialist assessment, advice, detoxification, relapse prevention treatment and follow-up in partnership with GPs and other primary care staff
 - Training and advice to primary care staff on management of ARBD, whether the person is still drinking or not
 - Joint working between primary care, social work, voluntary sector, community mental health teams and local Alcohol and Drug Action Teams
 - Direct access for referral to specialised services (Tier 3 or Tier 4)
 - Advice to Localities/Community Health Partnerships and local authority partners about need, service delivery, outcomes and quality
 - Advice and support to care homes and other supported housing settings.

6.4.5 People with ARBD are found in general or psychiatric hospitals, mental health and other health care services. They may be in contact through outpatient, accident and emergency (A&E) or in-patient facilities. An alcohol liaison service is one way of linking local services.

6.5 Tier 4 Services for People with Highly Specialised Needs

6.5.1 The Alcohol Problems Support and Treatment Services Framework identifies individuals with 'established ARBD' in Tier 4 under 'services for people with highly specialised needs'.

6.5.2 People with established ARBD will not necessarily require a highly specialised service input, although some people will do so because of their particular psycho-social needs.

6.5.3 People with ARBD sometimes require in-patient provision, especially when there are complex neuro-psychiatric problems or co-existing mental health problems or other types of brain injury. People with ARBD may also have complex medical problems, or severe physical disability, that need to be treated or managed in a hospital or other highly specialised setting. No one specialism, for instance psychiatry or addictions, can expect to meet the range of needs set out in Chapter 4.

6.5.4 Other people with ARBD have a complex mix of needs related to other types of Acquired Brain Injury (ABI) and dementia. They may also have behaviour that challenges services, problems with managing alcohol withdrawal and needs for other types of medical intervention.

6.5.5 Specialist services need to link closely with other tiers of the Alcohol Problems Support and Treatment Services Framework for alcohol problems and with other services provided, for example, through the Mental Health Framework and services for older people, especially with regard to specialist multidisciplinary assessment. **In view of the similarities and overlaps between ABI and ARBD some planning agencies may wish to address the needs of these groups of people on a joint basis.**

6.5.6 Activity based rehabilitation is essential. This could be provided (post discharge) by a specialised service - a core group of multidisciplinary staff could develop specialist skills of assessment and neurobehavioral rehabilitation. This specialist group could provide clinical expertise to Tiers 1-3 as appropriate. They could also liaise with the local Acquired Brain Injury (ABI) services. The new Acquired Brain Injury service in Glasgow reports that around 50% of referrals to their service have alcohol related problems.

6.5.7 There is a role for voluntary and independent sector organisations to provide appropriate accommodation, support and rehabilitation programmes during this fairly extensive period of rehabilitation - up to two years. Such services could also provide community detoxification support by providing appropriate twenty-four hour support facilities and care management programmes.

7 Care Management and Local Integrated Care Pathways

- 7.1 The Alcohol Problems Support and Treatment Services Framework identifies the need for an integrated spectrum of services.
- 7.2 Individuals should not be excluded from such services due to brain damage if their needs can be met by integrated services such as community and home detoxification, evidence-based psychosocial interventions, counselling and community based rehabilitation and day programmes.
- 7.3 People with even small degrees of ARBD often have difficulties gaining access to mainstream services and may need extra support. They may include people with sensory impairment, physical or learning disability, homeless people and those at risk of homelessness, older people, and vulnerable people already in some form of institutional care or supported housing such as care homes, hospitals or the criminal justice system.
- 7.4 Some of the service responses identified in the Alcohol Problems Support and Treatment Services Framework will be relevant to those with varying degrees of ARBD. It should be noted that people with ARBD are likely to need sustained support rather than brief interventions.
- 7.5 Detoxification services are important, especially those that can be supported in the community. People with ARBD are often excluded from detoxification at home because of lack of support. Availability of detoxification in specialist wards is limited. Supported community detoxification, for example in 24-hour staffed community units, may be worthy of development and evaluation.
- 7.6 Particular attention should be paid to the needs of people, both under and over 65, for whom admission to a care home is being considered. Assessors should be aware of the need for a care plan that encompasses their drinking history, as well as their potential for recovery and rehabilitation if abstinence is maintained.
- 7.7 Practical support and counselling may be needed to enable people with ARBD to remain in their own homes in the community or to access ordinary housing, and to support the management of their drinking problems if these continue. Housing support and joint working with housing departments are also of key importance.
- 7.8 Homeless people with ARBD need help and support to tackle their drinking problems, and a variety of others to do with health, accommodation and access to services.

8 Quality and Standards

- 8.1 People with ARBD use services that are regulated by different systems, depending on the point they are at in the pathway and the way that services are organised. Many services will be multi-agency, so it is even more important that the bodies responsible for the delivery of high quality care across health, social care, statutory and independent sectors recognise the specific needs arising from long term alcohol misuse and the impact of possible brain damage.

- 8.2 The Scottish Commission for the Regulation of Care (the Care Commission) registers and inspects a wide range of care services against agreed standards set by Scottish Ministers. Of particular relevance to people with ARBD are those for:
- Care homes for people with drug and alcohol misuse problems
 - Care homes for older people
 - Care homes for people with mental health problems
 - Housing support services
 - Services for people in criminal justice supported accommodation
 - Care at Home
 - Support services
 - Adult placement services
- 8.3 Care homes specifically registered for people with drug and alcohol misuse problems are few and most of these care homes are short stay. Consequently most people with ARBD (of all ages) not living at home, or homeless, presently live in other care homes, supported accommodation and hostels. Where the service being used is one which is regulated by the Care Commission, it will be subject to the Regulation of Care legislation, and standards and best practice set out in the relevant National Care Standards. The National Care Standards address a number of elements of care, including:
- Personal care plans - meeting health and social care needs
 - Eating well
 - Supporting communication
 - Skills and experience of staff available to meet needs
- 8.4 The National Care Standards are based on a set of principles that reflect the recognised rights that people enjoy as citizens. The principles include the right to make choices and the right to feel safe without being overprotected.
- 8.5 For people with ARBD, the risks associated with continued drinking should be specifically addressed in the health needs section of the personal plan within the care planning and review process.
- 8.6 NHS Quality Improvement Scotland (NHSQIS) has responsibility for the quality of the health care provided by NHS Scotland services, within a framework of clinical governance and clinical effectiveness. NHSQIS promotes the use of evidence based best practice in its clinical standards.
- 8.7 The QuADS project (Quality in Alcohol and Drug Services) has produced organisational standards for Alcohol and Drug treatment services. This sets out core management standards, core service user standards and service specific standards.
- 8.8 Additional tools and materials are under development by QuADS for the quality improvement of drug and alcohol services. Although the needs of people with cognitive impairment and ARBD are not addressed specifically, the guidance is useful for those concerned with improving the quality of care provided.

- 8.9 Jacques and Anderson (2002) propose more detailed standards for the care of people with ARBD in hospitals, care homes and supported accommodation. Their proposed standards do not cover acute medical treatments of Wernicke-Korsakoff's syndrome, delirium tremens or other acute conditions. Of relevance here is the Scottish Intercollegiate Guidelines Network (SIGN) guideline on the management of harmful drinking and alcohol dependence in primary care (SIGN 2003) The guideline includes recommendations and good practice points on the role of vitamin supplements in detoxification and the preferred setting for treating delirium tremens (see Appendix D).
- 8.10 Scottish Executive Health Department Letter (2002) 41 gives guidance on mental health care settings.
- 8.11 The Expert Group suggest that the management of drinking strategies, such as abstinence and harm reduction as well as referral routes to specialist support for people with ARBD, should be addressed within the health needs section of the personal plan of those receiving care from services registered by the Care Commission, and in the care plans of those in NHS care or care within the single shared assessment process and community care.
- 8.12 Care plans should include as appropriate:
- Health implications of drinking history and/or associated medical conditions/ARBD
 - Immediate management when intoxicated or otherwise affected by alcohol; the staff/services to be contacted, referral routes, e.g. primary care, specialist care
 - If abstinence is not practicable, a realistic plan of limited (controlled) drinking aiming for harm reduction set out in the care plan/personal plan, shared with key workers/support staff and family
 - Agreement with care managers of individual criteria for placement breakdown, and procedures to follow
 - Nutritional/medication aspects of personal care plan
 - Consideration of powers available in Adults with Incapacity Act 2000 or mental health legislation if appropriate, for more detail on this, see Appendix B.
- 8.13 The Expert Group invites the Care Commission and NHSQIS to consider these issues and the implications for the improvement of service quality and good practice.

9 Training and Education

- 9.1 Training, education and awareness raising is 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. For instance we know that basic awareness of alcohol related issues is generally lacking in primary care staff (Plant and Haw, 2000); (Anderson et al., 1999). Within specialised care home environments, staff report a lack of training. Staff working in care home settings said 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), demonstrating the scope for exchanging of information and peer support.

- 9.2 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.
- 9.3 Training and education needs exist in all sectors, and for the full range of professional health and social work and front line staff in care homes, home care, community services, hospitals, voluntary services and hostels/housing services. This was apparent to service users and those who care for them, as well as to staff.
- 9.4 Information from STRADA (Scottish Training on Drugs and Alcohol) confirmed that they provide some information on ARBD in their foundation course and mental health course, but a specific module on ARBD is not available.
- 9.5 We understand that STRADA will be working more closely on alcohol issues in 2003 - 2004.
- 9.6 The Expert Group recommends that relevant training in identifying and managing people with ARBD is required at all levels, (undergraduate and postgraduate) of professional education, Scottish Vocational Qualifications and short courses for face to face staff. Distance learning and other formats such as video/CD ROM should be considered.
- 9.7 Training needs may include:
- Increasing awareness and knowledge of ARBD
 - Knowledge and skills for treatment and support
 - Assessment and care planning
 - Managing behaviour that challenges practitioners
 - Rehabilitation programmes
 - Techniques to improve memory functioning
 - Providing support for family carers
- 9.8 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.

10 Evaluation and Monitoring Outcomes

- 10.1 Hardly any research has been carried out in Scotland on what works in the provision of service for people with ARBD. More research is needed on all aspects of the person's pathway through services: assessment, rehabilitation, community living and care home provision.

- 10.2 More guidance is needed for services to develop their own evaluations which includes the perspectives of service users and family members.
- 10.3 It would be helpful for information systems to reflect the use of services of an individual over time, so that the impact of services could be monitored and evaluated.
- 10.4 In agreeing local objectives for people with ARBD, Alcohol and Drug Action Teams and their planning partners may wish to agree collaborative schemes to measure progress and sustain change. These may include:
- Survey of GPs via practice managers
 - Audits of care plans (community care, care homes)
 - Numbers of people with ARBD with a rehabilitation programme in the care plan
 - Surveys of samples of service users and carers

Chapter 7 Conclusion

1 Conclusion

- 1.1 ARBD holds many challenges for everyone concerned to gain a better understanding of the condition, and to provide services that will more effectively improve the lives of those affected by it.
- 1.2 Some people with ARBD are no longer able to play an active part in this endeavour, though many are. Their rehabilitation and recovery, often after many set-backs, sends a positive message to families, friends, and carers - both paid and voluntary - and professional staff.
- 1.3 Supporting people with any addiction can involve a heartbreaking journey, with hopes of rehabilitation and recovery perhaps dashed after years of devoted emotional and practical support. Informal carers of people with ARBD, especially, are in need of recognition and support for their 'work'. Yet they frequently find themselves excluded from mainstream support networks because of the stigma associated with the condition.
- 1.4 Members of the Expert Group appreciate that an enormous volume of work has been generated by the Plan for Action on alcohol problems. Much of this falls on the Alcohol and Drug Action Teams and their local planning partners including the independent sector. Only a small proportion of those for whom these agencies are responsible will be people with ARBD, but we believe the quality of their response to this group to be of fundamental importance.
- 1.5 Like many other conditions that involve acquired brain damage, both progressive and non-progressive, ARBD provides a touchstone that gauges the responses, not just of health and social care agencies, but of society more generally. Can we provide services that really are person-centred? Or will we go on accepting care and support solutions that fail to maximise the potential of the individual to live a full life within the inescapable constraints of their condition? Will we allow messages of difference and exclusion to continue to be reinforced?
- 1.6 These questions have both ethical and resource dimensions. The Expert Group believes that more sensitive responses to individual needs will lead to more effective overall services in the longer term. Individuals and agencies across all sectors and professions are building up knowledge and expertise, learning from the evidence of what works in other fields, pioneering new services and redesigning existing ones. Welcoming these signs of progress, the Expert Group believes that more emphasis needs now to be placed on evaluation and research, so that a stronger foundation is laid for service development and improvement.
- 1.7 The Expert Group was somewhat daunted by its 'Expert' label. We have tried very hard to draw on all the professions, interests and areas of knowledge and expertise as we have carried out our work. We have learned much from each other and, especially, from the experiences of those directly involved - people with ARBD, carers and front-line staff. We hope that this report does justice to their concerns.

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Appendix A - Legislation

Adults With Incapacity (Scotland) Act 2000

This Act sets out duties and legal mechanisms for safeguarding the welfare and managing the property and finances of adults who lack the capacity to make all, or some, decisions for themselves due to a mental disorder or inability to communicate by any means. Mental disorder is as defined in the Mental Health (Scotland) Act 1984. This includes adults with alcohol related brain damage.

The Act places specific protective and supervisory responsibilities on the Public Guardian, the Mental Welfare Commission and local authorities. It provides for a series of interventions, which allow adults to make arrangements for the management of their own welfare and/or financial matters, in the event of their loss of capacity in respect of these matters.

The Act also authorises action to be taken by proxies, either on a short-term or ongoing basis, when a person has lost capacity, and such intervention is necessary. The powers granted under the Act must relate to specific areas of incapacity or of concern. This means that flexible powers can be sought to implement a care plan which otherwise might not have been possible, as long as they are in keeping with the underlying principles of the Act, such as the requirement that the Act must be used in the least restrictive manner to achieve the stated objectives; that the views of the adult, and relevant others, inform any action taken under the Act and that the intervention will benefit the adult. Both welfare and financial powers can be sought. This would allow, for instance, in some circumstances, the management of an individual's finances where they lack the capacity themselves, within an overall care plan which provides essential social care and supervision.

Mental Health (Scotland) Act 1984

While the Mental Health (Care and Treatment) (Scotland) Act 2003 has recently been passed, this will not come into effect until late 2004/early 2005. The current legislation allows for the compulsory detention for care, and/or observation and treatment, of individuals with mental disorder who meet the criteria of the Act. Essentially there must be a risk to the health or safety of the adult concerned, or the safety of someone else. An emergency (up to 72 hours) detention under either Section 24 (from the community), or Section 25 (for a person who is already an in-patient) requires consent, where practicable, from either a Mental Health Officer or a relative. A short-term (up to 28 days) detention may follow an emergency detention. It cannot proceed unless the person had been detained immediately previously under emergency provisions. These require the consent, where practicable, of a Mental Health Officer or a nearest relative.

Longer term detentions are possible only via an application by a Medical Health Officer (MHO), based on two medical recommendations, which has been approved by the Sheriff Court. They are approved for initial periods of six months, but can be renewed by the Responsible Medical Officer at intervals of up to six months, 12 months and thereafter annually. Whilst on long-term detention, a patient can be placed on leave of absence from the hospital for a period of continual leave of 12 months, at the end of which point the section must be discharged. The Responsible Medical Officer can impose conditions on the leave of absence, and can recall the patient where they meet the grounds for detention.

Appendix B - Medical Conditions

Neuropathy and/or myopathy (nerve damage and muscle weakness) can cause a mobility problem and disability. These conditions are important due both to their high association with alcohol dependence and to those planning care and services for people with ARBD. In their most advanced forms, these conditions may result in sufferers having to use wheelchairs.

Gastro-intestinal problems - these range from emergency presentations with bleeding from the gut, ulcer disease or heartburn through to cirrhosis of the liver and all its associated complications. Management of the burden of gastro-intestinal complications of alcohol misuse consumes a considerable proportion of NHS budgets. Increasing numbers of liver transplantations are being carried out for alcohol liver disease. Alcohol liver disease in itself can cause impairment of brain function due to unprocessed blood toxins interfering with brain function. This needs to be recognised by those doing cognitive assessments for alcohol related brain damage, and may also need to be considered if there is an unpredictable deterioration in an otherwise stable individual with ARBD.

Alcohol related seizures - people with alcohol dependence and alcohol related brain damage have a much increased risk of epilepsy. Epilepsy itself, and the drugs used to manage it, can result in cognitive complications, which again may need specialist assessment and management and may complicate cognitive rehabilitation of those with alcohol related brain damage.

Head injury - people with alcohol dependence have high rates of head injury, often related to falls when inebriated. Head injuries can cause specific or generalised cognitive impairment, and this effect is usually synergistic with the alcohol dependence itself. It is important that there is clarity of responsibility between head injury assessment and rehabilitation services, and those for ARBD, so that those whose brain injury results from a combination of reasons are not excluded by both services.

Cerebrovascular and cardiovascular disease - alcohol in large amounts is directly toxic to the heart and there are multiple cardiac conditions either directly caused by alcohol or worsened by it. These include toxic cardiomyopathy, hyperlipaemia (high blood fats), myocardial infarction (heart attack), angina and cerebrovascular accidents (strokes).

Cancer - many forms of cancer, especially head and neck, oesophageal and bowel, are directly caused by excess alcohol. People with alcohol related brain damage are, therefore, at increased risk of developing all such cancers and may have need of access to specialist cancer services or to screening if available for instance for (oral cancer)?

Appendix C - Clinical Conditions

Wernicke's Encephalopathy

Wernicke's Encephalopathy is an acute neurological illness resulting from severe thiamine (Vitamin B1) deficiency.

Someone with Wernicke's Encephalopathy will typically have the following:

- A global confusional state resulting in severe disorientation and difficulty retaining new information.
- Ataxia, which causes someone with Wernicke's Encephalopathy to walk with his or her feet spread wide apart. They may be unable to walk safely if severely affected.
- Disturbance of the muscles controlling eye movements leading to ophthalmoplegia (an inability to move the eyes normally) and nystagmus (involuntary jerking movements of the eyes).

These features occur in the **absence** of intoxicification with alcohol. Detection of Wernicke's Encephalopathy may of course be more difficult if the person is not relatively free of alcohol.

Prompt detection of Wernicke's Encephalopathy is **extremely** important in order that the individual receives urgent treatment with high dose thiamine given intravenously. The condition can be made **worse** if the individual is given carbohydrates (or intravenous dextrose) prior to intravenous thiamine as this **increases** the body's demand for thiamine.

With prompt treatment the majority will recover although there may be residual symptoms including a disorder of cognitive function- Korsakoff's Syndrome. Without treatment Wernicke's Encephalopathy can lead to coma and death.

Korsakoff's Syndrome

People with Korsakoff's Syndrome typically have the following difficulties:

- A profound difficulty in learning new information. As time passes this results in an increasing period of time for which the individual has little or no memory.
- The individual does have an immediate memory and so can recall new information for a very short time.
- Things learned prior to developing Korsakoff's Syndrome are remembered normally.
- Individuals tend to fill in the gaps in their memory with erroneous material. This is often very plausible but may be fantastic or grandiose.
- People with Korsakoff's Syndrome may show a lack of motivation or initiative.

These difficulties often show partial or, less commonly, full recovery with prolonged abstinence from alcohol.

Alcoholic Dementia/Alcohol Related Dementia

Excessive alcohol consumption also affects the brain in a diffuse manner causing more general cognitive impairment. Alcohol is a neurotoxin and may result in shrinking of the brain. It is also probable that alcohol affects how blood perfuses the brain and it may also interfere with neurotransmitter systems. This type of damage is referred to in many different ways, a common term being alcoholic or alcohol related dementia. This condition may be more common than Wernicke-Korsakoff syndrome but may be misdiagnosed as such.

Alcoholic dementia may lead to cerebellar atrophy affecting co-ordination and gait. It may also result in frontal lobe dysfunction. This part of the brain is important for our ability to plan and organise, judge, problem solve and behave in socially appropriate ways.

Alcoholic dementia is more difficult to diagnose and its existence is a matter of debate. Some suggest that it is merely part of Wernicke-Korsakoff syndrome while others state Wernicke-Korsakoff syndrome is a part of alcoholic dementia. More research needs to be done in this area. The differences between these two types of alcohol related brain damage are, however, important as they have different implications for treatment and the progression of the conditions.

Alcohol can affect the nervous system in other ways. Excessive alcohol consumption may lead to peripheral neuropathy which affects sensation in the feet and legs. Hepatic encephalopathy is caused by severe alcohol related liver disease. This can cause an acute disturbance of brain function with confusion initially but may develop to coma.

- Cerebellar atrophy - this primarily affects co-ordination and causes a wide-based gait.
- Peripheral neuropathy- leading to reduced sensation in the feet and legs, less commonly in the hands.
- Hepatic encephalopathy- severe alcohol related liver disease can cause an acute disturbance of brain function with confusion initially but may develop to coma.
- Frontal lobe dysfunction - this part of the brain is important for our ability to plan and organise, judgement, problem solving, be flexible in thinking and behave in socially appropriate ways.

Appendix D - Extract from SIGN Guidelines

4.4 THE ROLE OF VITAMIN SUPPLEMENTS IN DETOXIFICATION

There are very few high quality studies on which to base recommendations in this area. To do such studies now would be inappropriate.

4.4.1 TREATMENT OF ACUTE WERNICKE-KORSAKOV SYNDROME

Detoxification may precipitate Wernicke's encephalopathy (see below), which must be treated urgently with parenteral thiamine. There is a very small risk of anaphylaxis with parenteral vitamin supplementation. This is less likely with the intramuscular route. There has been one case of anaphylaxis solely attributable to intramuscular Pabrinex since 1996.

Signs of possible Wernicke-Korsakov syndrome in a patient undergoing detoxification

- Confusion
- Ataxia, especially truncal ataxia
- Ophthalmoplegia
- Nystagmus
- Memory disturbance
- Hypothermia and hypotension
- Coma

One Randomised Controlled Trial (RCT) has examined the role of parenteral vitamin supplements in inpatient alcohol detoxification using memory function as the outcome. This study was done in people who did not have Wernicke-Korsakov symptoms.

Any patient who presents with unexplained neurological symptoms or signs during detoxification should be referred for specialist assessment.

Patients with any sign of Wernicke-Korsakov syndrome should receive Pabrinex in a setting with adequate resuscitation facilities. The treatment should be according to British National Formulary (BNF) recommendations and should continue over several days, ideally in an inpatient setting.

4.4.2 TREATMENT OF THOSE AT RISK OF WERNICKE-KORSAKOV SYNDROME

There is no published evidence and conflicting expert opinion on the treatment of malnourished patients, and the specification and treatment of "at-risk" patients (those with diarrhoea, vomiting, physical illness, weight loss, poor diet), with the majority of experts recommending parenteral vitamin supplementation during detoxification.

For the malnourished patient in the community, intramuscular Pabrinex given in the GP surgery, A&E department, outpatient clinic or day hospital is indicated if facilities for treating anaphylactic reactions are available, such as in any setting where routine immunisations take place.

Patients detoxifying in the community should be given intramuscular Pabrinex (one pair of ampoules daily for three days) if they present with features which put them at risk of Wernicke-Korsakov syndrome.

4.4.3 ORAL SUPPLEMENTATION

No studies were identified that have looked at oral thiamine and its benefit to memory in either the recovering alcoholic or those who continue to drink in general practice. Absorption is diminished when patients continue to drink and should be given in divided doses to maximize absorption. The BNF recommended dose for treatment of severe deficiency is 200-300 mg daily.

Patients who have a chronic alcohol problem and whose diet may be deficient should be given oral thiamine indefinitely.

4.5 THE PREFERRED SETTING FOR TREATING DELIRIUM TREMENS

Delirium tremens is defined here as withdrawal symptoms complicated by disorientation, hallucinations or delusions. Autonomic overactivity is a potentially fatal aspect of this condition.

A Clinical Resource and Audit Group (now part of NHS Quality Improvement Scotland) good practice statement on delirium tremens recognises the serious medical aspects of this syndrome and recommends that local protocols for admitting patients with delirium tremens are used.

Although the proportion of such patients seen by psychiatrists varies across Scotland, the majority of cases are treated by the acute medical services. This is because there is often a coexisting medical condition such as pancreatitis, pneumonia or other infection and there may be life threatening complications.

Local protocols for admitting patients with delirium tremens should be in place.