

**THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)**

LIVING FULLER LIVES

June 2007

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FOREWORD

The Bamford Review of Mental Health and Learning Disability (Northern Ireland) consists of a number of interlinked reviews under one overarching title, and encompasses policy, services and legislation.

In consultation with Government, we have agreed to produce our reports separately in a phased manner.

This further report deals with dementia and the mental health issues of older people, and is the last of the Review's "service provision" reports.

In common with the other reports we have produced, this report reflects the evidence-based approach we have adopted to our task and the invaluable contribution of service users, their carers and families. This committee, for example, conducted a wide-ranging stakeholder consultation as part of its initial fact-finding work.

I thank Nevin Ringland, his committee and all who contributed to the production of this report, and I commend it to you.

Roy J McClelland (Professor)
Chairman

May 2007

PREFACE

CULTURE OF CARE

In undertaking this Review, we have asked ourselves a number of questions. Firstly, what do we want? We want the kind of health and social care we would like for ourselves. It would be tailored to our individual histories and circumstances. It would be given by a dedicated person or small group of people with enough time. They would be available to us and our carers at all times. Staff would be skilled in understanding and meeting our needs. They would be well supported to deal with our emotional pain. The help offered would be imaginative and start from the view that problems can be solved. It would allow us to be ourselves and to retain as much of our daily lives and routines that we want. **It is in the fine grain of care that quality is really experienced, the tiny details that show that our uniqueness has been recognised.**

This vision is highly problematic in an ageist society which also stereotypes people with dementia/mental illness. The fact that society in the 21st century is ever more risk-averse adds another layer of difficulty, in that staff may be under more pressure to protect rather than to enable.

The next question is whether the vision is achievable. Some of the examples of best practice described to the Review showed that this vision of health and social care is possible, although the degree of effort required at all levels of the organisation was quite exceptional.

The third question then is, how can the best practice the Review has seen become the norm and be sustained over time?

Organisations, especially public services, operate in a society with values and an ageist society will tend to have ageist organisations. The Review itself should make a contribution to changing these attitudes, in part by drawing attention to them, in part by providing information about the wishes and potential of older people with dementia and functional mental illnesses and their carers.

The culture of care in any organisation starts at the top. Remarkable individuals and teams do emerge, but they are rarely able to sustain the quality of their care over time unless the organisation is fully supportive. Ideally we need what Senge (1990) calls a “learning organisation”:

“... organisations where people continually expand their capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free and where people are continually learning to see the whole together.”

This is a useful concept in the fields of health and social care for people with dementia and functional mental illnesses because these are fields which are very dynamic at the moment. Attitudes, knowledge, skills and expectations are changing all the time as we learn what people need and what they are capable of. There are increasing amounts of research in all aspects, such as medication, communication, therapeutic interventions and user views.

There is also a great deal of innovative practice, which is constantly identifying needs and exploring new responses, thereby raising expectations. Knowledge and skill does not usually, or

even, often, reside only at the top of organisations. Users, carers and staff at all levels need to learn together about what can be achieved and how to achieve it. Traditional approaches such as training are now seen as only a small part of the process of culture change.

The Review is itself a demonstration of how a learning organisation can work in that all parties have learned from each other.

Professor Mary Marshall

INTRODUCTION

Background to the Review

A Review of the policy, practice and legislation relating to mental health and learning disability and including dementia and mental health issues of older people was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS) in October 2002. The impetus for establishing the Review included:

- recent reviews of mental health legislation in neighbouring jurisdictions;
- the need to ensure that law, policy and practice is in keeping with human rights and equality legislation; and
- the need to reflect current evidence of best practice.

The Review is managed by an overall Steering Committee which has delegated specific areas to ten Expert Working Committees. This Report summarises the findings and recommendations of the Dementia and Mental Health Issues of Older People Working Committee, whose membership can be found in Annex 1.

Key Purposes of the Dementia and Mental Health Issues of Older People Review

The primary aim of the Review is to provide a vision of what mainstream and specialist health and social care services for older people with dementia and functional mental illnesses should look like and how they should work together to ensure that service users and carers have their needs met irrespective of where they are in the system, without encountering discrimination or barriers to access.

In order to achieve this, the Review focused on:

- i. specific models of care and standards of provision in relation to the quality, comprehensiveness, effectiveness, accessibility and acceptability of provision;
- ii. detailed consideration of community/ primary, specialist and secondary care services and the interfaces between them; the interface between health and social care and links with other sectors such as housing; the complementary roles of statutory and independent services and the issues surrounding multi-disciplinary and multi-agency working; and
- iii. the strategies, systems, processes and resources which need to be in place to ensure that the recommendations made in the Report can be realised.

Service Users and Carers

The work included an extensive public consultation exercise involving service users, carers and service providers. This was facilitated by the Rural College and carried out in February and March 2005. Sixteen meetings took place at a range of venues across Northern Ireland, with a total of 294 people attending. This Report draws heavily on the views expressed by stakeholders at these meetings. There was also carer representation on the Working Committee.

It is also interesting to note, that of the 25 Working Committee members, approximately 90% have close relatives who have dementia and/or mental health problems. While this does not replace carer and user representation, it has brought an additional perspective and perhaps a greater sense of energy to the work.

Interface Issues

The Review acknowledges the need for this Report to be considered in conjunction with a number of its other Reports, particularly where there are clear interface issues. Some examples of these are:

- **Adult Mental Health Services** – Community based services for older people with Dementia and Functional Mental Illness (FMI) are sometimes managed within the Mental Health Programme of Care, sometimes by Elderly Services Programmes and sometimes split between both. There are also clear interface issues in terms of arrangements for those older people with enduring or episodic severe mental disorder who have reached the age of 65 and younger people who develop dementia.
- **Learning Disability** – The increasing number of adults with a learning disability who are living into old age has obvious implications in terms of prevalence rates for dementia, depression and other functional mental illnesses. People with Down's Syndrome in particular are at high risk of developing Alzheimer's Disease as they grow older. There are clear interface issues in terms of enabling older people with a learning disability to access mainstream dementia services. Joint working arrangements are also likely to become more commonplace.
- **Legislation** – There are many legal issues affecting older people with Dementia and Functional Mental Illness, for example consent and capacity, compulsory admission for assessment and treatment, management of financial affairs, issuing of advanced directives. Current legislative provision is often deemed to be inadequate in terms of the care and protection it affords to older people with dementia or severe mental health needs.
- **Alcohol and Substance Misuse** – The increasing numbers of older people drinking beyond recommended levels (3% in 1986 to 7% in 2003, NISRA) is likely to see accompanying increases in Alcohol Related Brain Damage (ARBD). People with ARBD typically present with complex physical, social and emotional needs which require a co-ordinated approach across health and social care professions and a range of agencies, such as housing, social security and, often, criminal justice.
- **Mental Health Promotion** – The Review's report "Mental Health Improvement and Well-Being – A Personal, Public and Political Issue" acknowledges that the prevalence of mental health disorders is relatively high in later life, with about a third of all admissions to psychiatric care and referrals to community mental health services involving people over the age of 65. Depressive symptoms affect 10-15% of those aged 65 and over (Psych. Bulletin 2003). Older people also have a higher risk of completed suicide than any other age group worldwide (WHO, 2002).

A range of preventative strategies is required, both to promote good mental health in older age and to reduce risks (where there are identifiable risk factors) of developing dementia.

CHAPTER 1

VISION, PRINCIPLES AND POLICY

- 1.1 The Review has provided a unique opportunity to address the full spectrum of issues relating to dementia and mental health issues of older people. This Report provides the blueprint: a blueprint that is as dependent on cultural change as much as on an investment of new resources. This incorporates a new sense of partnership and equality of esteem for service users, a valuing of carers as equal partners in service provision and effective team-working and collaboration within and between service provider groups.

Where We Have Come From

- 1.2 Over the past thirty years, successive local and national strategies and a growing body of research evidence have advocated refocusing of service provision away from hospital settings towards community based provision. This shift reflects the preference of service users for home life over institutional care (Allen et al. 1992) for local services over distant ones, for services sensitive to community needs and the pursuit of normalisation and integration for those who would formerly have been segregated and excluded in institutional care settings. This has led to an increased emphasis on the provision of more and better care in the community, embracing support for primary care services and the development of a spectrum of community based facilities and services. Alongside this has been an increasing commitment to the participation of service users and carers as partners in the planning, development, delivery and evaluation of services.

Where We Are Now

Management Structures

- 1.3 There is no agreed management structure for the planning and delivery of services to older people with mental health issues. The Dementia Policy Scrutiny 1994 recommended that responsibility for dementia services should be in Elderly Care Programmes. Subsequently, Boards and Trusts have organised services in a variety of ways. Some have developed integrated Mental Health Services for Older People teams, some located in elderly care and some in mental health. Other services have developed separate teams for dementia and functional mental illness (FMI), sometimes located in one programme of care (POC) and sometimes split between these POCs, both at Trust and Board level. As a consequence of different recoding systems being in place or even none in place, there has not been a comprehensive picture of the needs of these client groups. In addition, there has not been an overall mapping of many instances of best practice which do exist around Northern Ireland. Funding for dementia comes through the Elderly POC and for FMI through Mental Health, together with funding for General Adult Mental Health Services. There is no separate planning or funding for FMI in older people.
- 1.4 Older people with mental health problems have not historically been clearly identified as a service user group by commissioners (Finch, 2004). Commissioning arrangements have

consequently tended to be unco-ordinated and fragmented, leading to poor outcomes for older people with mental health issues. A number of inspections by the Social Services Inspectorate between 2002–2003 (DoH, 2003) found that there was also a frequent lack of clear transitional arrangements and of organisational coherence between mental health and older people's services.

- 1.5 The absence of any performance management of the Dementia Policy Scrutiny recommendations, has required the Review to consider, as part of its agenda, the issue of where mental health services for older people should sit.
- 1.6 There was a mixed response in the public consultation to this question, although the majority were supportive of the view that this provision should be the responsibility of a specialist multi-disciplinary team. Carers were generally of the view that proper resourcing of appropriate specialist services was the key consideration, rather than which programme services were aligned to.
- 1.7 The Review has considered this issue in some depth and can see advantages and disadvantages to having the service located in either the Mental Health or the Elderly Programme of Care. We believe, however, that there are definite disadvantages to having it split between both.
- 1.8 The Review's position is that while mental health services for older people can sit within either the older people's or mental health POC (there being clear evidence of services working well within both contexts) they should be provided as a discrete sub-speciality, with ring-fencing of money and specialism. There should also be a single, defined commissioning service, with clear protocols in place for interfacing with other programmes of care. It is essential that users and carers are integrally involved in the commissioning process.
- 1.9 The Review is mindful that traditional structures within Boards and Trusts are changing as a result of the Review of Public Administration. With increasing numbers of older people and increasing stress on health and social services, there is an awareness that traditional services for older people will need to change. Generally there is a move towards whole system planning. This would involve fundamental changes in primary, community and secondary care and should include mental health services for older people. Dementia and severe FMI are chronic, complex conditions and would fit well within a chronic disease management model such as is currently beginning to be used for conditions such as diabetes or chronic obstructive airways disease
- 1.10 In Great Britain, some services for this population have developed further to form Care of Elderly People Programmes, e.g. in Nottingham and Newcastle, where Mental Health of the Elderly and Geriatric Medicine are merged under the one management umbrella. Also, In England, the National Service Framework for Older People initiative is now piloting the development of complex community care networks or teams involving secondary care specialist and specialist community health and social services staff in order to redesign care for people with complex needs with emphasis on assessment and management of long term

care rather than episodic acute care. The Review sees these developments as very relevant, particularly to the needs of people with dementia or severe, enduring mental health problems.

- 1.11 With regard to resources, the Review sees it as critical that information systems are sufficiently sensitive to accurately track expenditure on all aspects of the service.

RECOMMENDATION

1. While services for older people with mental health issues may be located within either a mental health or older persons' programme of care, they should be provided as a discrete sub-speciality, with a ring-fenced budget and clear protocols for accessing other programmes of care.

Key Considerations

- information systems should be in place which are sufficiently sensitive to determine expenditure on service provision for this population;
- there should be a single, defined commissioning service.

Current Service Provision

- 1.12 In the consultation with service users, carers and service providers, it was evident that there are many examples of excellent services and best practice in Northern Ireland. However, it would appear that many of these have developed organically, without in many instances an overall strategy either within or between Boards and Trusts being in place. A number of the Boards and Trusts consulted were either beginning to develop, or had just developed, a Dementia and Mental Health Issues of Older People Strategy, as this Review was getting underway.

- 1.13 A number of deficiencies in current services identified by service users, carers and service providers highlighted the need for:

- a more collaborative and inclusive approach to care planning, i.e. involving service users where possible and carers at all stages of the planning process;
- a whole systems approach to designing services where the social, physical, emotional and spiritual needs of the individual are taken into account; and
- equity in accessibility to services.

Where We Want to Be

- 1.14 The Review considers that older people with mental health issues should be able to look forward to a response from services which:

- respects their individual autonomy and is person-centred;

- demonstrates fairness and justice – resources for services should be allocated and managed according to criteria which are transparent and which demonstrate equity;
- offers partnership with users and carers in the development, evaluation and monitoring of services;
- provides delivery of high quality, effective treatment, care and support;
- provides services which are readily accessible;
- delivers continuity of care and support for as long as is needed;
- provides a comprehensive and co-ordinated range of services and accommodation based on individual needs;
- provides comprehensive and equitable advocacy support, where required or requested;
- promotes independence, self-esteem and social interaction through choice of services and opportunities for meaningful employment;
- promotes safety of service users, carers, providers and members of the public;
- provides staff with the necessary education, training and support; and
- subjects services to quality control, informed by best practice evidence.

1.15 To achieve this, it will be essential that:

- i. there are sufficiently trained staff to directly deliver care and support;
- ii. different disciplines from health and social services backgrounds work in partnership both within and between the disciplines to provide a joined-up and coherent service to service users and carers;
- iii. sufficient information is provided to service users and carers to empower them to be part of the multi-disciplinary team in influencing the care and support they receive; and
- iv. an implementation and monitoring mechanism is established to help ensure that the proposals put forward in this Review are acted upon over the next 5, 10, 15 years and beyond.

CHAPTER 2

THE NATURE AND MAGNITUDE OF MENTAL HEALTH PROBLEMS IN LATER LIFE

- 2.1 The main mental health problems in later life include dementia, depression, delirium and other psychiatric disorders, including anxiety, psychoses and drug and alcohol problems. None of these are inevitable consequences of ageing, although the prevalence of dementia does increase with age.
- 2.2 The Review focused primarily on dementia and the functional mental illnesses which older people can experience, i.e. depression, anxiety and other psychiatric illnesses. Consideration of drug and alcohol related issues is covered in the Review's report, "Alcohol and Substance Misuse"; Alcohol Related Brain Damage, although referenced in chapter 8, is dealt with primarily within the Review's report, "A Strategic Framework for Adult Mental Health Services". Delirium is considered within the section on liaison psychiatry in chapter 7.

Dementia

- 2.3 Over the past 15-20 years, definitions of dementia have become much more precise in terms of the clinical features by which it should be identified. Deterioration in intellectual performance from a previous level must be accompanied by a significant decline in personal and social function and other causes for these impairments must also be excluded, e.g. general medical illness or toxicity (Cantley, 2001).
- 2.4 Dementia is a clinical syndrome characterised by a widespread loss of mental function, with some or all of the following features:
- memory loss;
 - language impairment;
 - disorientation;
 - change in personality;
 - self neglect; and
 - behaviour which is out of character.
- (NSF for Older People, 2001)
- 2.5 It has a number of causes, the most common of which is Alzheimer's Disease.
- 2.6 Different dementia sub-types can generally be identified by their mode of onset, the presence of particular neurological or psychiatric features and the course which the illness takes.
- 2.7 The Social Care Institute for Excellence, in their Practice Guide on Assessing the Mental Health Needs of Older People (January 2003), highlight the limitations of adopting a "disease only" perspective:

“If we view dementia only as a ‘disease’, then we are tempted to abdicate our fundamental responsibility as human beings for the welfare of our fellows, and leave it to scientists in laboratories to discover the pill, potion, gene or magic bullet that will ‘treat’ or even cure dementia. But if we see dementia as a condition of which degenerative brain disorder is only one part, but which is fuelled by the fear, anxiety, shame and incomprehension of both the person concerned, those who they are in contact with and the wider society – then we can begin to see that we have a role to play for ourselves.”

Functional Mental Illness (FMI)

- 2.8 The term “functional mental illness” is a generic term coined when it was believed that these disorders were not associated with a biological cause, although we now know that biological factors can play a part in many of these conditions. Although the term “functional mental illness” is still widely used, the Review is mindful that this term may become obsolete in the future.
- 2.9 In older people, the most prevalent functional illness is depression. Less common, but also present, are other psychiatric illnesses, such as delusional disorder (schizophrenia/paraphrenia), schizo-affective disorder and bipolar disorder (manic depressive disorder).

Terminology

- 2.10 The Review has adopted the term “mental health issues” as a summary term for use throughout this Report. This term includes anxiety disorders, mood disorders such as depression and mania, alcohol and drug misuse, psychotic mental disorders such as schizophrenia, acute confusion (delirium) and dementias.

Prevalence Rates

Dementia

- 2.11 Dementia is predominantly a disorder of the very elderly. At age 75, the prevalence rate is approximately 10 per cent. The prevalence doubles with every five years of increasing age, with approximately 40% of the total population over the age of 85 likely to be affected. There is some evidence to suggest however that beyond the age of 90, the risk of developing dementia begins to level off.
- 2.12 It is difficult to arrive at precise prevalence rates for dementia given the large number of people with the condition who are not in contact with health and social care providers. The Dementia Policy Scrutiny Report (1994) estimated that there were 12,448 people with dementia in Northern Ireland (Regional Information Branch, DHSSPS). A recent report to the Alzheimer’s Society (2007) on the prevalence and economic cost of dementia in the UK (produced by King’s College, London and London School of Economics) however estimates that there are 16,000 people with dementia in Northern Ireland and that this figure is projected to increase to 20,500 by 2017 and to over 47,000 by 2051. This represents a percentage increase of 30% and 200% respectively.

- 2.13 The Report estimates that of these 16,000 people, 396 have young-onset dementia (onset before the age of 65 years). However given that data is based on referrals to services, this number is likely to be an underestimate. The true figure may be up to three times higher.
- 2.14 Also of significance is the fact that, of the late-onset dementia group, there are approximately two women for every man affected.
- 2.15 As can be seen, the population of people with dementia is set to increase by 30% in the next ten years (by 2017). This will have a major impact for planners and commissioners involved in health and social care provision. It is imperative that services are planned now to meet increased need in to the future.
- 2.16 Of those people in the 65+ age group who have dementia, 30% will have mild dementia, 42% will have moderate dementia and 28% will have severe dementia. These figures are also significant for planners and commissioners in helping to determine likely demand for each type of service across the continuum of care.

Functional Mental Illness (FMI)

- 2.17 Mental illness in older age is very common across all care settings, however is often unrecognised due to the nature of the symptoms and the fact that many older people live alone. Depression in people aged 65 and over is especially under-diagnosed (Le Katona C. et al. 1991; Freeling P. et al 1985) and this is particularly true of residents in care homes (Mann A. et al. 1984). Rates of depressive illness in older people vary between 1 and 3%, but 10-15% of older people have depressive symptoms (Burns et al 2002; Simpson and de Silva, 2003). Unlike dementia and many other disorders, there is no obvious age-related increase in prevalence. People in their 90s have lower rates of depression than people in their 60s and 70s.
- 2.18 Conservative estimates of mental health problems in older adults suggest a prevalence of perhaps 40% of people attending their GP (Kendrick et al. 1991). Forty per cent of older people in residential care and up to 65% of those who are medical in-patients experience depressive symptoms (Burns et al 2002). The exclusion of these two groups of service users from most community surveys of mental ill-health has probably led to the relative under-estimation of depression in older people.
- 2.19 Prevalence rates for mental health problems in Northern Ireland are estimated to be 25% higher than in England (DHSSPS, 2003) linked to higher levels of social and economic deprivation, unemployment and the impact of the troubles. While there are no age-specific statistics available, older people have not been immune from the impact of these factors and indeed may have been particularly affected by them. One could therefore assume that this statistic is equally applicable to the over 65 year old population.

Interface of Depression and Dementia

- 2.20 Major and minor depression often occurs in patients with dementia and can be associated with deterioration in cognitive functioning. Although the majority of people with dementia do not develop major depression, more than half suffer from one or more depressive symptoms (Gruber-Baldini, 2003). There is an overlap between dementia and depressive symptoms and it is often difficult to determine whether the dementing illness or depression is the underlying pathology.
- 2.21 Depression in dementia brings additional disability to patients and their carers. Clinicians treating people with dementia, should routinely assess for depression and treat it, because successful treatment can improve many dementia-related outcomes (Boustani and Watson, 2004).

Ethnic Minority Groups

- 2.22 Prevalence rates of dementia and functional mental illness among ethnic minority groups are difficult to determine. Marshall (1998) as cited in Patel N. (1990) suggests that “the world of dementia is colour blind and minority communities are dementia blind”. Difficulties in arriving at precise figures are exacerbated by language barriers, reluctance to accept outside intervention, difficulties negotiating complex health and social care systems and the inappropriateness of diagnostic tools which were developed for use in white, indigenous populations.
- 2.23 The Chinese community is the largest single ethnic minority group represented in Northern Ireland, comprising 51% of the total ethnic population. There are estimated to be 8,000 Chinese people living in Northern Ireland, the majority of whom are located in the Greater Belfast area. There are also significant numbers in Craigavon, Lisburn, Newtownabbey and North Down. The Chinese community is growing at a faster rate than the general population (Irwin and Dunn) highlighting the need for this user group to be reflected in commissioning and service planning processes.
- 2.24 There are currently no statistics available in relation to prevalence rates for dementia or functional mental illness within ethnic minority populations, highlighting the need for primary local research in to this area. The difficulties in obtaining accurate statistics is acknowledged, given for example that less than half of Chinese people are registered with a GP (Chinese Welfare Association, 2006).

RECOMMENDATIONS

2. Health and Social Services Commissioners and Providers must have in place a detailed analysis of the demographic detail of their respective rapidly expanding older populations to effectively assess need and plan for current and future provision for those older people with mental health issues. This analysis should include identification of older people from ethnic minorities.
3. Health and Social Services Commissioners and Providers should undertake a scoping exercise of current service provision for older people with mental health issues, identifying shortfalls in provision, unmet need and the service provision anticipated for the next 10 years.

Legislative and Policy Context

Dementia Policy Scrutiny

- 2.25 While the community care policies developed in Northern Ireland in the 1990s (People First, DHSS, 1991) provide a policy framework that embraces dementia, this overarching policy had only limited impact on the development of coherent dementia services. The Dementia Policy Scrutiny, commissioned by that Department in 1994, provided an opportunity to establish a strategic direction for the development of dementia services and to provide guidance on best practice for purchasers and providers.
- 2.26 The Scrutiny Action Team's major recommendations were grounded on the need to establish dementia services on a sound and regular footing, with a clear administrative base, ensure the development of effective and well-targeted services, identify and meet need in a timely and appropriate manner and contribute positively to enabling people with dementia and their carers to live full and independent lives, ideally in a community setting. Recommendations (33 in all) were split into two groups: those which were to be implemented immediately, with limited resource consequence; and those which would be implemented progressively as part of a dementia strategy. The latter were recognised as possibly having more substantial resource consequences.
- 2.27 No formal audit of achievement in relation to meeting recommendations has been undertaken by the Department since the launch of the Scrutiny Report in 1994. Progress in meeting recommendations has been variable throughout Northern Ireland and many of the issues identified still remain and as such have formed part of the considerations of this current Review. The Policy Scrutiny Report also confined its terms of reference to dementia: the needs of older people with functional mental illness were not considered.
- 2.28 A summary of key legislation and policy underpinning work with older people with mental health issues and their carers is included in Annex 2.
- 2.29 The Bamford Review has also given detailed consideration to the need for new legislation for Northern Ireland, the overall purpose of such legislation, the guiding principles which

should underpin it, and the need for a comprehensive approach to respecting and protecting the dignity of people with mental health problems or a learning disability. The report on its proposals for reform will be published in the near future.

- 2.30 Capacity legislation, which has been introduced in Scotland and in England and Wales, is the main source of guidance in relation to dealing with consent, property and lifestyle issues. This legislation is predicated upon an assumption of capacity, unless it can be proven otherwise, and incorporates the values, principles and philosophy which underpin it. Staff will need to adopt more of a value-based approach to their work in this area, starting with the presumption that people can make decisions.
- 2.31 To help ensure that vulnerable people can make their voices heard, the legislation introduces independent mental capacity advocates. There is currently very limited access to advocacy services available to older people with diminished capacity in Northern Ireland.
- 2.32 Legal issues formed part of the public consultation exercise which was undertaken as part of the this dementia and mental health issues of older people Review. The key issue highlighted was the considerable lack of accurate information among staff and carers.

Human Rights Issues

- 2.33 The Review has identified a range of areas in the context of work with older people with mental health issues which may give rise to human rights concerns. Key areas of risk in current practice include:
- i. People with dementia being cared for in locked wards/care homes.
This practice could contravene Article 5 (The Right to liberty) and Article 8 (Right to family life). The recommendations of the Review promote long-term care options for people with dementia to be extended to include options such as specialist home care, supported housing options, assistive technology, dementia design specific care homes, all of which can manage risk in more sensitive, person-centred ways. It is essential that commissioners and providers continue to develop these care options.
 - ii. Consent to admission to care homes.
Admission without informed consent could contravene Article 5 (Right to liberty) and Article 6 (Right to a fair hearing). This issue should be addressed through capacity legislation, in particular, the assessment of capacity and use of advocates.
 - iii. Financial ceilings imposed on the provision of home care.
Boards and Trusts will need to be able to clearly demonstrate policies on fair access to care, with clear criteria for home care, including equality screening.
 - iv. Delayed discharges/waiting lists/lack of preventive services.
This could give rise to challenge in relation to Article 8 (Right to family life) as lack of resources can cause health to deteriorate, thereby adversely affecting family life. This is primarily a resource issue and it is unclear what the legal position in relation

to human rights would be. The Review clearly endorses the view that older people with mental health issues should have access to the same range of services, including intermediate care, as the rest of the population and that services should not be denied on the basis of age.

- v. Use of Restraint.
This could contravene Article 3 (Prohibition of torture), Article 5 (The Right to liberty) and Article 14 (Prohibition of discrimination). Trusts will need to ensure that policies on the use of restraint are value-based and comprehensive in order to address all of the manifestations of restraint. These policies need to be supported by the required procedures, training and education, as well as regular audit feedback loops. This issue is further explored in chapter 6.
- vi. Lack of Advocacy Services.
This could also contravene Article 14 (Prohibition of discrimination). The provision of advocacy services has been recommended by the Royal College of Psychiatrists (2005). It is possible that new capacity legislation will require the availability of advocacy. This issue is further addressed in chapter 3.
- vii. Elder Abuse.
Article 3 (Prohibition of torture) is the key consideration here. All Trusts, including hospitals, will need to ensure that the regional policy concerning the protection of vulnerable adults is fully and effectively implemented.

Funding of Long-Term Care

- 2.34 The Review's public consultation exercise supported the view of the Royal Commission that personal care should be provided free of charge.
- 2.35 A key issue of concern for carers related to top-up fees. The position adopted by the Review is that top-up fees should not be applied in relation to provision of basic minimum standards of care. The DHSS Circular HPSS R (3) 1/93 prohibits Trusts from "requiring a contribution from a third party in cases where the Trust itself decides to offer someone a place in a more expensive home than it would normally use, for example, where there is at the time no substitute available accommodation at the cost the Board would usually pay for accommodation".

Realistic tariffs for residential and nursing care which reflect the additional care and supervision needs as well as the social/diversionary needs of older people with mental health issues should be agreed. This process would be facilitated by the development (by the Regulation and Quality Improvement Authority) of a set of specifications which reflected the particular needs of this service user group.

RECOMMENDATION

4. Realistic tariffs for residential and nursing care, which reflect the particular needs of older people with mental health issues, should be agreed.

Review of Public Administration

- 2.36 The Review is mindful that the decisions on the Review of Public Administration announced by the Under Secretary of State in November 2005 will have major implications for the way health and social services are delivered within Northern Ireland. The Review considers it essential, however, that the commitment offered by the Minister to the development of new ways of managing performance which are patient-led, patient-centred and patient-responsive is realised. This will only be achieved through robust and comprehensive consultation with users, carers and service providers.

CHAPTER 3

INFORMATION AND ADVOCACY

Introduction

- 3.1 Too often people with mental health issues and their carers have difficulty accessing the information they want and even when they do, there can be problems understanding it, due to jargon, unclear language and hard-to-follow instructions. It is widely acknowledged that for older people with mental health issues and their carers, information regarding their condition is limited and not easily accessible (User Workshop, Age Concern Northern Ireland (2000). Without sufficient and timely information, it becomes more difficult for people to cope.
- 3.2 There are many sources of good general information available, however difficulty accessing this has been a dominant issue raised in consultations and discussions with all stakeholders involved.
- 3.3 A public information/awareness strategy is of highest priority and should help older people with mental health issues and their carers to understand their condition and become fully involved in decisions about their care and well-being.
- 3.4 The strategy should also provide information on the care options and all aspects of care available, particularly if these would have a significant effect on their daily life.
- 3.5 In order to meet individual needs and to provide the necessary support, the extent of information required needs to include definitions of the condition and illness, various treatments and interventions available and the possible impact of these on the individual's life. It is also essential that the individual is aware of all the current services that can be provided, including details on how and when to access these. The choice of services should include the full range of flexible support services, respite care etc, including information about advocacy, competency, legal issues and complaints procedures.
- 3.6 Resources need to be in place to enable people to have ready access to services, as and when required, in order to support both the individual and his or her carer. The information (including access to a 24 hour help-line and web-based provision) should be freely available and accessible in a range of public places, with programmes designed to educate society (including service providers) about care of older people with mental health issues.
- 3.7 There also needs to be a co-ordinated approach in relation to the access and provision of information and training. Joint working is important among all stakeholders, as without this, resources are wasted through repetition and duplication of services.
- 3.8 Information points should be available in a variety of locations, including Health and Social Services buildings. It may be advantageous to have, for example, the GP surgery as the main information point.

- 3.9 Public awareness information, including details on “prevention” and “early signs” should be in the general public domain to highlight the importance of a healthy lifestyle. People should be encouraged to see their GP at an early stage if there are any concerns regarding memory or mental health difficulties as research indicates the benefits of early interventions (Pratt and Wilkinson, 2001).

Best Practice Example

Directory of Care Organisations, Local Services and the Service you can Expect – Easy to read and understand Charter for People with care needs in Cornwall, 2004.

The special version of this booklet has been produced using graphics and language that are easy to understand and which may appeal to, engage with and inform a wide range of people.

People with Dementia Speaking Out

“I wanted to find out as much as I could about dementia, but all the books I read were for carers and made me think what a burden I was going to be” (Spicker and Gordon 1997).

- 3.10 After diagnosis, or even before, some people with dementia will often search out information about what is happening to them in order to gain a better understanding. There is, however, often little information available.
- 3.11 Information for people with dementia should be provided in a clear, easy-to-read format and address possible areas of concern, information about available treatments, the prognosis, how to deal with problem situations, the type of help available and where this can be accessed. Other sections should include information on legal and financial matters. It is essential that information is available, free of charge and provided in a variety of forms that are acceptable and easy for the target audience to understand. Internet options should also be explored.

Best Practice Example

“Facing Dementia” booklet published by Alzheimer Scotland. This booklet is for people who have a diagnosis of dementia and helps to give an understanding of the condition. It is written by people with dementia.

Carers Speak Out

“People in general don’t understand dementia and it gets so much negative publicity. I felt lost when my husband was first diagnosed and had so many unanswered questions. It took a long time before I got information and found out who I could contact for help when it was hard to cope at home. People need information as soon as they get the diagnosis so they know what they are dealing with.” (a carer)

- 3.12 All carers have a need for information and advice on the condition and prognosis, the practical implications, how and where to access services to support them, benefit entitlements and legal aspects (Gilliard and Rabins, 1999).
- 3.13 Information on the condition and available services are one of the supports which carers value most, alongside acknowledgement of their role and attention to their distress (New Zealand Guidelines Group, 1997; Nolan and Keady, 2001).
- 3.14 Some carers will want to know everything about dementia as soon as possible, while others will want a more gradual and staged exposure to information (Keady and Nolan, 1995). Both positions are equally valid and it is important that the professional should be led by the carer in determining the nature and level of information provided. Carers may also need to hear the same information repeatedly (Cantley, 2001).

Best Practice Examples

“ACROSS” – An information booklet for carers produced by Newry and Mourne Trust in partnership with the Alzheimer’s Society

“Dementia Handbook” – An information booklet for people with dementia, their carers and professional staff produced by Down Lisburn Trust.

General Public Awareness

- 3.15 Information about mental health issues in older age needs to be widely dispersed in many formats so that general knowledge regarding early signs of these conditions are well recognised by the public. While there has been increased media exposure of mental health issues for older people, particularly in relation to dementia, there is still a long way to go before there is wider acceptance and social inclusion. It is imperative that the health promotion needs of older people with mental health issues are given the same priority as other service user groups. It must also be recognised that a health promotion strategy must encompass physical as well as mental health perspectives.

Best Practice Example

Alzheimer Scotland has produced a guide and leaflet, “Dementia-friendly communities”, to encourage everyone in the community to be more aware of people with dementia and the ways in which they can be helped.

Training and Education

- 3.16 Training and education programmes are required for all staff working in public places so that they have the necessary knowledge and skills to respond to queries regarding services and to direct people to where they can obtain information and advice.

- 3.17 Investment in further education and training for people working in this field of work is needed as the lack of experienced staff to meet current service demands has been noted by both carers and service providers as part of the consultation process. This also needs to include training for staff working in the independent sector.
- 3.18 Carers and older people with mental health issues have an important role to play in shaping the training that is provided (Killeen, 2001).
- 3.19 There is also considerable evidence of the benefits of education and training programmes for carers. It has been found to improve adjusted rates of survival at home, with fewer deaths and to delay institutionalisation (Brodaty et al. 1997).

Best Practice Examples

“Depression and Dementia in Older People” – an interactive training CD Rom specifically aimed at doctors and other health care professionals (produced by Kiss of Life Multimedia Ltd.).

“Coping with Maggie – Caring for Margaret”. This is a training and information resource pack for carers of people with dementia produced by Homefirst Trust.

“A Clear Path” DVD and training manual – an information resource for Carers and training pack for all staff groups.

RECOMMENDATIONS

- 5. A Policy and Practice Development Centre for Mental Health Services for Older People should be established which would provide information, training, consultation and research and help secure comprehensive and relevant dementia service provision.
- 6. Public education programmes, focusing on promotion of good mental health and prevention, should be developed.
- 7. The DHSSPS should ensure from a strategic point of view, that health promotion in relation to mental health issues is given the same priority as for other service user groups.
- 8. Dementia and mental health issues in older age should be included in all training programmes for health and social care staff (including those working in the independent sector). This should be undertaken on an inter-agency and multi-disciplinary basis where possible. Training and education programmes for carers should also be provided.

[Unsuccessful attempts were made to achieve a viable Dementia Services Development Centre in Northern Ireland between 1992-1999. An inter-professional, inter-agency group established Dementia Development N.I. in 1995 as an incorporated company limited by guarantee. It was dissolved in 1999 after persistent efforts failed to secure sufficient sustainable support. Although the need for such a centre was recommended in the Policy Scrutiny Report of 1994, Northern Ireland remains the only part of the United Kingdom without a Dementia Centre.]

Key Considerations

Local information directories for all areas, detailing the services and facilities available for people with dementia, should be developed. On-line directories have the advantage of being easily updated to ensure the currency of information.

- An information package (specific to Northern Ireland), including a booklet on dementia, should be made available to people with dementia and their carers at the time of diagnosis, with access to additional information as required/requested.
- All information should be made available in a range of formats (e.g. posters, leaflets, internet, CD) and languages to meet the needs of people with disabilities, different ethnic backgrounds. The information should be written in a user friendly, non-jargon format, with the use of symbols and pictures in addition to text to assist people with dementia and functional mental illness to understand their diagnosis and how and where they can obtain support.
- Individuals and their carers should have access to a contact point or 24 hour helpline to ensure that advice and support is readily accessible, thereby minimising the risk of a crisis developing.

The Provision of Advocacy for People with Dementia

3.20 Dementia advocacy seeks to support people in communicating their views and wishes and to enable people to access their rights. Dementia advocacy also seeks to enable people with dementia to make informed choice about, and to remain in control of their own care.

3.21 Many people with dementia face serious disadvantage and are vulnerable to various forms of discrimination and abuse. For many, the experience of the illness is characterised by reduction and exclusion – often unintentional but nonetheless damaging to individuals whose worlds have already been eroded. People are denied a part in decision-making about most aspects of their lives and frequently denied the knowledge of their own condition. Perceived difficulties of communication are used to justify non-engagement with a person with dementia; and issues around risk may lead to further disempowerment.

3.22 Independent advocacy for people with dementia aims to redress some of the effects of such disadvantage through supporting people with dementia, for example, to:

- play as full a part as possible in decisions about everyday matters affecting their lives;
- play as full a part as possible in major life decisions, e.g. about moving home;
- obtain outcomes which they want;
- prevent outcomes which they do not want;
- ensure that their needs are met;
- protect their rights and secure their entitlements;
- promote their well-being; and
- improve their quality of life.

- 3.23 A specialist dementia advocacy service should offer specific expertise and understanding of communication with people with dementia, of the variable progression of dementia illnesses and of best practice in dementia care. Expertise should also include substantial knowledge around welfare and legal rights and can also be used where dementia may be an additional barrier to expression of individual need, for example, with people with alcohol-related dementia or those with other mental health problems.
- 3.24 Advocates must work within a declared code of conduct to ensure that the person's wishes may be expressed despite the complexity brought about by multiple health concerns.
- 3.25 Dementia advocacy will involve some or all of the following processes:
- building a relationship with the person with dementia;
 - ascertaining the person's views and wishes;
 - enabling people to exercise choice;
 - supporting people in having their views heard;
 - representing people's interests;
 - influencing (often powerful) others; and
 - resolving conflicts.
- 3.26 Dementia advocacy must be underpinned by these values and principles:
- autonomy;
 - empowerment;
 - consent;
 - acceptance and respect;
 - choice;
 - citizenship;
 - inclusion;
 - confidentiality;
 - loyalty to the person with dementia; and
 - independence from other interests.

Advocacy for Older People with Functional Mental Illness

- 3.27 Many of the principles outlined above apply equally to the provision of advocacy support to people with functional mental illness, who are often similarly excluded from decision-making processes affecting their own lives, particularly where there are perceived to be high levels of risk.
- 3.28 Carers' views are important in their own right, but may be different from those of the older person with the mental health issue.
- 3.29 The role of advocates in supporting and assisting people to represent their views should be welcomed.

RECOMMENDATION

9. Independent, specialist advocacy services should be available for older people with mental health issues. These should be commissioned on a regional basis to ensure equity of access and service delivery to agreed standards.

CHAPTER 4

PERSPECTIVES FROM SERVICE USERS AND CARERS

Introduction

- 4.1 At the heart of any review of mental health services for older people is the person with dementia or mental illness and his or her carers. As part of the Review, a series of consultation meetings were held to capture the views and experiences of users and carers so that this information could be used to influence and shape this Report and its recommendations.

Service Users

- 4.2 For the individual, the onset of dementia or a serious mental illness can be devastating. The things they were once able to do independently, or remember, they are no longer able to, resulting in frustration and confusion. Understandably, this can lead to anger and “challenging” behaviours, as they try to make sense of what is happening. Often no one tells them their diagnosis to help them understand. As their condition deteriorates and “strangers” increasingly do things for and to them, they lose more and more of their dignity and self-worth.
- 4.3 It is vital to remember that the individual with dementia or mental illness is a person with a full life story who has been a valued member of his or her family and society for possibly 60 or 70 years. Dementia or mental illness does not take this away. They are still a person of worth and value and should be treated as such, with dignity and respect. They should be given the right to be involved in planning their own care and enabled to make decisions as far as possible. They should be treated as an individual, with support tailored as far as is possible, to take account of their needs, likes and dislikes.

Carers

- 4.4 Family carers provide the vast majority of care and support to older people with mental health issues. Community care policies largely depend on the continuing contribution of carers who significantly reduce the amount of input that social services and other agencies need to make.
- 4.5 The Valuing Carers Strategy (DHSSPS, 2002) highlights that “it is in society’s interest to sustain this motivation to care and to see that appropriate packages of support are assembled for people who are willing and able to care for others.... without jeopardising their own health or financial security or reducing their expectations of a reasonable quality of life”. It is also important, however, to recognise when it is inappropriate to expect a carer to continue and when strategies should be aimed at helping them to relinquish this role (Nolan et al. 1996).
- 4.6 Carers’ central role must be fully acknowledged by commissioners, planners and service providers in how they modernise services to provide ongoing and meaningful support to

carers. A systematic, planned approach that engages the carer as an integral part of the system of care has benefits for users, carers and services (Oyebode, 2005).

- 4.7 The Forgetful but not Forgotten Report (RCPsych, 2005) states that there should be special sensitivity to the effects that caring for a person with dementia may have on a caregiver. Caring for people with dementia in particular is associated with higher levels of depression and stress (Livingston et al. 1996). Relationship changes which occur in the caring relationship can be very emotionally distressing and can involve both practical and health implications for the carer.
- 4.8 Carers often report that they feel isolated and have to cope alone. During the consultation exercise, carers stated that they found it “difficult to access support outside of the home due to their caring responsibilities”. The example was given by one carer of ‘feeling like a prisoner in their own home’. Carers spoke of “feeling abandoned” and “being left to get on with things if they seemed able to”. Others spoke of having to sell property or re-mortgage their home just to keep going. A number of carers stated that they had had to give up their jobs to continue with their caring responsibilities.
- 4.9 Carers’ distress did not cease when their relative was admitted to a care home. Rather, this decision led to another set of concerns, including feelings of guilt and despair, feeling excluded from care planning and concern over the quality of care provided.
- 4.10 The content of the remainder of this chapter is taken directly from the consultation report and provides a summary of the key concerns of users and carers. Recommendations in relation to addressing these issues are integrated throughout the Report.

First Contact and Appropriate Pathways for Specialist Support

- 4.11 The GP is often the first point of contact for both user and carer, offering an important opportunity to provide information, support and treatment, which can make a real difference to the lives of users and carers. GP training is required to facilitate earlier identification of dementia, appropriate referral pathways and signposting of support for both users and carers.
- 4.12 Carers report feeling excluded by the primary care team and left to cope alone after a diagnosis has been made.

Prevention

- 4.13 The link between unhealthy lifestyles and dementia should be explicitly promoted.

Information

- 4.14 Users, carers and families need more help to :
 - understand the diagnosis;

- know about the range of support services and treatments available;
- understand the legal issues involved and receive appropriate guidance and advice;
- access information from one source on an ongoing basis. The information should be locality specific; and
- look after their own needs.

4.15 There is a need for increased public awareness about dementia.

Advocacy

4.16 There is a need for advocacy services and support for vulnerable individuals.

Making Complaints

4.17 Carers need better information and support to complain when dissatisfied with services.

4.18 The Regulation and Quality Improvement Authority needs to exercise more rigorous monitoring and regulation of the care provided in independent homes.

Equity of Access

4.19 Ageist attitudes within the system need to be challenged.

4.20 Access to services for those over 65 are inequitable compared to younger people.

4.21 A wider range of treatments, therapies and activities need to be available including Cognitive Behavioural Therapy, Physiotherapy and appropriate activities in all care settings.

4.22 There should be increased access to day care.

4.23 Provision for younger people with dementia is limited and needs to be considered in a more strategic way.

4.24 There is recognition that mental health services for older people fall between service areas.

4.25 Accessing relevant services is more difficult for people in rural areas.

4.26 Users and carers in all settings, expect staff to be appropriately trained, patient and competent and services to be much better co-ordinated than they are at present.

Person-centred Services

4.27 The culture of care in all care settings should have user needs at the centre and clear leadership in place to promote this.

- 4.28 Approaches to care planning need to be much more person-centred and carers need to be included in the care of their relative. Carers and families need to be supported to be involved as they wish, in the care of their family member, whether they are in hospital, residential or nursing home settings. Good communication is the key to this.

Integrated Services

- 4.29 There is a need for more effective liaison between general hospitals and psychiatric services.
- 4.30 Communication between the relevant professionals across all settings needs to be promoted and supported to ensure appropriate information sharing.
- 4.31 Dementia services should be specialist and should sit where service users most benefit and are likely to attract resources.
- 4.32 The needs of older people with a learning disability and dementia require joined up approaches between the relevant specialisms to ensure their needs are recognised and met.

Medication

- 4.33 Review of medications needs to be more regular and thorough with relevant professionals clear about their respective responsibilities.
- 4.34 Improved medicines management is needed, from better co-ordination between existing medication regimes and new medications prescribed in hospital to helping carers cope with the proper administration and review of medication at home.
- 4.35 There are concerns about over sedation in some circumstances.

Carers and Employment

- 4.36 Carers, who choose to return to work following a caring role, need support to do so.

Respite Care

- 4.37 Access to good quality respite services needs to be improved. Carers need the reassurance of knowing that they have easy access to emergency respite options should they become ill themselves.

Long-Term Care and Support

- 4.38 Service users should not be kept in hospital for long periods of time. They should be enabled to stay at home if at all possible, facilitated by intensive support mechanisms.
- 4.39 Housing options should be further developed, including use of assistive technologies. It is essential that these services are actively integrated in to local communities.

- 4.40 There are currently insufficient places available in specialist dementia units.
- 4.41 Physical care environments need to be in keeping with the needs of people with dementia.
- 4.42 Ongoing staff training is needed for non-specialist staff working with people with dementia. This should be supported by specialist staff/teams.
- 4.43 Long-term care settings are increasingly recruiting staff from overseas. Communication issues inevitably arise. This needs to be recognised and addressed through ongoing training and education programmes.
- 4.44 Continuity of care is important to users and carers and service providers should make this a priority through appropriate recruitment and retention practices. Building caring relationships with service users should be encouraged and supported.

In-patient Care

- 4.45 More attention should be paid to the needs of older people with dementia or mental illness in acute medical settings.
- 4.46 Carers are concerned about the quality of basic care available and the increasing expectations that families should provide that care.

Ongoing Engagement with Users and Carers

- 4.47 Users and carers expect that following the Review, they will be afforded ongoing opportunities and mechanisms to assess progress and provide feedback.

CHAPTER 5

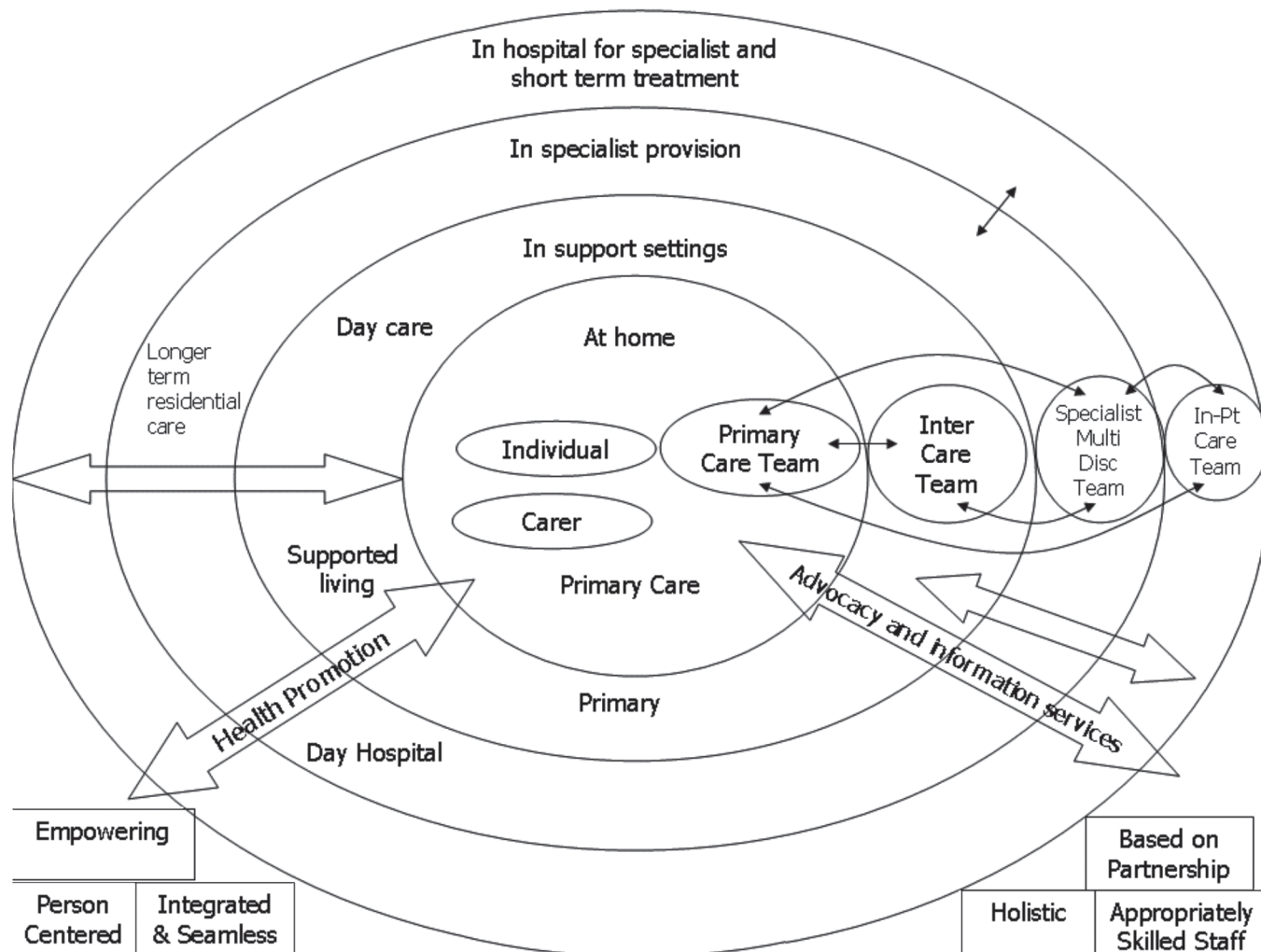
THE CONTINUUM OF CARE

Introduction

- 5.1 The Review is committed to ensuring that the continuum of care available for older people with mental health issues is:
- person-centred;
 - empowering;
 - reflective of the range of presenting needs and care preferences;
 - holistic;
 - flexible in response;
 - responsive to changing needs;
 - locally delivered, as far as possible;
 - as seamless as possible, offering continuity of care;
 - focused on achieving positive outcomes in terms of health and quality of life; and
 - effectively monitored.
- 5.2 The needs of older people with mental health issues change throughout the span of their illness. Services and supports which are required at the stage of initial diagnosis are likely to be very different from those required in the latter stages of illness. The diagram in Annex 4 seeks to depict this journey.
- 5.3 Services also need to be individually tailored to meet identified needs and reflect the care preferences and aspirations of service users and carers.
- 5.4 Highly individualised, needs-led responses require a complex array of services across a range of tiers. To ensure that the care pathway for service users and their carers is as seamless, coherent and integrated as possible, it is essential that these services are underpinned by careful planning, good management practices, flexible budgets, robust communication systems, effective multi-disciplinary and multi-agency working and meaningful engagement with service users and carers.
- 5.5 The Review has endeavoured to develop a model of care for older people with mental health issues which considers the likely supports and services which will be required, from independence and low level practical home-based support through to specialist care, and the relationships which need to exist between community and primary care, specialist services and hospital based provision.
- 5.6 The Review supports the view that older people with mental health issues should be looked after in the context of their own home for as long as possible, unless there are very good reasons why this cannot be the case.
- 5.7 The Review also acknowledges that in this context, much of the support offered to the older person will be provided by family, community and voluntary sector services.

- 5.8 The next two chapters consider the framework of services across the care continuum, identifying key issues, underpinning principles and recommendations.
- 5.9 The diagram on page (?) represents the continuum of care for the older person with mental health issues and his or her carer across this continuum of care. It highlights that people can move both ways across the care continuum dependent on their needs at any given point in time. Advocacy and information support and health promotion should underpin all service responses.
- 5.10 Services, irrespective of level, should be person-centred, holistic, integrated and seamless, based on partnership, empowering and delivered by appropriately skilled staff.

The Care Continuum



CHAPTER 6

CONTINUUM OF CARE - PRIMARY AND COMMUNITY CARE SERVICES

- 6.1 For the majority of older people with mental health issues, it will be the primary care team who will provide most of the care required. Primary care is the cornerstone of health and social care provision and most people look to primary care for help, in a local setting, near to where they live. It acts as a first point of contact and as a gateway to a wide variety of services, both within the primary care system itself and to other parts of the wider health and social services system. It is important to recognise, however, that community care comprises both primary and specialist provision.

The “Everybody’s Business” Report (DoH, 2005) sees the key tasks of primary care as comprising four elements:

- health promotion and helping people to care for themselves and their condition more effectively;
- recognition of mental health problems;
- formulation of a care plan, including support for family carers; and
- referral to specialist services for the those who have complex needs or who pose high levels of risk.

Primary Prevention of Dementia and Mental Health Problems in Older People

Dementia

- 6.2 In recent years there has been increased interest in understanding the factors that cause dementia, or increase the risk of it developing and in investigating how these factors could be modified. The prevalence of dementia could be reduced by as much as 50% if risk reduction strategies were successful in delaying the onset by five years. There have been several recent reviews of the subject (NHS Health Scotland, October 2003; Purandere et al. 2005).
- 6.3 The research on risk factors for dementia is complex and much remains to be clarified. Evidence suggests that there is no single cause for dementia and hence no single solution, but there are some suggestions of possible scope for intervention. The clearest evidence is of an association between the so-called vascular risk factors (i.e. risk factors for stroke and heart disease) and dementia. Stroke itself increases the risk of dementia by 5 to 10 times. Hypertension and high cholesterol (especially in the form of increased low-density lipoprotein) in middle life, diabetes and smoking have all been associated with dementia and it seems reasonable that improvement of these is likely to reduce risk of vascular dementia. Recent work has suggested that these factors are also independently associated with Alzheimer’s Disease. Obesity has also recently been linked with dementia.
- 6.4 The evidence for other factors is less clear, but there is some evidence suggesting stress management, physical and psychosocial activity may be helpful (Wang et al. 2002;

Mahandra and Arkin, 2003). Other work has looked at various components of the diet and, while there is not enough evidence to recommend specific supplements, it seems likely that a healthy diet with adequate levels of Vitamin B12, folic acid and Vitamins C and E may be useful.

Depression

- 6.5 Depression is the most common functional mental illness in older people and studies have shown it is often under-diagnosed and under-treated (DoH, 2005). Depression is the major cause of suicide in older people; it adversely affects quality of life and disability from physical disorder and is associated with an increased mortality.
- 6.6 About 13.5% of older people living in the community will have clinically significant symptoms of depression and, overall, about 2% will have a major depressive illness (Beekman et al. 1999).
- 6.7 There is little definitive evidence for prevention of depression in older people. However, depression in this group is known to be associated with social isolation and poor physical health. It seems likely that measures to promote social integration and a healthy lifestyle are likely to prevent some depression.
- 6.8 Depression is particularly associated with vascular disease (Baldwin and O'Brien, 2002) and improvement of vascular risk factors as mentioned above may reduce depression as well as dementia.
- 6.9 High levels of depressive symptoms are found in carers, especially those caring for someone with dementia (Alzheimer's Society, 1993; Livingston et al. 1996). A major contributor to stress is behavioural disturbance (Huckle, 1994). It has also been shown that psychosocial interventions can reduce the level of depressive symptoms in caregivers (Brodaty et al. 2003) and so seems likely that they may also prevent depressive symptoms in caregivers.

Early Detection/Case Finding

"The GP said I was getting old - what do I expect at my age. He wouldn't listen to me or my wife. I knew I wasn't well and when I got treatment I really felt better".

man with dementia following GP refusal to test for dementia

- 6.10 There is general agreement on the need for early detection of mental health issues in older people (NSF for Older People 7.7; Mental Health Services for Older People, Regional Report, DHSSPS 2003; User and Carer Consultation Report, 2004).
- 6.11 With dementia, early detection allows the person the opportunity to discuss their symptoms and treatment options, make informed choices about their future and, possibly by lifestyle choices related to cardiovascular risk factors, modify the course of their illness.

- 6.12 In functional mental illness, it will reduce distress to sufferers and their carers by earlier access to information, support and treatment and potentially reduce serious consequences such as self-neglect, self-harm or suicide.
- 6.13 Early detection will begin in primary care. GPs and other members of the primary care team require training in recognising the early signs of mental health issues in older people and must know who to refer to for further advice and assessment.
- 6.14 GPs are often the first point of contact for older people with mental health issues or for concerned carers or family members. It is clear, however, that many GPs have not received an update in dementia care since their undergraduate training. There is also often concern that GPs fail to detect mental illness, particularly depression in older people

The Forget-me-not Report (Audit Commission, 2002) found that less than half of the GPs surveyed felt they had sufficient training in dementia. Unless doctors are aware of the early signs of dementia, they are unlikely to consider the diagnosis (Rait and Walters,1999).

- 6.15 There is often uncertainty as to what is the best screening/assessment tool to use and debate as to whether a GP has time during a normal 10 minute surgery consultation to use it effectively.
- 6.16 Many of the carers who participated in the public consultation exercise, highlighted difficulties in making contact with the GP surgery, obtaining suitable appointment times and in getting repeat prescriptions. One of the suggestions made was for the establishment of a mechanism to fast-track help for carers, such as the caller being identified as a carer on the computer screen in the surgery.

RECOMMENDATIONS

- 10. Health and social care professional education and training at undergraduate and postgraduate level should include more training in the area of dementia and functional mental illness. This education should include experience of dealing with these conditions in the community.
- 11. Primary care staff should receive more training in the early detection of dementia and functional mental illness and recognise the benefits of doing this. The use of standard assessment tests should be encouraged.
- 12. Systems which are sensitive to the particular needs of carers should be in place within GP surgeries, e.g. flexible access.

Key Consideration

- There should be training and education programmes in place for all care providers, including domiciliary care staff, care assistants and community nurses to encourage earlier referral within primary care.

Arrangements for the Delivery of Primary Care

- 6.17 The first General Medical Services (GMS) contract for GPs, introduced in April 2004, strongly influenced the disease areas on which doctors in primary care focused and it made no specific reference to dementia or functional mental illness in older people. The new contract, starting in April 2006, has points allocated for the quality of care of patients with dementia and depression. The fine detail of this remains unclear and it is uncertain how GPs will tackle the new targets relating to these disease areas. It will take at least until April 2007 to get feedback on whether quality of care has improved.
- 6.18 It is also clear that effective communication with mental health professionals improves patient care. The option of having a lead GP within a practice, with a special interest in dementia, may help this process. A concise care pathway will allow the team to work efficiently and in a co-ordinated manner.
- 6.19 In some areas, the development of a locally enhanced service (LES) for the management of patients with dementia and functional mental illness may improve care further. This will require careful planning, with input from primary and specialist services to ensure they complement each other.
- 6.20 Where mental health issues are detected, protocols should be in place for the care and management of the person, agreed with specialist services. These should address issues of initial assessment, initial management and guidance for referral to specialist services.
- 6.21 Primary care should remain responsible for interventions for physical co-morbidities, sensory deficits and other disabilities.
- 6.22 All primary care staff should be able to offer a degree of support to people with dementia and functional mental illness. A tiered approach should be adopted, with simple, less intensive treatments available in primary care. This should include access to psychological therapies for older people. These should be delivered by practitioners with suitable training, experience and supervision. Link workers liaising between primary and secondary care may be appropriately placed to provide some of these skills. Local protocols should specify when more specialist interventions are necessary.
- 6.23 The voluntary sector makes a critical contribution to primary care of older people with mental health issues. Close links should be established and voluntary agencies should be encouraged to work together to provide local service/resource directories or to develop web-sites, which can be constantly updated.

RECOMMENDATIONS

13. Clear, local protocols should be drawn up jointly between primary care and specialist services.
14. Dementia care and care of older people with functional mental illness in the community should be considered as a Locally Enhanced Service (LES) within the GMS contract.

Generic/Specialist Interface

- 6.24 All people with symptoms suggestive of dementia should have an assessment from a health professional competent to make an accurate diagnosis, and to prescribe drug therapy, if appropriate. This is likely to be a doctor with training in dementia, but could include a specialist nurse (if part of a specialist multi-disciplinary team with medical input).
- 6.25 The consultation exercise has highlighted that users and carers are confused about how the service is organised and believe that communication needs to be improved and links between primary and secondary care strengthened.
- 6.26 Many patients with longstanding functional mental illness or new onset symptoms in later life will be managed in primary care but should have services readily available to them from secondary care.

Best Practice Example

North and West Belfast Projects in Ballyowen and Bruce House Assessment Centres, with nurse-led pre-assessment screening.

Domiciliary Care

"Our care worker is like a ray of sunshine - cheers up the day and lets me out for a while"

carer of man in receipt of domiciliary care

- 6.27 Most older people with mental health issues wish to continue to live in the community, where possible, with the support of informal carers. However, of those with dementia, 89% need some help with personal care, including continence, at least once a day. 62% need help with personal care at night (Assessment of Needs of Older People with Dementia, Scottish Report, 2002).
- 6.28 Consequently, there is considerable dependence on domiciliary support. For it to be effective, however, it must be flexible, responsive and delivered by trained staff.
- 6.29 Domiciliary care is support provided to individuals in their own home. It includes assistance with personal care, getting up/going to bed, feeding, medication, toileting and essential household tasks. For people with mental health issues, it can also include practical management e.g. assisting and prompting, ensuring bills are paid, medication is complied with or prevention of isolation.
- 6.30 The Dementia Policy Scrutiny (1994) stated that:
- “Purchasers should explicitly require dementia services to be delivered by adequately trained and skilled staff; and all service sectors should develop training strategies in respect of specialist dementia teams and all staff working directly with elderly people.”

- 6.31 Whilst greater emphasis is now placed on training, this is an area that requires considerably greater investment and development. The introduction of Domiciliary Care Standards by DHSSPS and the planned Registration and Regulation of the workforce is welcomed. This must, however, be adequately resourced. A balance needs to be established between ensuring good levels of service provision and recruiting and retaining adequate levels of staff to provide this service.

Best Practice Example

Age Concern's Dementia Home Support Service in North and West Belfast provides specific support programmes for older people with advanced dementia, enabling them to live at home. The service includes administration of medication and personal and social support and offers continuity of care, with the staff member being linked with the person with dementia at the initial assessment stage and then providing any follow-up support required.

- 6.32 Domiciliary support, to be effective, must be available when it is needed. Carers report particular pressures at night, often resulting in frequently interrupted sleep. This is often cited as a reason for carer breakdown and a precipitating factor in the admission of the person to residential or nursing care. Some Trusts have developed Mobile Night Services which provide support to people who require assistance going to bed, medication, toileting or security during the night. Such schemes have facilitated greater numbers of people with high level needs to remain at home.
- 6.33 Carers within the public consultation highlighted the potentially intrusive nature of domiciliary care and the need therefore for continuity and consistency of care.

RECOMMENDATIONS

15. Specialist domiciliary care services for older people with mental health issues should be developed. These should be available over a 24-hour period. Continuity of service delivery is vitally important and every effort should be made to ensure this is central to any new care plan.
16. Good quality domiciliary care requires adequate resources to be made available to attract good staff and allow for proper training. Trusts must identify the appropriate resources to develop specialist domiciliary support services. These services must be supplemented by assistive technology and multi-disciplinary crisis/rapid response.

Key Considerations

- Domiciliary care needs to be developed as an attractive job with career development opportunities. A regional approach to the development of the domiciliary workforce should be adopted, supported by a realistic costing of the delivery of sustainable Home Care Support services.

- Demographic trends indicate that there will be a significant increase in numbers of older people presenting with dementia and mental health issues requiring domiciliary support. This needs to be reflected in service and development planning and adequately resourced.

Emergency Care

- 6.34 Most older people with mental health issues continue to live in the community. Many live alone and depend on support from family and other carers. Many of the services provided are not available outside normal working hours. A problem may arise, either because of an exacerbation of illness or problem in their personal or social situation. There may be a sudden increase in risk of self-harm, harm to others, self-neglect, risk taking behaviour or sudden change in their support system. In people with dementia, a sudden worsening of the mental state is often due to a delirium caused by some underlying physical health problem, such as infection, drug toxicity or heart problems. It is essential that assessment of these individuals includes a full urgent medical examination and this is likely to be best provided through primary care.
- 6.35 Carers report a lack of responsive and flexible support to allow them to continue to care in their own homes safely at these times.
- 6.36 The change in “Out-of-Hours” GP care means that it is very uncommon for the doctor seeing the patient to know anything about the situation or background of the patient. This often makes hospital admission more likely.
- 6.37 Managing the person at home will nearly always be the preferred option and while some older people will need admission to hospital for treatment of their condition, it is important that they are not admitted solely to ensure their safety when, what is really required is an urgently increased level of care in the community. Community based services should be able to provide urgent assessment of their social needs and have immediate access to a range of support services, both at home (including care at night) and in residential facilities. The use of patient/carer held case notes documenting essential information, including key worker, medical issues and medication would help facilitate this.
- 6.38 In some parts of Northern Ireland, initiatives on chronic disease management are being piloted. These aim to develop new ways of thinking about chronic disease, in particular case management for the most frail elderly people. The literature in chronic disease management argues for joint approaches at a local level and consideration to setting up clinical directorates that span primary and secondary care, based on a clinical governance approach, information sharing and joint working. The Review sees merit in considering integration of services for people with dementia and severe FMI with future development of chronic disease management programmes.
- 6.39 The Review notes the development of crisis and home treatment services within general adult mental health services in a move to reduce hospital admissions, e.g. Home Treatment/Crisis Response Teams. These teams are well placed to include older people suffering from functional mental illness.

- 6.40 There has also been a range of developments in relation to Rapid Response Services. Again these teams are well placed to include people with dementia.
- 6.41 In extending these services to include older people with mental health issues, it is imperative that staff are given appropriate training to enable them to effectively meet the additional care and supervision needs of this service user group.

Best Practice Example

Ireland Lodge Resource Centre, Brighton. Provision of a crisis response team to deal with acute problems/carer breakdown in the community.

RECOMMENDATIONS

17. Support for older people with acute mental health issues should be available on a twenty-four hours a day, seven days a week basis. Support should be available both for those with dementia and functional illness.
18. A person with dementia in the community who develops acutely increased confusion/agitation should have an urgent medical assessment to check for delirium.
19. Older people should only be admitted to hospital if their medical or psychiatric condition requires it. No-one should be admitted to hospital solely to provide a place of safety when what is needed is an increased level of care in the community.
20. Older people with dementia and FMI should have access to similar crisis/home treatment teams as younger people with mental health problems or those with physical illness. Crisis/Rapid Response Services should include older people with FMI and dementia and be sensitised to their specific needs.

Key Considerations

- The use of patient/carer held case-notes documenting essential information, including key worker, medical issues, medication should be introduced.
- Consideration should be given to integrating services for older people with dementia or severe functional mental illness with future development of chronic disease management programmes.

Direct Payments

- 6.42 Direct Payments allow service users or their carers to purchase their own care and provide greater autonomy for individuals. Take-up levels are however low. Carers consulted identified the unwelcome responsibilities of being an employer and also the difficulties associated with finding staff to provide care.

- 6.43 It is important to note that care purchased through Direct Payments will not be subject to the Care Standards or Registration and Regulation requirements. Alternative safeguards will therefore need to be considered for individuals who purchase their own care.

Key Consideration

- People who choose to purchase care through the Direct Payment scheme must be offered some protection. Minimum standards of care should be established and monitoring arrangements developed.

Day Time Support/Respite Care

- 6.44 People with dementia have been found more likely to use day care services than other older people, particularly by those with severe dementia and those with co-resident carers (Philip et al. 1995; Moriarty and Webb, 2000). Services provide an opportunity for support, respite, therapeutic intervention, maintenance and social integration, as well as respite for carers. It is often highly valued by individuals and their carers (Levin et al. 1994; Moriarty and Webb, 2000), but is not always widely accessible. Opening hours are usually not sufficiently flexible to allow a carer to continue working.
- 6.45 A range of models of day care for older people with mental health issues exist, including generic and specialist community based day care settings as well as that provided within residential or nursing care homes. There is some evidence to suggest that in generic day centres, people with dementia are often not accepted or are marginalised (Curran 1996). Some generic day centres do, however, cater specifically for people with dementia by designating certain days for their attendance or providing separate facilities within the same building. Where day care is provided within residential or nursing care homes, there is some evidence to suggest that it is more acceptable to attendees, as well as to the existing resident group, if this is provided separately (Pickard, 1999).
- 6.46 Existing models of day opportunities tend to be very traditional and are much less likely to be based on principles of social inclusion than services provided for younger groups (Harding, 1999). The concept of “day care without walls” i.e. support provided within the community or mainstream community services needs to be further explored in relation to older people with mental health issues. The provision of day care at home should also be considered.

Best Practice Example

The Joint Dementia Initiative in Scotland has developed the “Home from Home” day care project where trained and approved local carers, working in pairs, open their homes to groups of three to six older people once or twice a week, providing company and activities in a domestic environment, with an emphasis on person-centred care. An evaluation of this model (Mitchell, 1999) found that people with dementia seemed to feel more in control and were more likely to believe that they could make things happen.

RECOMMENDATION

21. A range of models of day-time support which are responsive to user and carer need and which promote social inclusion, should be developed. Particular consideration should be given to people in rural settings and the need to develop creative responses to their needs.

Respite Care

"It shouldn't be too much to ask that I get the help I need - at the time I need - to care for my husband"

Carer in relation to poor availability of respite care

- 6.47 Respite care is the provision of care for a period of time, in the home, in a day care facility or care home, by people other than the primary caregiver, to give the primary caregiver respite from their care giving responsibilities and hopefully ameliorate to some degree, the stresses associated with being a caregiver (Cameron and Lee, Cochrane Review Protocol, 2004). The nature of delivery can be planned, offered on a crisis basis or offered on demand of the carer (RCPsych, 2005).
- 6.48 Respite care is considered to be critically important in providing much-needed breaks that allow carers to continue caring, even though there is limited evidence of efficacy in achieving stated goals (Lawton, 1989). It has been found that caregivers often perceive that respite care provides benefits of self-care and relief to themselves at the expense of the safety and comfort of their family members during respite care episodes (Perry, 2001; Gilmour, 2002). There often tends to be concern about the impact of residential forms of respite, including disruption of routine.
- 6.49 For respite care to be effective, it needs to be accessible, flexible responsive to needs and provide good quality care (Briggs and Askham, 1999). It also needs to be a positive and beneficial experience for the older person.
- 6.50 Respite provision is patchy across Northern Ireland. The public consultation highlighted gaps in domiciliary based respite care in particular, including night time care. There is a need for a broad range of respite services to be established which provide carers with real relief. Service providers consulted also highlighted the potential in exploring "foster-care" models of respite. Trusts should consider appointing a designated co-ordinator to work in partnership with the voluntary sector to stimulate the further development of day time support and respite care in community settings.

RECOMMENDATION

22. Respite care provision should be a clear and identifiable part of any commissioning or service planning process. A range of models should be delivered. It should be provided locally, be flexible, responsive and of benefit to older people with mental health issues and their carers.

Housing

Introduction

- 6.51 Housing is referred to in People First (1991) as the “cornerstone of community care”, yet its potential to either enable or prevent older people to remain living in their own homes is often underestimated. Poor housing conditions for people with additional needs can inhibit their ability to function and can add unnecessary stress on them and their family units. Conversely, well-designed, age-appropriate housing has been linked with providing optimum physical and mental health (Biggs S. et al. 1999; Blackman et al. 2001).

Current Provision

- 6.52 Most older people express a wish to remain in their own home for as long as possible (Burholt, 1997) yet much contemporary design remains ill-suited to frail older people and, in particular, people with dementia. The public consultation also highlighted the waiting times involved for housing adaptations.
- 6.53 In Northern Ireland, the majority of housing which has been provided for the home ownership market (the private sector) has been designed along very traditional concepts. Only in recent years have the needs of vulnerable people begun to be catered for, with the development of supported housing models and lifetime homes. The term “lifetime” homes refers to a home which will suit a person throughout their lifetime, so that they are not forced to move by having to overcome barriers in the dwelling. In Northern Ireland, lifetime homes standards, incorporating 17 specific design features, have been adopted in the social housing sector since 1998. These standards do not, however, incorporate any dementia-specific design features.
- 6.54 Despite these exceptions, housing options for people with dementia remain limited. There is also very little specific housing provision for older people who have experience of functional mental illness.

Future Planning

- 6.55 Future planning must allow for a wider range of housing options for people with dementia. While many people with dementia will remain in their own homes, there needs to be a choice of supported self-contained dwellings which are both domestic and homely and a choice of small group settings for those unable to live independently, but for whom a large nursing or EMI unit would prove unsuitable. The Dementia Policy Scrutiny Report (1994) recommended units for between 8-10 people in a group living environment recognising that people with dementia need to see staff and be able to contribute to domestic chores to enable them to feel relaxed and comfortable.
- 6.56 Older people with functional mental illness should be afforded the same rights as any other older person with equitable access to housing solutions to meet their needs. Housing provision should include floating support, home support/personal care services and supported living accommodation.

- 6.57 Future design of housing for older people with mental health issues must recognise, not only the particular needs of this group, but also the needs of their carers. Two-bedroomed accommodation should be developed as standard to provide individuals and their permanent or temporary carers adequate space and privacy. All property should be constructed to a “Secured by Design” standard to ensure maximum security and safety.
- 6.58 Housing must be designed to be suitably flexible to adapt to an individual’s changing needs, with the capacity to accommodate daily living equipment and assistive technology that can be installed when necessary.

Best Practice Example

St. Paul’s Court in Lisburn, a Choice Housing Association Scheme, which provides 15 self-contained dwellings with a minimum of two bedrooms and communal facilities within a secure environment. The model has been designed to promote social interaction.

Assistive Technology

- 6.59 Assistive technology is defined in research for the Royal Commission on Long Term Care as:

“an umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed” (Tinker A. et al. 1999).
- 6.60 Assistive technologies range from simple low-tech items, like automatic clock-calendars to sophisticated sensor technology which detect movement or departures from usual patterns of behaviour.
- 6.61 Many people with dementia face difficulties and challenges in managing practical tasks and in maintaining their own health and safety. This can, at times, compromise their dignity and independence. Assistive technology provides a real opportunity for individuals with dementia to maintain a level of independence and to be supported in a less intrusive way. Recent developments in assistive technology are providing new solutions to some of the needs of people with dementia and their carers. One study (Northampton “Safe at Home” Project, 2002) found that use of assistive technology reduced carer anxiety, helped maintain existing levels of independence of the person and reduced some of the behaviours which had been giving carers most cause for concern.
- 6.62 It must be acknowledged, however, that assistive technologies may not provide solutions in themselves, but are or can be, an addition to the raft of support and solutions that are available. It must also be recognised that the use of assistive technology may not be appropriate for everyone with dementia. Each individual has their own experiences and contexts which require a person centred approach to finding the best way forward.
- 6.63 Any assessment for provision of assisted technology must take into account ethical considerations (Marshall, 2000). The views of all the people involved in the proposed

actions should be considered. The Social and Technological Response to meeting the needs of Individuals with Dementia and their carers Report (ASTRID, 2000), suggests that four principles can be applied in these considerations:

- respect for autonomy;
- beneficence (doing one's best for the person);
- non-maleficence (not harming the person); and
- justice.

6.64 Where the technology is intended for direct use by the person with dementia, it needs to be designed to take account of the nature of the condition, e.g. impaired memory and learning. It is also important that any devices blend in as far as possible with the user's natural environment

6.65 Assistive technology may also be of benefit in the care of older people with functional mental illness, for example in monitoring high risk situations or providing prompts to take medication. The potential for use of assistive technology with this group has not been adequately explored or exploited.

Best Practice Example

Sydenham Court in Belfast, which provides fifteen flats for people with dementia within a shared complex. Each tenant has an individually tailored monitoring package which produces an alert if a normal lifestyle pattern is broken. Staff are then on hand to assist as required. This facilitates a non-intrusive support service. The technology also has the capacity to monitor a range of movements/activities e.g. frequency of getting out of bed at night and can adjust levels of assistance provided accordingly. This allows for the early detection of deterioration in people with dementia and more timely intervention. Within Sydenham Court, this has resulted in a very small turnover of tenants as most can be accommodated by a flexible support service which is responsive to their changing needs.

RECOMMENDATIONS

23. Providers and commissioners must contribute to NIHE strategic planning in order to ensure that the needs of the increasing population of people with mental health issues are fully considered. Future planning must guarantee a range of housing options, internal design solutions, adaptations and use of assistive technology which promotes people's independence both in their own homes and in supported housing settings.
24. Providers must ensure that support models promote empowerment, independence and social inclusion.
25. Department for Social Development (Housing Division) funds should prioritise the provision of 2 bedroom bungalows for one person in order to encourage a carer and/or family to live with the individual on a permanent or regular basis (including overnight and weekend stays).
26. Assessment processes should include consideration of the potential to use assistive technology. The use of assistive technology should be promoted and extended. This will require adequate resourcing and clear assignment of budgetary responsibility.

Key Consideration

- Supporting People monies should be identified for maintaining older people with mental health issues as independently as possible in the community.

Nursing and Residential Care Homes

Introduction

- 6.66 A number of older people with mental health issues will find themselves in a nursing or residential home at some point in their illness. Several studies suggest that the proportion of older people in care homes with dementia is at least 60-70% (Mann et al. 2000). Specialist provision for people with dementia is provided in “Elderly Mentally Infirm” (EMI) homes, although it is important to note that people with dementia have a range of needs and for many people, these can be met within generic care homes. Similarly a proportion of people with severe FMI may require the support of a care home. Functional Mental Illness is common in care homes and, in particular, depression, which has been estimated at around 40% (Mann et al. 2000). These high levels of mental health needs in care homes have implications for staff training.
- 6.67 While the aspiration of service users and carers to remain at home can and should be accommodated by the provision of a range of supported housing and community care services, for some people, there will come a stage when the complexity of their needs demands a more intensive support package which can only be met in a residential or nursing care setting. Any care continuum developed for older people with mental health issues therefore needs to incorporate this type of provision.
- 6.68 The crisis-led nature of many admissions to care homes can often result in a rushed decision, with a person being inappropriately admitted to a care setting without being afforded the time to consider and try out alternatives. It is important that procedures are put in place to ensure that assessments for long-term care are, as far as possible, made in an environment which is familiar to the person and afford sufficient time to allow alternative options to be explored and where appropriate, tested out. Long-term decisions should not be made at time of crisis or in an inappropriate setting.
- 6.69 The disruptive effect of moving residents from one care home to another as their illness progresses was also highlighted very strongly within the consultation exercise. There was strong support for the development of settings which are able to provide a continuum of care for the person throughout the course of their illness.

Care Practices

*" I wish staff in the home would stop talking to my mother as though she is deliberately difficult - she is ill - she has Alzheimer's - she can't help it"
daughter of resident in care home*

6.70 While it must be acknowledged that the service provided by many care homes is excellent, there are, however, a lot of issues in respect of the quality of care provided within this type of setting. This was very evident from the number of concerns raised by carers, voluntary organisations and service providers during the consultation process. Some of the views expressed included:

- the routinised and programmed nature of daily life and the need for a more person-centred approach;
- the need to provide appropriate and accessible activities for stimulation;
- the need for more individualised care; and
- building design needs to be in keeping with the needs of the person with dementia.

6.71 The Joseph Rowntree Foundation in their research study “Designing and Managing Care Homes for People with Dementia”, March 2002, sets out principles for the management of care homes, including care practice. Their research identifies best practice, including:

- staff should communicate with residents in every aspect of life in the home;
- appropriate activities for residents should be facilitated;
- palliative care should be available when necessary;
- residents’ links with their local community should be maintained as far as possible; and
- a good balance between the protection of residents and the quality of life gains that come from taking some risks should be struck.

Person-centred Care

6.72 Best practice suggests that a personal history should be taken on the admission of each resident, to build up a picture of who the person is, what his or her life experiences have been, what their likes and dislikes are and the things they value. Family and friends, as well as staff who have worked with the individual in the community, should be involved in putting this personal history together, as well as the person themselves. This should form the basis of a person-centred care plan. The availability of this personal history is especially important where the individual is no longer able to communicate easily themselves. All people living in care homes, whether they have dementia or mental health problems, or not, should be treated with dignity and respect and be valued for who they are and for their past life and experiences.

Staffing

6.73 To ensure that a high standard of care is provided, it is essential that care homes have adequate staffing levels with appropriate skill mix. The level of physical care and supervision often required for people with mental health issues, particularly dementia, can be intensive and it is essential that staffing ratios reflect such demands. The Residential Care Homes Regulations (Northern Ireland) 2005 require that “at all times, suitably qualified, competent and experienced persons are working in the home in such numbers as are appropriate for the health and welfare of the residents”.

- 6.74 Throughout the consultation process, service users and carers highlighted the need for “continuity of care” and “commitment from staff to be there”. The role of the manager within the care home was seen as pivotal in ensuring there are shared values, commitment to residents, good communication and support and recognition for staff.
- 6.75 The need for on-going training in the care of older people with mental health issues was also seen as critical. Dementia Care Mapping, a tool which provides a way to measure the quality of interactions within care homes, can be a useful, if expensive, staff development aid.
- 6.76 There is also a need to ensure that informal carers should be enabled, if they wish to continue, to input to the care of the resident. Some carers described being “prevented” from playing a part in the care of their relative.

Access to Primary and Community Care Services

- 6.77 Often, once a person is admitted to a care home, he or she does not receive any further review from a doctor, unless a problem occurs. Medication is not always routinely reviewed. Residents of care homes should have the same access to primary and community care services as those living independently. This should include access to Allied Health Professions, dental and optical services, rehabilitative services and regular medical review by a GP, including review of medication.
- 6.78 Community pharmacists may be well placed to extend their current role of supply to further advise re: effects and interactions of medication and to offer regular review. In the USA, nursing homes are required by law to employ a consultant pharmacist to review medication every 1-3 months.
- 6.79 In a randomised controlled trial, Furniss et al. (2000), concluded that a brief medication review from a pharmacist reduced the amount of medication overall, with no detriment to the mental or physical functioning of the residents. In a Northern Ireland survey of pharmacists (Schweizer, 2004), 75% of all respondents stated that they wished to be more involved in providing services to care homes.

Use of Medication

- 6.80 A number of studies (McGrath and Jackson, 1996; Passmore et al. 1996) have indicated high levels of prescribing of sedative drugs in residential and nursing homes. This trend may be reducing as more information about the adverse affects of such drugs has become available. Sedative drugs play a modest part in the management of severe behavioural difficulties in homes. They should not, however, be a substitute for skilled management of the situation and non-pharmacological strategies should always be tried first. A behavioural assessment should be completed in an attempt to identify triggers to reduce or alleviate behaviour, before medication change is considered as often a person’s behavioural change can be due to a reaction to their environment or physical ill-health or pain. Nurse behaviour therapists, where available, or clinical psychologists, can assist in this practice. Sedative drugs, where used, must be regularly reviewed.

Restraint

- 6.81 Older adults with dementia have the highest risk of all individuals of being restrained while being cared for (Cotter and Evans, 2003). At particular risk of restraint are those individuals whose behaviour is judged to be “unsafe”, i.e. contributing to falls and interfering with treatment and/or medical devices. Restraint can be physical, chemical or environmental. Restraint is not just an issue in care homes but across settings, in both the community and hospital.
- 6.82 The use of physical restraint in older adults is associated with poor outcomes such as functional decline, decreased peripheral circulation, pressure ulcers, agitation and social isolation (Cotter and Evans, 2003).
- 6.83 Best practice supports individualised care based on knowledge about the person’s usual behaviour and function that permits nursing/caring for the person safely and without physical or chemical restraint. Research provides strong support for ensuring that older people in care settings are free from restraints, for example, Neufeld et al. (1999) found that restraint reduction reduces serious injuries in nursing home residents.
- 6.84 It is crucial that all staff receive appropriate training and that facilities have clear policy/guidelines regarding restraint. Staff training in the use of restraint has been found to lead to significant reductions in its use (Testad et al. 2005).
- 6.85 The Review adopts the position that restraint should only be used in accordance with agreed guidelines and recommends that policies and guidelines are continually monitored and kept under review.

Best Practice Example

Cedarhurst Lodge Care Home in Belfast undertook in 2003 a complete review of all restraint requested and piloted a ‘Minimal Restraint/No Restraint Policy’ in conjunction with South and East Belfast Trust. The home has now adopted this policy in practice.

Therapeutic Activities

- 6.86 While therapeutic activity with older people with mental health issues should not be confined to care home settings, there is a need to ensure that residents are provided with appropriate and acceptable opportunities for interaction and engagement as well as access to counselling support. A summary of these approaches, including compensatory techniques such as reality orientation; engagement techniques, for example reminiscence therapy; life review and person-centred counselling can be found In Annex 3.

The Built Environment

- 6.87 Acknowledging that the care home becomes the person’s home, it is important that the environment is as homely as possible, and that the care maximises quality of life. There is

general consensus in the literature about the optimal physical design for care environments for people with dementia (Regnier and Pynoos, 1992; Marshall, 1997; Ministry of Health, New Zealand, 1997). Such features include the need for small homely units with many characteristics that are as familiar as possible, age appropriate furniture and fittings; obvious location of essential places, such as bathrooms, good lighting to maximise visibility and designs which provide opportunities for normal domestic activities.

- 6.88 The environment is known to play a particularly important role in the care of people with dementia. Parmelee and Lawton (1990) suggest that the lower a person's level of competence, the more his or her behaviour will be determined by the environment. Paradoxically, this coincides with a time when they have less influence on shaping their environment and are less likely to be able to employ internal coping mechanism to compensate for deficiencies in their environment (Holden and Woods, 1995).
- 6.89 A local study (Thornton and Robinson, 2000) which examined how the factors of design influenced the well-being and functional ability of older people with dementia, found that certain features of a dementia-design specific, e.g. total visual access to bedrooms, en suite facilities, use of visual cues, reduced disorientation and wandering.

Best Practice Example

Meadowbank House in Omagh, a purpose-built care home for people with dementia which provides care on a small-scale basis, i.e. three bungalows, each accommodating eight people.

Regulation and Inspection

- 6.90 A strong message throughout the consultation process, from service users, carers and service providers, was the need for more robust arrangements for regulation and monitoring of care homes. It was suggested that the Registration and Inspection Units had "little power over the standard of care being offered in the homes" and "that very few homes had sanctions imposed against them despite failings on their part to provide adequate care." Some carers also indicated that they were afraid to complain, feeling that "if they issued a complaint against the home, that the patient would be adversely affected."
- 6.91 The recent establishment of the Regulation and Quality Improvement Authority (RQIA) is timely, to ensure that the standards in all care homes are raised and that these standards continue to develop as advances are made in the care of people with dementia and functional mental illness. The RQIA alongside the DHSSPS (who are responsible for setting standards) also has a role in ensuring that care homes providing high quality care are supported to continue to do so.
- 6.92 Consideration should be given to the development of dementia/ mental health specific standards in relation to care homes.

RECOMMENDATIONS

Restraint

27. Organisational structures should support restraint-free/minimal restraint care and provide the required staff education, consistent staffing levels and the equipment and technology necessary to support this care strategy. Audit frameworks to monitor employment of restraint policies should be in place within all care settings. A regional directive that is dementia specific should be developed.

Primary and Community Care

28. Older people with mental health issues who are resident in care homes should have the same access to all primary and community care services as those living independently in the community, e.g. dental, podiatry and optical services, rehabilitation, falls prevention services and day care services if that is their choice. This should also include regular medical review by a GP.

Quality of Life

29. Standards of care in all care homes should reflect not only high quality nursing care, but also a culture that promotes a positive and enjoyable quality of life, including appropriate activities, enjoyable and appropriate food and promotion of independence. This should be regularly reviewed.

Standards and Staffing

30. Staffing levels should adequately reflect the high level of needs of older people with mental health issues.
31. There should be adequate induction, supervision and ongoing training for staff, particularly in the management of dementia and mental health needs.
32. There should be effective and rigorous monitoring and reporting of standards and quality, including the quality of life and lived experiences of residents, within care homes by the Regulation and Quality Improvement Authority.

User and Carer Involvement

33. Users and carers should be fully involved in all decisions about care and care provisions.

Key Considerations

Assessment

- Assessment for ongoing care and accommodation should be made, where possible, in a familiar environment in the community.

Assessment should be:

- On-going and reviewed;

- Person-centred, reflecting abilities and strengths as well as needs;
- Empowering and enabling;
- Inclusive of the person, their carers and families and supported by professionals; and
- Reflective of the person's life history.

Environment

- Care homes should provide individual, small-scale living units in a homely design, incorporated within local communities to meet the needs of residents with dementia or functional mental illness. Possibilities for providing a continuum of care within the same setting should be explored.
- Design should reflect changing needs of individuals, e.g. adequate room sizes for aids and adaptations, suitable doorway and corridor sizes to accommodate wheelchairs.
- Appropriate living accommodation to promote independence, enabling privacy to permit relative/carer involvement. Access to gardens, community amenities and accessible transport to facilitate socialisation are also vital.

Primary and Community Care

- Pilot projects of enhanced community pharmacy input to residential and nursing homes should be developed.

Standards and Staffing

- Dementia/mental health specific standards in relation to care homes should be developed.

User and Carer Involvement

- Where the resident is unable to communicate his or her views and preferences or does not have a carer to speak on his or her behalf, the services of an independent advocate should be considered.

Interim Care

- 6.93 Interim care challenging behaviour facilities for the relatively small number of the most disturbed people with dementia must be developed and funded according to individual need. This care must be tailored to the individual, delivered in appropriate, small, local, domestic environments by specialist mental health nursing and allied professional staff.
- 6.94 This care, whether delivered by the statutory or independent sector, must be multi-disciplinary in its delivery, to the same standard as that delivered by current statutory inpatient high dependency psychiatric units, with access to expert medical input. These facilities must fall within the remit of new mental health legislation.

- 6.95 This level of care must be available where it is needed, at a time when it is needed, for as long as it is needed, as part of the range of services provided for this small but significant vulnerable group. Recognition that this level of care will be required for a finite period as the illness progresses is necessary to ensure provision of onward nursing care, when appropriate.
- 6.96 Providing this level of care will have inevitable funding implications. It is important that tariffs reflect this. There will be a need for specialist, tailor-made contracts for people with very complex needs. In these situations, money should follow the need.
- 6.97 These facilities must be subject to robust regulation and quality assurance.
- 6.98 There is an equal imperative to provide interim to long-term care for those people suffering chronic disabling mental illness who are not confused. These facilities must also be small and domestic in nature and be staffed by specialist mental health nursing and allied professionals. They should also be subject to the same robust regulation and quality assurance processes.

RECOMMENDATION

34. Interim care challenging behaviour facilities should be developed. These must be appropriately staffed and funded.

Palliative Care

- 6.99 Patients with advanced dementia are often cared for in a nursing home. A study by McCarthy et al. (1997) found that approximately 40% of people with dementia die in residential or nursing care homes. It is important to stress, however, that it is possible for patients with advanced dementia to be cared for at home if the appropriate supports are in place.
- 6.100 The palliative care approach provides appropriate control of symptoms, emphasises overall quality of life, takes a holistic approach, involves the person and family in decisions and fosters good supportive communication between all concerned. Whether it is the dementia process that is the “terminal” event, or another co-existing illness, these patients have the same need and right to have their physical symptoms relieved and to receive appropriate psychological and spiritual support. Their carers also require support in the terminal phase and in bereavement. It is more difficult to assess levels of pain and other symptoms in patients with dementia, and this must be taken in to consideration. Decisions regarding intervention and the use of advance directives may need to be discussed with the patient at as early a stage in the illness as possible.
- 6.101 Specialist hospices for people with advanced dementia have existed in the USA for some time. These units make control of symptoms a priority and tend to limit medical interventions including tube feeding and cardiopulmonary resuscitation, which might add to discomfort without definite benefit (Balfour et al. 2003). While serving a function, these

units create the further dilemma of having to move people on from their current residential or care home, which may not be in their best interest (Hughes et al. 2005).

6.102 Hughes et al. (2005) suggest that the palliative care approach for people with advanced dementia should be pursued in all community and hospital settings. As yet there is no consensus in how this should be achieved. Clear links should be established between primary care, specialist services and palliative care with regard to the special needs of older people with mental health issues towards the end of life.

RECOMMENDATION

35. Commissioners should seek proposals on how a palliative care approach for people with advanced dementia can be rolled out to all care settings.

Key Considerations

- Closer links between primary and specialist teams and palliative care specialists should be encouraged.
- Existing specialist palliative care teams should have training on the special needs of patients with functional mental illness or dementia.
- Involvement of the patient in end of life decision-making should be facilitated. Protocols may be helpful here.
- Where possible, older people with mental health issues should have the option of terminal care at home.

CHAPTER 7

CONTINUUM OF CARE - INTERMEDIATE, SPECIALIST AND IN-PATIENT CARE

Introduction

- 7.1 Intermediate care is a short-term intervention to preserve the independence of people who might otherwise face unnecessarily prolonged hospital stays, inappropriate admission to hospital or residential care (King's Fund, 2004). Intermediate care can involve "step up" care to prevent hospital admission in the first instance (this usually takes the form of intensive domiciliary/nursing support provided in the person's own home) or "step down" care which facilitates early discharge from hospital (this level of care can be provided in the person's own home or within a care home facility). The primary focus in intermediate care is on rehabilitation, with therapeutic input from a range of professionals.
- 7.2 Older people with mental health issues are often excluded from mainstream intermediate care services. This is largely based on an erroneous assumption that the potential for rehabilitation, particularly for older people with dementia, is limited. There also tends to be concern that people with dementia and more severe psychiatric disorders pose too high a risk to be managed by intermediate care services, many of which are provided in the person's own home.
- 7.3 Often, the criteria for acceptance on to intermediate care schemes, are service rather than needs driven, for example, the need to clearly define the time limits of the intervention and the date for the withdrawal of the service at the outset. This can prove difficult in the care of older people with mental health issues where there is perhaps more unpredictability about "recovery" timescales. There is also a lack of confidence and skills in working with this group among mainstream intermediate care staff.
- 7.4 The DoH "Everybody's Business" Report (2005) identifies two models which have developed in response to these circumstances:
- developing the skills of staff in mainstream services, with additional specialist support, where the primary need is for physical rehabilitation, but where there may be underlying mental health problems; and
 - developing separate specialist teams or resources where the primary need is the mental health problem.
- 7.5 The Report identifies the essential elements of a responsive service as including:
- proactive searching for older people who may benefit from intermediate care;
 - avoiding unnecessary admissions, but when that happens, enabling the older person to move through the system quickly;
 - training carers and support staff to observe and recognise some of the common causes of illness that often result in hospital admission, e.g. urinary tract infection; and
 - liaison psychiatry to support staff in mainstream intermediate care services who may have limited knowledge or experience of working with older people with dementia or functional mental illness.

- 7.6 Where intermediate care is provided within care home settings, it is important to ensure that these beds do not become used for long periods for patients who are discharged from hospital and awaiting a care package in the community or placement in residential or nursing care.

Best Practice Example

The 24-hour Elderly Mental Health intermediate care service set up in Portsmouth to provide intermediate care services for older people with mental health problems. The service gives people the choice to remain at home.

RECOMMENDATIONS

36. Older people with mental health needs should have access to suitable intermediate care services.
37. Specialist teams should provide the necessary support to staff working in mainstream intermediate care services. This may include in-reach by link staff from specialist teams to provide support, training and coaching.

Key Consideration

- Hospital and community staff should be proactive in identifying individuals who would benefit from intermediate care services.

Specialist Services

- 7.7 Specialist services should be available for consultation and treatment of the range of mental health issues in older age. They should provide a range of services from diagnosing and treating more complex problems, to providing community and in-patient support for those with a clinical need. The emphasis should be on promoting the independence of older people with mental health issues and their carers in the community, wherever possible and practical (NSF Older People, 2001).
- 7.8 Older people with mental health issues should be referred to specialist services when their needs become more complex. They should have access to assessment, information and advice and a range of health and social care interventions which will promote optimum levels of recovery, independence and quality of life. Triggers for referral to specialist services might include:
- there are diagnostic issues that need clarification;
 - there is lack of response to initial intervention strategies;
 - distress or risk are particularly severe;
 - problems are complex; and
 - legal issues require their involvement.
- (“Everybody’s Business” Report, DoH, 2005)

- 7.9 From the user and carer point of view, the service should be seamless, with movement between mainstream and specialist care and back, occurring with minimal delay and disruption and in relation to this, clear protocols should be in place.
- 7.10 Users and carers value having a named/key worker (Public consultation) and anyone with a diagnosis of dementia or long-term severe functional mental illness, should have a named/key worker throughout the course of their illness. In some instances this role may be undertaken by the person's GP. Where the person's needs are not complex, the key worker role may be limited in nature and be more about the individual and/or their carer having a point of contact. Systems should be in place to ensure that it is always clear who the named worker is. This is crucial to the success of a service and is particularly important where there is a transfer of responsibility between primary and secondary care.
- 7.11 The Review sees merit in the development of an “enhanced practitioner role” within the specialist team, with responsibility for developing closer links with primary care. The role could involve health promotion, education, advice, therapeutic input etc.
- 7.12 Several innovative pilot schemes in General Adult Psychiatry, such as those in Limavady and Mid-Ulster, have been found to be effective in reducing delays in actioning referrals and in ensuring the development of timely, accessible assessment services and have been very positively evaluated by service users and primary and secondary care staff (A Strategic Framework for Adult Mental Health Services, 2005).
- 7.13 The enhanced role practitioner for older people with mental health issues is likely to be a senior practitioner who is part of the specialist multi-disciplinary team and obtains support and supervision there. They would work closely with generic services providing education, advice, a degree of assessment and possibly other specialist skills such as psychological treatments. They would help to ensure a seamless transfer for people between primary and secondary care and vice versa.

RECOMMENDATION

38. Anyone with a diagnosis of dementia or long-term severe functional mental illness should have a key worker for the duration of their illness.

Specialist Multi-disciplinary Teams

- 7.14 Specialist services for older people should be comprehensive, multi-disciplinary, accessible, responsive, individualised, accountable and systematic (NSF Older People Standard One).
- 7.15 The specialist multi-disciplinary team is the cornerstone of delivery of care to older people with dementia and functional mental illness within the context of specialist services. It will be firmly embedded in the locality. Core disciplines will include psychiatry, nursing, social work, occupational therapy, and medicine. It is also important to note the emergence of new roles within multi-disciplinary teams such as OT technicians, physiotherapy and nursing

assistants and mental health support workers. Specialist teams have still not been established in some parts of Northern Ireland.

- 7.16 Clinical psychologists should also be core members of the specialist multi-disciplinary team, as recommended in the NSF Older People (2000). This service is currently poorly developed throughout Northern Ireland. A more detailed outline of professional roles can be found in Annex 5.
- 7.17 Teams should have an adequate skill mix e.g. bereavement counselling, psychotherapeutic expertise or specialist training in management of behavioural problems in dementia. Teams should further develop to include patient advocacy and input from physiotherapy, speech and language therapy, dietetics, podiatry and community pharmacy, all of whom should have suitable training. Adequate administration and management support is crucial.
- 7.18 They should work closely with generic elderly care services and primary care teams to provide a seamless, quality service. The specialist team should also have close links with a wide range of community resources across statutory, voluntary and private sectors, including day-care, day hospital, inpatient services. It will also have a significant educational and training role.
- 7.19 Historically, specialist teams have functioned in a variety of ways, with some holding cases throughout the entire course of the person's illness, while others pass less complex cases on, following assessment, to generic services in primary care. While holding cases indefinitely clearly has advantages in terms of continuity, experience has shown that teams can become overwhelmed and waiting lists develop. We see the role of the specialist team as involving assessment, intervention and complex case management, together with education and training.
- 7.20 The Review proposes an enhanced service at primary care level with added training and support to enable these services to manage people with less complex needs. As mentioned above, this might link in with chronic disease management models. There should be clear protocols in place to support transfer of responsibility between primary and specialist teams.
- 7.21 The specialist team should deal with all aspects, stages and varieties of psychiatric disorder arising in older age, especially all stages of dementia (RCPsych, 2005). The key functions of the team will be to:
- provide timely information on a person's problem, available treatment and support;
 - ensure that people's physical health needs are being addressed, in co-ordination with mainstream older people's rehabilitation services;
 - provide on-going care, support and treatment for older people with more complex mental health problems and their carers;
 - ensure that carers and family members are adequately supported and that their strengths are maximised;
 - provide outreach support to users of other services who have mental health problems, e.g. residents in care homes; and

- provide support, advice and training to staff in the range of mainstream organisations that provide care to older people with mental health problems, including voluntary agencies and carers' organisations.
(based on "Everybody's Business" Report, DoH, 2005).

Staffing Ratios

- 7.22 In 2000, the Faculty of Old Age Psychiatry of the Royal College of Psychiatrists, produced a set of "norms" to describe basic services expected to support each Consultant Old Age Psychiatrist. These, whilst useful, were not sufficiently robust to determine service provision and as a consequence are no longer recommended as a guide to new appointments. They do, however, form a template to describe an ideal team where all other community and hospital based services are in place.
- 7.23 To provide a service to an appropriate standard of care, the recommendation is for 1 whole time equivalent (WTE) Consultant for 10,000 aged 65 and over. Large geographical catchment areas with high socioeconomic levels of deprivation and few supporting medical staff will inevitably increase Consultant workload, as will the extent of responsibility for those older people with enduring or relapsing functional mental illness and younger onset dementia. The effectiveness of social services and Elderly Care Medicine will also be important factors. The issue of staff ratios will be considered in further detail in chapter 9, "Making it Happen".

RECOMMENDATIONS

39. Specialist Multi-disciplinary Teams for Older People with mental health issues should be introduced where not currently in place.
40. Pilot projects which include the development of enhanced practitioner roles should be set up and monitored.

Key Considerations

- Input from clinical psychology is currently inadequate and yet is important in terms of psychometric testing and psychological help for patients and carers. Input from clinical psychology should be strengthened.
- Specialist teams should develop to include patient advocacy and input from physiotherapy, speech and language therapy, dietetics, podiatry and community pharmacy, all of whom will require specialist training in mental health issues of older people.
- The core business of a specialist team will include assessment, intervention, complex case management with education and training. To allow this to happen, investment will be required in services at primary care level to provide additional training and staff who are equipped to look after people with less complex needs.

Assessment

- 7.24 Assessment will take place in a range of facilities, including the person's home, the health centre, day hospital, outpatients or other facilities and it is good practice for at least part of the assessment to take place at home (RCPsych, 2005).
- 7.25 Timeliness is important and yet increasingly difficult as referral numbers increase with the ageing population. Teams will organise assessments as suits the local circumstances. It is crucial that the team deals with referrals efficiently and the Review sees merit in moving towards a single portal of entry for referrals, whereby referrals are dealt with at team meetings and allocated by the multidisciplinary team rather than in the traditional model, where the team and consultant work in parallel. There should be minimum duplication and any team member should be able to provide an initial assessment on behalf of the team.
- 7.26 Assessments should encompass the overall care situation and should consider physical, psychological, social and spiritual needs. Risk should always be considered and documented in a standard way.
- 7.27 Assessment will usually include a diagnosis, but not necessarily at the first contact. People with mental health issues, and, if appropriate, their carers, should be given the diagnosis in a sensitive manner, taking account of their capacity to understand and with open discussion of issues. This is an ongoing process and should not be limited solely to the initial contact. For all patients, but especially those with dementia, it is important that post-diagnostic support is available. The diagnosis will usually be given by a doctor trained in mental health problems of older people, but as services develop, could be made by another professional in the context of a well functioning multi-disciplinary team with medical input such as a nurse specialist.

Memory Assessment Service

- 7.28 Services for people with dementia should include a service for those who have concerns about their memory. Not all of those individuals who present with concerns will have dementia – some will have mild cognitive impairment, some depression and some no identifiable mental health problem. The main purpose of this service is the early detection and diagnosis of dementia, while identifying treatable causes of cognitive impairment. Some services run pre-screening clinics to ensure that all investigations are in place before the assessment and this may increase efficiency, e.g. Mater Hospital and Homefirst Trusts.
- 7.29 The service should provide pre- and post-diagnostic counselling and support where appropriate, information, risk assessment, advice on driving and medico-legal issues, support for carers, access to the full range of support services and psychological and pharmacological treatment as required. A study by Simpson S. et al. (2004) concluded that memory clinics might be less suitable, however, for patients with prominent psychiatric complications.
- 7.30 Service providers who participated in the consultation process, commented on the lack of

local access to memory clinics and also highlighted the fact that hospital locations are not always appropriate/suitable to host memory clinics.

- 7.31 Many memory clinics were set up following the introduction of the anticholinesterases in 1997. The Review considers that anti-dementia drugs play an important part in the range of services available for people with dementia. Currently there is controversy surrounding, not their efficacy, but their cost effectiveness and the Review expects that a decision will be made on this in due course by CREST.
- 7.32 Although each case should be considered individually, in general the diagnosis of a dementia should be disclosed to the person and his or her family. The process should include a discussion of prognosis, advance planning, treatment options and available support.
- 7.33 There is a growing body of evidence which highlights the perceived benefits to the person with dementia of being told their diagnosis at an early stage. In a study by Pratt and Wilkinson (2003) participants identified a range of positive opportunities gained by knowing the diagnosis, including planning, accessing appropriate support and making the most of their time. They identified few limitations from knowing the diagnosis.
- 7.34 In practice, however, almost half to two thirds of general practitioners in a Scottish-based study, did not tell the person their diagnosis (Downs M. et al. 2002).
- 7.35 It is also important to note that carers may have a yet different perspective and wish to protect the person with dementia from the knowledge of their condition (Maguire et al. 1996).
- 7.36 Exceptions to disclosing prognosis might be severe dementia, where understanding of the diagnosis is uncertain, phobia about the diagnosis or severe depression (Patterson et al. 1999).

Best Practice Example

CANDID (Counselling and Diagnosis in Dementia) is based at the National Hospital for Neurology and Neurosurgery. They provide a clinical assessment and diagnosis to UK residents, under the NHS. E-mail support groups are provided as part of their web based resources and an interactive virtual carer support group, which allows users to talk on-line with other carers.

RECOMMENDATIONS

- 41. Pre- and post-diagnostic support should be available for people with dementia and their carers.
- 42. Consideration should be given to moving towards a single point of entry for referrals to specialist services with multi-disciplinary allocation of referrals as suits local circumstances.

Key Consideration

- The diagnosis of dementia and related information should be given in a sensitive manner, taking account of the person's capacity to understand and wish for information. Information about diagnosis will be an ongoing process.

Models of Service

7.37 The "Everybody's Business" Report (DoH, 2005) suggests that a useful concept in integrating diverse models of service, is that of the "virtual" team, where staff may not necessarily be based in the same location, but have closely co-ordinated roles. There may be core team members, for example, such as the team manager; part-time members who work in other care sectors and "associate" members who work closely with the team but whose work is generated from a range of sources.

Acute Mental Health Inpatient Care

7.38 While it is unusual for older people to require in-patient admission for treatment of their mental health problem, there will be occasions when admission is essential for purposes of assessment, treatment and rehabilitation of older people with a range of diagnoses, including dementia where they cannot be cared for in the community or other settings due to the level of care and expertise required. A number of older people will also be detained under the Mental Health (Northern Ireland) Order 1986 for assessment or treatment.

7.39 The Review recommends that provision of acute mental health in-patient care for older people should be underpinned by the following principles:

- i. All older people should have equal access to healthcare provision that is timely and appropriate, determined by need without regard to age.
- ii. Older people with functional mental illness, requiring in-patient care, should receive treatment in separate in-patient facilities tailored to their needs within a local General Hospital site alongside other psychiatric and acute medical wards. (Royal College of Psychiatrists, 1999). The Forget-me-not Report (Audit Commission, 2002) recommends that there should be "separate living spaces available on wards" for patients with dementia and those with functional disorders.
- iii. Siting of assessment and treatment units within a local General Hospital permits ready and timely access to the full range of diagnostic and treatment services required for a population with significant levels of co-morbid physical illness.
- iv. In-patient mental health assessment and treatment bed provision should be sufficient for the target population in order to avoid delay to admission or necessitate placement outside of the locality.
- v. Cognisance must be taken of the fact that in-patient provision for older people with mental health issues often requires a longer total admission compared to younger

people, given the complexity of their presenting complaints. This must be taken in to consideration when planning in-patient facilities.

- vi. Older people admitted to mental health care should have access to an appropriate therapeutic environment with the full range of specialist mental health professionals as well as Clinical Psychology, Occupational Therapy, Physiotherapy, Podiatry, Speech and Language Therapy and complementary therapies. (NSF for Older People, 2001).
- vii. Strong links are required with physicians within Medicine for Older People, Medical Assessment Units and Surgical In-patient facilities as well as Accident and Emergency (RCPsych, 2005).
- viii. Older people should have timely and equitable access to Specialist Liaison psychiatry services of older people. It is of note that two thirds of NHS beds are occupied by people aged 65 years or older. Up to 60% of general hospital admissions in this age group will have or will develop a mental disorder during their admission. Such mental disorder can have a significantly detrimental impact upon the patient's recovery and ultimate prognosis. A prolonged length of stay in hospital may also arise as a consequence.
- ix. Older people presenting to Accident and Emergency (A&E) departments must also have timely and equal access to 24 hour social care support and Intermediate Care provision without prejudice. Consideration should also be given to systems which could fast-track people with dementia/FMI through A&E, for example a liaison nurse or acknowledgement of dementia within the triage system.
- x. It is unusual for older people to require in-patient admission for treatment of their mental health problem. Those who do require admission are likely to have very high levels of need. Wards must be staffed accordingly for the safety and well-being of all staff and users. It is essential that intensive and close supervision can be provided, where necessary.
- xi. Admission to any mental health unit, whether for functional mental illness or dementia related care, must be for the appropriate treatment of a medical condition. The admission must not be solely for the purpose of safety where social care needs cannot be adequately met out of hours in the community.
- xii. Older people with severe mental illness requiring hospital admission should have timely access to in-patient beds in a unit functionally separate from the younger patient's unit. The trend towards a greater severity of illness in younger adults on admission can cause distress to older patients. Purpose built units for older people reduce fear, injury and discrimination on the basis of time given by mental health staff.
- xiii. There should also be provision for single-sex provision within wards.

RECOMMENDATION

43. In-patient facilities for those with functional mental illness should be located within a function-specific unit for older people, alongside other psychiatric admission facilities within a local general hospital site. Strong links are required with the professional staff within the district general hospital.

Key Considerations

- Provision of hospital care for older people with mental health problems should be equitable, timely and person-centred.
- Adequate numbers of in-patient beds are required to facilitate timely access and unnecessary delays.
- Patients must have access to an appropriate therapeutic environment and the necessary professionals allied to medicine in an equitable and timely fashion.
- There should be ready access to Specialist Liaison psychiatry services for older people with mental health issues.

Treatments

" In the hospital, my mother got no physiotherapy after a broken hip because staff said that you can't help people with Alzheimer's - they won't co-operate. My mother will never walk again, all for the want of a physiotherapist who is trained to work with people with Alzheimer's. Surely a lot of people with broken hips have Alzheimer's"

son of patient after hip fracture treatment

- 7.40 Older people should have access to all recognised evidence-based treatments without prejudice. This should include all therapies recommended by the National Institute for Clinical Excellence (NICE Guidelines, 2006)
- 7.41 A holistic approach to the treatment of mental illness is to be promoted with attention to psychological therapies and other non-pharmacological treatments supported by recognised bodies, including Royal College of Psychiatrists, National Institute Clinical Excellence, British Geriatric Society in the first instance. The prescription of medication should only be necessary when initial strategies are ineffective or as a last resort. The NICE Guidelines on Dementia (2006) specify that people with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance "only if they are severely distressed or there is an immediate risk of harm to the person or others".
- 7.42 Acknowledgement of the significant potential for drug induced problems such as low sodium levels and GI bleeding as well as the risks associated with many drugs being taken together must be addressed when prescribing medication. Attention to dosage schedules, side effect and adverse event profiles specific to older people is necessary when prescribing medication. Preparations with the most favourable profiles are recommended.

Psychotherapy Services

- 7.43 Older people should have access to the full range of psychotherapeutic services (NSF for Older People, 2001). There is ample evidence for the effectiveness of non-pharmacological treatment approaches with this user group across a range of settings. Psychological interventions tailored for the treatment of mental health problems in older people have been shown to be effective (Woods and Roth, 1996; Neidhart and Allen, 1993; Knight, 1986; Woods and Britton, 1985) and also highly acceptable to older people (McGarry, Bhutani and Watts, 1997). Cognitive therapy adapted for use with older people suffering from depression has been shown to have similar efficacy to that demonstrated for younger adults (Thompson et al. 1996) as has brief psychotherapy (Mather, 2002). There was strong support for the provision of a fuller range of treatments, including psychotherapeutic interventions among carers who participated in the consultation process.

Dementia Therapies

- 7.44 All older patients should have access to all treatments supported by an evidence base without discrimination on the basis of age. Many different activities have been advocated to enhance well-being in people with dementia and increasing physical activity for older people has been recognised as essential within the National Services Framework, 2001. Activity therapists, of whom there is presently a marked deficit, provide an extremely valuable service within the therapeutic setting.

Day Hospital Provision

- 7.45 Access to appropriately staffed day hospitals with flexible opening hours for those with severe mental illness is seen as a priority. The provision of such facilities is invaluable in helping to prevent admission to a mental health in-patient facility or to aid recovery following admission. The times of opening should reflect need, 8am-8pm, seven days per week to complement day programmes. This, along with appropriate community models, will help reduce displacement from the home environment. In addition, it will assist with the reduction of the stress of illness for the patient and their carers, without prejudice.
- 7.46 While the term day “hospital” has traditionally been used to describe this type of provision, the service does not have to be located on a hospital site. It is likely that a range of service models will develop, based on local needs and circumstances.
- 7.47 Key elements of the service will include a comprehensive multi-disciplinary mental health assessment which will take account of any risk factors as well as the development of a treatment plan to include a range of individual and group based psychological interventions. Education and advice should be provided for carers and staff should also monitor prescribed medications. An outreach role to support staff in mainstream services should also be provided.
- 7.48 Consideration should be given to flexibly combining specialist day care and day hospital provision to enable better joint health and social care planning and a more seamless delivery of services for the service user.

RECOMMENDATIONS

44. Older people should have access to all evidence-based treatments according to need, including psychotherapeutic services.
45. Access to appropriately staffed Day Treatment Units with flexible opening hours for those with severe mental illness should be seen as a priority.

Key Considerations

- Prescription of medication should only be necessary when alternatives are ineffective. Preparations with the most favourable profiles are recommended.
- Professionals working with older people should be trained in the effects/side-effects of drugs.
- The needs of older people with disability and sensory impairment must be addressed.

Liaison Psychiatry Service for Older People in General Hospitals

- 7.49 As already highlighted, studies have shown that the over 65s occupy 60% + of hospital beds. Up to 60% of this population have a co-morbid mental illness. Eighty per cent of this co-morbidity is dementia, depression and delirium. This will increase as the proportion of society entering late age increases. Mental disorder in general hospitals is therefore 3-4 times more common than in the community.
- 7.50 Co-morbid mental disorder is an independent predictor of poor outcome. Those patients presenting with co-morbid mental health problems have increased mortality, greater length of stay, greater likelihood of developing hospital acquired complications (MRSA, falls, pressure sores) and are more likely to lose independent function leading to premature entry to institutional care.
- 7.51 In many instances the need for in-patient care will be as a result of physical, rather than mental health issues, with the older person being admitted to acute wards and settings.
- 7.52 There is also a growing body of research which highlights the deficits in care and treatment provided to older people, particularly with dementia, in acute hospital settings (George et al. 1997; Tibbs, 2001). People with dementia often become increasingly confused in hospital settings and their symptoms are often exacerbated as a result.
- 7.53 The public consultation exercise highlighted many concerns about the experience of people, particularly those with dementia, in acute hospital wards. There was a clear sense that staff had a poor level of understanding about the needs of the patient with dementia and that this often resulted in poor standards of even basic care and attention. This was exacerbated by inadequate staffing levels. Difficulties were also highlighted in relation to experiences within A&E, particularly in relation to waiting times. Concern was also

expressed about the inappropriateness of people with dementia being cared for in mixed-sex wards. Service providers and carers also felt that staff had a poor understanding of the impact on the person with dementia of being moved around the hospital to different wards and departments.

- 7.54 Typically, 2-3% of elderly admissions to general hospitals are referred for a specialist psychiatric consultation. As such, older people are under-represented when comparing rates of referral in relation to bed occupancy and morbidity with that of younger adults.
- 7.55 There are few guidelines developed for sedation of patients who are disturbed as a consequence of mental disorder or delirium with over prescription of sedative and neuroleptic medications.
- 7.56 There are no psychological therapies available in the general hospital setting.
- 7.57 Literature shows that detection and treatment of mental disorders in older patients by general hospital staff is poor. Fick et al. (2000) in a study of general nurses, found that 75% did not understand the difference between dementia and delirium.
- 7.58 Studies have shown that structured intervention programmes can reduce delirium rates post-hip fracture (Inouye et al. 1999; Marcantonio et al. 2001). Antidepressants have proven beneficial in depressed patients with serious mental illness. Studies have shown reduction in length of stay, particularly for post-hip surgery patients (Evans et al.1997; Gustafson et al. 1991).
- 7.59 In the UK, there is neither structured training for Liaison Psychiatry for older patients, nor a coherent model or strategy for training. The majority of services are additional, reactive, providing a psychiatric assessment and advice on management, if requested, often without follow-up. As a consequence, the Liaison Psychiatrist depends on general staff to identify and refer the appropriate patients with limited contact and opportunity to provide teaching or training as to the presentation of mental illness or selection of patients for referral. The referrals are often vague without focus.
- 7.60 Further difficulty arises after the assessment in that the advice given is often not implemented (one randomised study showed that 50% of recommendations were not implemented, including antidepressant prescription) Holmes et al. (2002). Outcomes were shown to be no better than for standard care.
- 7.61 Ideally the psychiatric liaison provision for older people in hospital should be scheduled, proactive and multi-disciplinary. It should be an integral part of case working in a continuous sense. The opportunity exists to raise the profile of mental health as a co-morbidity, collaborate with general staff in shared care through involvement in joint meetings and education and training provision. Such a service should be readily accessible, responsive and effective.
- 7.62 The “Who Cares Wins” Report produced by the Royal College of Psychiatrists in January 2005, highlights the characteristics of a liaison mental health team, including the need for

proper induction, training and clinical supervision for staff, a clinical lead and identified consultant psychiatrist with dedicated time to perform service planning and other duties and a liaison model of working for any services which offer consultation.

Best Practice Example

A liaison psychiatry for older people website, managed by the liaison psychiatry for older people research team based at the University of Leeds, has been developed to help facilitate collaboration between practitioners, researchers and others to promote improvements in the care of older people with mental health difficulties in general hospital settings. (see www.leeds.ac.uk/lpop)

Discharge Planning

- 7.63 The majority of people whose discharge from hospital is delayed are older people with mental health needs (DoH, 2003). Dementia is a principal cause of delayed discharge because of the complexity that having dementia plus a physical illness produces in terms of developing a good discharge plan (House of Commons Select Committee on Health, 2002).
- 7.64 Discharge should be an actively managed process which begins at the point of admission (DoH Good Practice Checklist, 2003). Older people with mental health issues should not be excluded from general hospital discharge policies and should benefit from the same provisions, for example, pre-set discharge dates. There should be an agreed care pathway for this patient group in place. All discharge decisions should be made by a multi-disciplinary team and there should be a named person with appropriate expertise responsible for discharge co-ordination. In some Trusts (e.g. Craigavon and Banbridge) Dementia Liaison Nurses have been employed to positive effect. Consideration should be given to replicating this post for older people with FMI.
- 7.65 Delayed discharges of older people with mental health issues should be monitored separately.

Best Practice Example

Down Lisburn Trust, as part of a programme run by the Department of Health, Social Services and Public Safety Clinical and Social Care Governance Support Team, undertook a project to improve the quality of inpatient experience and the effectiveness and efficiency of hospital discharge for older people with confusion from the Trust's two acute hospitals, the Downe in Downpatrick and the Lagan Valley in Lisburn. A number of developments were initiated, including use of a multidisciplinary protocol for confusion, addition of trigger questions to Nursing Admission and A&E profiles, work undertaken in relation to process mapping and patient flow, closer links with dementia services, the development of a pathway/protocol for confused patients.

Assessment for Placement in Residential or Nursing Care

- 7.66 The Review acknowledges that many older people with mental health issues in general hospital settings are disadvantaged by being assessed in an unfamiliar environment, often

while ill and not functioning at their optimum capacity either functionally or cognitively. This often results in inappropriate placements in care. The Review supports the view that, as far as possible, older people should be discharged back home following hospital admission, with appropriate support services so that the very major decision about their long-term care is made in the community.

Long-Term Care in Hospital

7.67 The Review's position is that there should be no long-term care provided within a hospital setting. Older people with mental health issues should be discharged no later than 6 weeks after medical fitness is determined. While in-patients, they should also be subject to regular review.

RECOMMENDATIONS

46. Protocols for the management of common psychiatric conditions and referral to the Psychiatry of Old Age Liaison team should be introduced in to general and specialist hospital wards supported by education and training delivered by a dedicated multi-disciplinary Old Age Psychiatry Liaison team.
47. Care pathways for older people with mental health needs in the acute hospital setting should be developed.
48. There should be an appropriately qualified designated person to co-ordinate discharges for older people with mental health issues.
49. Where possible, decisions about long-term care should be made in the community, in a setting familiar to the older person.

Key Considerations

- Older people with mental illness in general hospital care must not be disadvantaged in terms of age, but have timely access to quality specialist mental health assessment and treatment.
- Funding of psychiatric services for older patients with psychiatric illness in the general hospital setting should be agreed between those NHS agencies commissioning the service and those receiving the service.

CHAPTER 8

SPECIAL GROUPS

Early Onset Dementia/Younger People with Dementia

Introduction

- 8.1 The provision of care to younger people with dementia has been patchy and variable throughout the United Kingdom. Several healthcare specialities have played a part, but no speciality has taken a lead to establish a co-ordinated policy for the development of services. They are increasingly recognised as a very needy group who present to many agencies, yet are not well served by present services (Marshall, as cited in Cox and Keady, 1998; Strategic Framework for Adult Mental Health Services, Bamford Review 2005).

Prevalence and Causes of Dementia in Younger People

- 8.2 Dementia in younger people is a significant problem with an estimated prevalence of 67 per 100,000 population aged 30-64 (Harvey, 1998). The causes of dementia in younger people include degenerative disorders – Alzheimer’s Disease, Vascular dementia, Lewy body disease, fronto-temporal dementia; genetic disorders – Huntington’s Chorea; neurological disorders – Alcohol related, MS, CJD, tumours, syphilis, epilepsy, trauma, hydrocephalus. Although Alzheimer’s Disease remains a common cause for early onset dementia, there is a much higher representation of rare and unusual dementias in the younger age group compared to the over 65s.
- 8.3 Early onset dementia is particularly common in Down’s Syndrome. 40% of people aged 50 with Down’s Syndrome have signs of dementia (RCPsych, 2002). These individuals require access to specialist dementia services preferably within learning disability teams.

Current Practice

- 8.4 Delay in diagnosis, lack of information, absence of specialist services and the lack of support for carers on a long-term basis are a common, current experience of service users and carers (McErlean, 1999).
- 8.5 Users and carers may often not receive adequate services because there are small numbers in their locality. No single service has responsibility for provision, and points of entry into the health and social care system are varied. Unavailable or inappropriate services can lead to rapid breakdown of care packages in the community and early “burnout” of carers. Without appropriate services, at least half of patients require long-term hospitalisation within 5 years (Newens, 1995).
- 8.6 Requests from Psychiatrists of Old Age have increased with the reduction in NHS continuing-care beds and the emergence of new specific treatments for Alzheimer’s Disease (RCPsych, 2002).

Needs of Younger People with Dementia

- 8.7 Young people with dementia tend to have a shorter life expectancy and their symptoms present in a different order than may be expected, which has implications for service delivery (Tindall, 1993).
- 8.8 Younger people with dementia have different needs compared to older people. It is argued that the social and psychological context for younger people is different from that for older people with dementia (McErlean, 1999). The implications of the disease for someone in middle age are different from those of someone who is nearing the end of their natural life span. There is a greater level of psychological distress such as anger and depression. The loss of independence and possible social isolation may lead to feelings of low self-esteem and depression (Woods, 1999).
- 8.9 Loss of social role may be more significant, e.g. giving up work. Financial problems may be more severe and loss of benefits such as pension rights may place a further financial strain on the family.
- 8.10 A family member may have to give up work to assume a carer role. Younger people with dementia are more likely to have dependent children and heavy financial commitments. Consequences of being prevented from driving may be considerable.
- 8.11 Behavioural disturbances such as wandering, agitation and aggression are usually more severe. Service users more often have complex medical and neurological problems. They tend to be more ambivalent about engaging in services and understandably do not see themselves as the same as older people with dementia. They want a separate service.
- 8.12 Individuals and family members may need genetic counselling. For conditions such as Huntington's Disease and some familial Alzheimer's Disease, specialist genetic counselling and support is required.
- 8.13 Carers also have greater levels of psychological distress reported (Keady and Nolan, 1997) with higher carer burden showing an inverse relationship to the age of the person for whom they are caring. The consequences for taking on the caring role may be greater e.g. spouse giving up work. There are greater levels of isolation for family and carer. Younger carers rate themselves more lonely and more resentful of their caring role (Fitting, 1986). Psychological and financial impact on families and children is more severe as they are often very young teenagers and even babies. They should be involved in care, yet encouraged to continue with their normal lives (ADS information sheet). Carers see themselves as very different from carers of older people with dementia and again want a separate service.

Views of Service Users and Carers

- 8.14 There is a lack of user involvement in service development (Cox 1998). Younger people with dementia can articulate their experiences of dementia and what they want from care and services (Beattie 2004). Increasingly younger people with dementia are insisting on their right to the diagnosis (Fearnley, 1997).

- 8.15 A consultation with service users and carers undertaken by Tees and North Yorkshire Trust (2000) found that service users, as well as wanting to be told their diagnosis, also wanted contact with other young people with dementia for mutual support, the ability to carry on with recreational and occupational activities and somewhere to socialise.
- 8.16 Carers wanted age-appropriate day care and respite, access to anti- Dementia medication, preventative service responses, an out-of-hours contact point and a single access point.

Service Proposals

- 8.17 All younger people with dementia, their families and carers should have access to comprehensive specialist services from diagnosis to long-term care (ADS workshop, 2003).
- 8.18 A service for younger people with dementia should have a number of elements:
- education and awareness raising;
 - advice to and liaison with Primary Care;
 - early investigation, assessment and diagnosis;
 - access to neurology and genetics services;
 - assessment and care planning including considerations of financial issues;
 - flexible day care and alternatives;
 - acute assessment inpatient facilities;
 - respite care;
 - intensive own home care; and
 - support and training for carers – family and professionals.

Best Practice Examples

Foyle Trust, in partnership with the Alzheimer’s Society, has developed a respite service for younger people with dementia, which is an activity based service determined by the person themselves.

Teeswide Young Onset Dementia Team (Tees and North East Yorkshire Trust) provide a “one-stop shop” service which aims to make organisational boundaries invisible to users. There is an open referral system to facilitate access and direct access to services that normally operate as tertiary services (neurology, neuropsychology and neuropsychiatry). There is liaison between services to co-ordinate care and pro-active monitoring of users and carers to prevent ill-health and breakdown.

The service has been found to reduce the time from first symptoms to diagnosis by a year and waiting lists for diagnostic assessments from a year to two months. Levels of psychological problems in carers have also reduced over time.

RECOMMENDATIONS

50. Services for younger people with dementia should be located within either the mental health programme or older people's programme of care. There must be a clear policy in place and a dedicated lead for the planning and delivery of services for young people with dementia. Services must also be appropriately funded given the complex needs of this group.
51. There should be adequate financial support for young people with dementia and their carers to enable them to meet the extra costs of caring. Employers and the Social Security System should adopt practices which recognise dementia as grounds for early retirement and which protect a person's entitlement to pension rights and other benefits.
52. Residential respite is important for short breaks and could have links with an assessment/rehabilitation unit. There may be opportunities for joint developments with the Brain Injury service for assessment facilities, respite care and specialist units for extreme behavioural problems.

Key Considerations

- The DHSSPS should recognise the existence and special needs of younger people with dementia and require health and social care purchasers and providers to work together to develop services for them. There should be a clear statement of local policy in relation to allocation of responsibility for the population aged under 65 with dementia (RCPsych Council Report, 2000).
- Younger people with dementia should have access to a full range of assessment and support services, including acute assessment in-patient facilities, home care, day care, respite care and continuing residential/palliative care which recognise the different life circumstances and environment of younger people and their carers. Specialist counselling should also be made available. There must be support for family and carers.
- There should be appropriate education, training and information for all health and social services professionals to ensure an effective and sensitive response to the needs of young people with dementia and their carers.
- Collaboration with neurology, neuropsychology, medical genetics, neuropsychiatry, liaison psychiatry, substance misuse, rehabilitation and learning disability services is essential for establishing accurate diagnosis and the dovetailing of services. Non-statutory services are important and should be supported.

Learning Disability, Dementia and Functional Mental Illness

"I need help - I need to know what is in front of us - and I need help to do my best. Who is going to care for her later when I die."

man whose daughter has a learning disability and dementia

- 8.19 The Review's "Equal Lives" report points out that the numbers of people with a learning disability who will live into their sixties and seventies is increasing rapidly in Northern Ireland. Over the next 15 years, numbers will increase by 95%. Planning needs to start now to meet the needs of this group who also experience dementia and/or depression, anxiety states and other functional mental illnesses as well as the other difficulties and challenges of ageing.
- 8.20 Cooper (1997) for example found in her research that older people with learning disabilities have a greater prevalence of psychiatric morbidity than younger controls (68.7 v 47.9%). Rates of depression and anxiety disorders in his sample are also high and dementia is common. There are equal rates of schizophrenia/delusional disorders. Hatzidimitriadou and Milne (2005) provide other references which support this finding.
- 8.21 The Review has a fundamental message, which is that dementia and functional mental illness in older people need a great deal more planning and service improvement than is currently given and this is equally necessary for older people with complex combinations, which include learning disability.

Dementia

- 8.22 The risk of dementia for people with learning disabilities, except Down's Syndrome, is similar to the general population. Jokinen (2005) reminds us to bear in mind that older people with learning disabilities are less likely to have married, had children or had a job providing a pension.
- 8.23 People with Down's Syndrome are at high risk of Alzheimer's Disease as they grow older. "Equal Lives" provides tables to show that percentages for this group of people increase from 10-30% in those aged 40-49 to 30-75% in those aged 60-69 (McQuillan et al. 2003).
- 8.24 Clearly, awareness raising about dementia is needed among families and care staff as well as material on how to provide help in a way that maximises potential. Jokinen (2005) found in her research, that there was a lack of good practice material although she draws attention to the Edinburgh Principles (Wilkinson and Janicki 2002) and the work of McCarron and Lawler (2003) and Watchman (2003). The Scottish Down's Syndrome Association has produced some useful booklets (1995) for the relatives and staff of this group. Kerr and Wilson (2002) have produced a training guide for staff.
- 8.25 Early diagnosis is needed as it is for any other group with dementia. Diagnosis is often late due to lack of awareness across the board and because it can be difficult given communication and other difficulties.

Functional Mental Illness (FMI)

- 8.26 The Equal Lives report highlights that "between 20-40% of people with a learning disability are liable to have a mental health problem" (Parry ed 2002). There is now a considerable literature on the high risk of psychiatric disorder in people with learning disability, the majority being depression and/or anxiety. Hatzidimitriadou and Milne (2005) take the view that a significant proportion may be experiencing reactive depression to age-related physical illness and to the loss of a carer.

- 8.27 Moss et al. (1998) found low levels of referral for psychiatric assessment due to the challenge of identifying the problem, lack of co-operation and communication problems.
- 8.28 It would also seem likely that older people with learning disabilities will experience similar or greater rates of other functional mental illnesses as older people generally and again there is likely to be a failure to diagnose and treat.

Complex Needs

8.29 There is currently increasing policy interest in meeting the needs of people with complex needs. Those with learning disabilities along with dementia and/or functional mental illnesses are a prime example of people for whom our present models of service organisation fail.

8.30 This report endorses all the recommendations of the section of the Equal Lives report on older people, including recommendation 53:

“Arrangements should be developed to enable people with a learning disability who have dementia to access mainstream dementia service. This will include mechanisms to provide a skills boost between dementia services and dedicated disability services”.

8.31 Consistent with the recommendations of the Strategic Framework for Adult Mental Health Services report, people with mild learning disability must be given choice of mainstream and specialist learning disability services.

8.32 Dementia services and health and social care for older people with functional mental illness are also far from adequate at present and even more deficient for older people with learning disabilities. These inadequacies must be addressed. Awareness raising is a key issue in both learning disability and older people’s services which should be addressed as a priority.

RECOMMENDATION

53. People with a learning disability should have access to good quality dementia care. Those individuals who develop dementia and are already known to learning disability services should remain within this programme of care for the purposes of continuity of care. “In-reach” expertise and support should be available as required. People with a mild learning disability who develop dementia should be cared for within mainstream services, if that is their choice.

Alcohol Related Brain Damage

8.33 The term 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 a lack of information on the extent of ARBD within Northern Ireland. Most Health and Social Services Trusts will be able to identify people with ARBD in terms of hospital bed occupancy and nursing home placements, however this population is likely to be interspersed throughout several programmes of care, often without a formal diagnosis.

- 8.34 Research would indicate that ARBD accounts for 10% of the overall dementia population and 12.5% of dementias in people under 65. The peak age of those with ARBD is between 50 and 60 years of age (Scottish Report, A Fuller Life). Demographic trends and increasing patterns of alcohol consumption in the over 65 population are likely to increase incidence levels of ARBD.
- 8.35 People with ARBD present with a complex array of physical, social and emotional needs which require a co-ordinated approach across medical and social care boundaries as well as across different agencies such as housing, social security, voluntary and private providers.
- 8.36 The needs of adults with Alcohol Related Brain Damage are addressed within the Review’s report, A Strategic Framework for Adult Mental Health Services as part of Services for People with Acquired Brain Injury or Progressive Brain Disease (Sections 6.16-6.22). This report endorses the recommendations made in that report in terms of the development of a pathway which addresses emotional, cognitive, behavioural and social need. The Review supports the view that older people with ARBD should have access to exactly the same range of services as younger people and should not be discriminated against in terms of age.
- 8.37 The specific needs of older problem drinkers are also considered as part of the Alcohol and Substance Misuse Report (Sections 10.1-10.10). This report highlights the need for addiction services and resources to be sensitive to the specific additional needs of the older population.

Best Practice Examples

Both Foyle Trust and the Northern Ireland Community Addiction Service (NICAS) have developed counselling and support services specifically designed for older people and their carers. These services offer domiciliary based visits and provide a range of individual based interventions. They also provide awareness raising, training and support to other professional staff working with this service user group.

RECOMMENDATION

54. A report should be commissioned to establish the extent of ARBD in Northern Ireland. This could form part of the overall scoping exercise and needs assessment proposed in recommendations 2 and 3.

Older People with Enduring or Relapsing Functional Mental Illness

Introduction

- 8.38 Individuals who have suffered enduring or episodic severe mental disorder in adulthood and have reached the age of 65 are often described as “graduating” from services designed for adults of working age to those designed for older people. Service users in this position

are often referred to as “graduates”. The Review has, however, chosen not to adopt this term.

- 8.39 The life expectancy of the general population as a whole has increased during the course of the last century. Indeed, this also applies to those suffering with major psychiatric disorders such as schizophrenia, bipolar affective disorder or depression, most of whom now survive into later life.
- 8.40 Over the last 50 years there has been considerable restructuring of mental health services, including the development of community based services and a move away from institutional care. Consequently those who would at one time have been cared for as in-patients in psychiatric hospitals must now have their needs met in other settings – in their own homes, with their family and other carers or in residential or nursing care settings.
- 8.41 At the same time, mental health services have been organised into specialities, such as acute adult, rehabilitation and old age psychiatry. Specialist old age psychiatry services accept the majority of people with mental health problems over the age of 65 who are referred at first presentation with mental health problems. There is, however, some variability in practice with respect to the transfer of these people from general adult sector mental health services to specialist old age psychiatry services. Of note also is the fact that within social services, older people’s and mental health services are usually managed within separate directorates. This means that people who have been cared for within the mental health programme of care may be transferred, at retirement age, to more generic older people’s services.
- 8.42 As individuals with severe or enduring mental illness grow older, their needs take on new levels of complexity, with increasing physical ill health, declining memory, social care issues and particular psychological problems relating to the ageing process itself. Some will also develop additional mental health problems as well as Alzheimer’s Disease and other dementias.
- 8.43 These individuals are, however often “uniquely disabled by a combination of personal, social, mental and physical health disadvantage” (Jolley et al. 2004) and are often not a high priority for general psychiatry services.

General Principles

- 8.44 The service which offers the greatest expertise in the care needs of an individual should assume responsibility for their care. It is recognised that there are instances where a person’s needs cannot be met in entirety by one service. In this instance, clear planning of an individual’s care, so that areas of responsibility are delineated, is a prerequisite of effective delivery of care.
- 8.45 Where individuals are physically well, and do not have dementia, but are older than 65 years of age, and receiving ongoing care from general and community psychiatric (GC) services, the imperative principle is that of continuity of care. This must take preference over automatic referral at a particular age.

- 8.46 It is recommended that the standard cut-off age for service boundaries should be 65 for individuals presenting for the first time with psychiatric disorder. Where the person has been discharged back to primary care i.e. his/or her GP, from the GC sector at or around 65 years, only to re-present within a short time, then the arrangements for this needs to be agreed locally. Otherwise, if a substantial time has elapsed, or there are other difficulties such as cognitive impairment, perceptual difficulties or carers issues, then the referral is more appropriately made to old age services. The individual must be central to any clinical decisions.
- 8.47 In-patient and day care facilities should be provided according to that which best meets the individual's needs. In addition, the value of continuity of care, with existing staff, rather than age alone must be considered. This also applies after a patient's discharge.
- 8.48 Individuals may be assessed by one service but long term care provided by another service. The person's needs must take priority in such a case. (These principles are based on two papers published by the Royal College of Psychiatrists, 2002 and 2004).

RECOMMENDATION

55. At around the age of 65 years (or an age agreed within the local service) individuals with enduring or relapsing mental illness should have a comprehensive review of their health and social care needs. The individual's ongoing care should be provided by the team which is best placed to meet their identified needs. However, if someone has significant physical health problems, complex care requirements or significant cognitive impairment, then a transfer of care to the specialist old age service should be considered. It is important that the person's GP is kept fully informed of any transfer of responsibility.

Key Consideration

- Each Board/Trust area should undertake a survey to determine the needs of this service user group as resources should follow service demand. The funding of these services should relate to the relevant contribution of each element of the service to the total care provision. This will need to be reviewed and developed locally to ensure that service demand and need is met.
- 8.49 The needs of people becoming older with enduring or relapsing mental illness are also considered within the Review's report, A Strategic Framework for Adult Mental Health Services (Sections 4.61-4.62). This report endorses the recommendations made in terms of agreement of local arrangements for meeting the needs of this population, the need for transitional review and for identification of need in the population of people entering older age and their carers.

CHAPTER 9

MAKING IT HAPPEN

- 9.1 This Report is being written at a time of major restructuring of health and social care services in Northern Ireland. The recommendations are wide-ranging and will present challenges to both commissioners and providers of services. However, if these challenges can be realised, services for older people with functional mental illness or dementia related illnesses and their families will be radically reshaped and enhanced.
- 9.2 What will make this report a reality? There is a need for increased resources inclusive of buildings, finance and human resources to meet deficits in current services as well as taking into account the significant increases in the population over the next few decades and subsequent increased demand. However, there is a need to ensure that current resources are used effectively and efficiently. Therefore, there are challenges for all providers of services inclusive of statutory, independent and private sector providers, to re-configure and reshape services to meet changing demands and needs and realise these recommendations. It is not just about asking for more resources but being more creative also with what is already provided.

Strategic Framework

- 9.3 The Report provides a vision of services for the future that challenges commissioners and providers to ensure that:
- services for older people with functional mental ill-health and/or dementia should be provided in non-institutional settings;
 - people are maintained in their own homes or appropriate domestic type accommodation;
 - robust primary care and community based services are in place for everyone irrespective of geographical location;
 - free nursing care at point of delivery;
 - user and carer involvement is critical to service commissioning and implementation;
 - within statutory provision, mental health services, irrespective of which directorate they sit within, should be a discrete sub-speciality, with a ring-fenced budget and clear protocols in place for interfacing with other programmes of care;
 - the voluntary, independent and private sectors should be key providers of services;
 - appropriate data collection for performance monitoring and planning; and
 - information and advocacy services are embedded in service delivery.

Organisational Framework

- 9.4 The challenges for organisations are that:
- visionary and creative commissioning and provider organisations are required;
 - good performance management and information systems in organisations are a prerequisite;

- partnership and collaborative approaches across a range of organisations are facilitated and promoted; and
- intra and inter-agency working is embedded in service delivery.

Services Framework

9.5 The challenges for services for a fast growing, ageing population that this Report has highlighted are:

- the need for flexible and responsive services that are not fettered by unhelpful bureaucracy;
- the need for a single point of entry and assessment;
- simple referral systems with good follow through so that people do not get lost in systems;
- the importance of the coordination of different disciplines;
- the necessity of audit and monitoring;
- the centrality to service provision of carer and user involvement;
- the need for seamless interfaces across professions and carers formal and informal;
- the need for information accessibility; and
- clarity on the funding of services and who pays for what.

9.6 It is not within the remit of this Report to define how services need to be structured and delivered, but rather that the aforementioned challenges should be addressed.

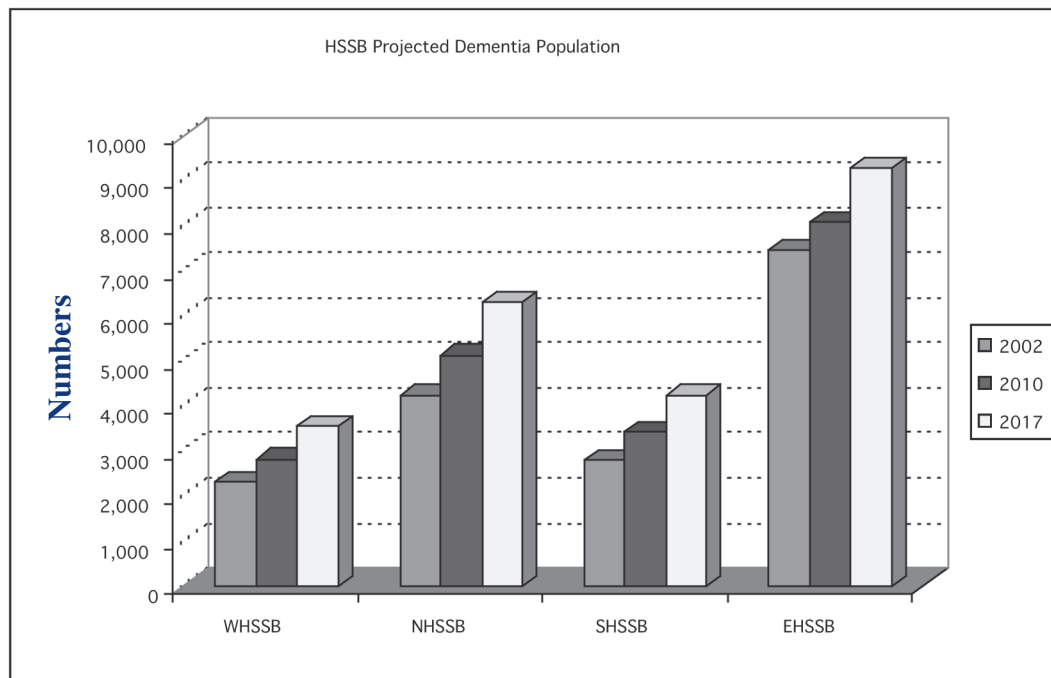
9.7 There are two key requirements to making reform happen: namely a competent workforce and adequate resources.

A Competent Workforce

9.8 In 2002 in Northern Ireland, the estimated population of people 65 + was 227,000. By 2042, this will increase to 457,000 - an increase of 98.6%. In 2002, the population of 80 + was 55,000. In 2042 this will be 156,000 - an increase of 185%. This is of major impact to planners and commissioners involved in health and social care provision.

This data can be further broken down into Health and Social Services Board projections for the next 12 years.

Summary of projected Dementia population for each Board.



- (1) The Eastern and Northern Board areas will have the largest growth in the dementia population but all Board areas need to plan for the future workforce to meet this reports recommendations

Workforce Requirements

Who and How Many?

- 9.9 There are no norms of ratios of staff requirements per population that can be applied to ascertain workforce needs and workforce requirements. This will be determined by the types of supported living/care models of services that will be provided. The emphasis on future service provision is enabling people to remain in their own homes for as long as possible, with appropriate models of support. These should be inclusive of meaningful day activity services and home care/support or providing suitable housing alternatives that are not based on institutional living i.e. residential care homes, nursing homes or hospitals, although there will still be a need for those services.
- 9.10 It is also worth noting that between the present and 2025 there will be an unusually high volume of “young” old in the population. Assuming these people retire from paid employment if they can afford to do so, this age group provides a potential high rate of volunteering which will be important in community and service development initiatives.
- 9.11 Current service provision is delivered by a range of professional medical, health and social work staff, as well as an expansive workforce of non-professionally qualified social care/health staff - the latter of whom make up the majority of the workforce in community based provision such as domiciliary care, floating support, day centres and

residential/nursing homes. With the emphasis on enabling people to remain within community settings, this section of the workforce will need to be expanded, resourced and trained to meet the increasing needs of the older population.

- 9.12 Significant service provision is also provided by an unpaid workforce, i.e. family carers, community groups, church organisations etc. They also require training, support and financial assistance to carry out their caring role. They are also a potential pool of skilled paid workers to recruit from. There are also opportunities to be explored in relation to using Direct Payments to make effective use of these skilled people.
- 9.13 The recruitment of staff within Northern Ireland will be a significant challenge and consideration will also have to be given to recruitment of staff outside Northern Ireland and Great Britain and the infrastructure required to effectively support foreign workers.
- 9.14 It is difficult to quantify precisely by how much the professional and non- professional workforce will need to expand without knowledge of the types of service provision that will be made available to this target population. Nevertheless, a community based approach, enabling people to be diagnosed, treated, cared for and supported in non -institutional settings will place significant demands on primary and secondary care services and require the development of increased specialist services within hospital and community settings.
- 9.15 A range of services for people with Dementia or Functional Mental Illness may include the following personnel:
- Consultant Psychiatrists of Old Age;
 - Staff grades;
 - SHOs;
 - OTs;
 - GPs;
 - Memory Clinic personnel;
 - Psychology services;
 - Physiotherapists;
 - Speech and Language Therapists;
 - Service Managers;
 - Outreach workers;
 - Social workers;
 - Nurses;
 - Care Managers;
 - Direct payment co-ordinators;
 - Community care assessors;
 - Social Care/Health Care workers (domiciliary);
 - Residential / Supported Housing Staff;
 - Floating Support workers;
 - Day activity staff;
 - Day Hospital staff;
 - Ancillary staff;
 - Specialist therapists, i.e. reminiscence, sonas, alternative therapies; and
 - Drivers.

9.16 Currently many of these professionals, such as physiotherapists, speech and language therapists, psychologists, are not dedicated to older people services, yet their inputs are an essential part of a holistic treatment and care service. More memory clinics are required to ensure accessibility to these services throughout Northern Ireland and there is a general shortage of qualified nursing and social work staff to work in the area of older people with EMI or FMI. More GPs are required who are effectively trained in diagnosis of mental illness and dementia type illnesses. Many domiciliary and support services are already experiencing staff shortages. While it may be possible to apply some ratios per head of population to the provision of professional workers, it is more difficult to quantify the numbers of home care, domiciliary type workers as the model of service provision will impact on the numbers required.

9.17 Based on the recommendations of this Report, it is estimated that over the next 5 years the additional professional workers required are:

- 76.5 wte nurses Bands 5-8;
- 138 wte staff Bands 2-4 (for acute and assessment services);
- 10 wte CPNs;
- 10 advocacy workers (may be from a variety of professions);
- 5 wte Trainers;
- 14 wte social workers
- 16wte Occupational therapists;
- 7.5 wte Consultant Psychiatrists of Old Age;
- 2wte SHOs;
- 1.5 wte staff grades;
- 22 wte crisis workers (may be from a range of professional groups);
- 8 HCOs;
- 2 wte Pharmacists;
- 15wte Psychologists;
- 13wte Physiotherapists;
- 2.5wte dietitians;
- 4 wte podiatrists; and
- 15 wte speech and language therapists.

9.18 The required expansion in the non-professionally trained workforce which will make up the bulk of paid carers, is difficult to estimate. There is insufficient data about this workforce, but it is estimated that 90% of the social services workforce in Northern Ireland (36,140) are social care workers (Workforce Planning Review, DHSSPS, 2006) working in a range of settings and agencies. While this information is not broken down in to programme of care, it can be assumed, given proportional expenditure across service user groups, that the vast majority of the social care workforce is employed in older people's services.

9.19 In an analysis of one Trust's provision for a specialist Dementia/Older People FMI service (with a known dementia/FMI population of 1,475) the domiciliary work force would need to expand by at least 20% to meet projected demand, based on current service provision.

Recruitment and retention

9.20 Recruitment and retention of both professional and non-professional staff is a major concern for service providers. There are currently significant difficulties in obtaining suitable staff for care work such as domiciliary and home care and retaining them to provide consistency in service provision. This is due to a range of factors, including:

- low pay for social care workers;
- better terms and conditions and rates of pay in retail/other sectors;
- lack of career structures;
- anti-social hours and weekend working;
- inadequate travel allowances particularly in rural areas;
- lone working;
- lack of flexible working arrangements;
- differing pay scales, terms and conditions between service providers that leads to “poaching” from service to service; and
- heavy insurance premiums for use of car for business purpose particularly for under 25s.

9.21 There is a current shortage of mental health nurses and a low uptake in training programmes for mental health that will have a major impact on professional recruitment. Psychologists need to be an integral part of older people services.

9.22 Remuneration levels need to be explored across professional and non-professional staff groups but other factors also need to be considered such as:

- promoting social care as an attractive career;
- providing flexible job contracts;
- positive presentations about working with older people with mental health needs;
- provision of training and development of competences; and
- ensuring robust management and support infrastructures for all staff.

9.23 The non-paid workforce need to be encouraged and supported to maintain their caring roles as they will be a resource to recruit from.

9.24 The use of foreign workers needs to be explored and consideration given to the racial interface with the local workforce and development of appropriate infrastructures to support mobility of workers.

Training Support and Standards

9.25 The knowledge base and skills required to meet the needs of older people with FMI and those with dementia, need to be addressed for all professional and social/health care workers, as well as volunteers.

9.26 Professional training programmes in medical, health and social work courses need to address key areas of early diagnosis, assessment and treatments, which should be further

enhanced by post-professional specialist training opportunities. The Centre of Excellence at the Dementia Centre, Stirling University, is one example of a provider of specialist training in working with people with dementia for all professional and non professional staff groups. However there is a lack of similar resources for older people with functional mental illness.

- 9.27 The social care workers of the future need to be multi-skilled in general areas of competence in working with older people and receive specialist training in the particular needs of those with FMI, depression and/or dementia. Such training must encompass the social, emotional and spiritual needs of older people, their immediate carers and family as well as physical care needs. Staff will need to develop competence in the area of assistive technologies and use of telemedicine as well as particular interventions to stimulate cognitive functioning and mental well being e.g. reminiscence therapies, creative therapies. Understanding of depression in old age, self harm, communication skills are all prerequisites of a competent workforce. There are numerous opportunities for skill development within vocational training and organisations should actively strive to embed occupational standards within management processes such as appraisal, supervision and performance management as well as enabling staff to undertake NVQs.
- 9.28 Service providers have a responsibility to ensure that all staff are appropriately trained and fit for purpose. The Professional Regulatory Bodies also have an important role to play in ensuring this happens. The Regulation and Quality Improvement Authority will concern itself with ensuring the competence of service providers as organisations and inspect services against clearly defined standards of practice and governance. A robust regulatory framework is essential in achieving and maintaining those standards and ensuring public confidence in all providers of services.
- 9.29 Service provider organisations need to support staff, especially those with direct service user contact who are often working alone. Robust, supervisory management systems need to be in place for all staff as well as sound quality assurance systems that monitor service effectiveness and ensure quality standards. Providers of services to older people are diverse and encompass statutory, voluntary and independent sectors that include paid staff and volunteers. Whether a small privately owned company or a large statutory provider, workforce and workplace competence need to be capable of effective service provision.

Resources

- 9.30 The recommendations in this Report provide an overall guide to required developments and outline additional resources required. More detailed analysis is, however, required to determine baseline service provision and projected service demand. Each Provider Trust will need to develop implementation plans for their resident populations and map out the services which will be required to meet identified needs.
- 9.31 As part of the work of the Review, a detailed costing of each of the recommendations has been undertaken. The Review anticipates that £50 million of additional income is required to implement the recommendations and ensure that the strategic framework for health and

social care needs is achieved. This figure does not reflect the investment that will be required to meet demographic changes. Neither does it reflect (apart from a £5 million additional capital spend) any of the capital costs associated with reconfiguring buildings or housing costs. It is important to highlight, however, that there are likely to be some savings from reconfiguring existing services and resources.

- 9.32 It has not within remit of the Review to look at how additional funding is raised to meet these costs but charging for services will become a major challenge for service users. Commissioners and providers need to ensure, if introduced, fair and equitable charging policies so that primary carers are not disadvantaged.
- 9.33 To make this Report a reality, there needs to be additional resourcing of services but, alongside this, determination will be required, to ensure that this document does not sit on a shelf and gather dust but rather becomes a live and dynamic framework which is used to deliver excellent services to older people with mental health needs.

SUMMARY OF RECOMMENDATIONS

1. While services for older people with mental health issues may be located within either a mental health or older persons' programme of care, they should be provided as a discrete sub-speciality, with a ring-fenced budget and clear protocols for accessing other programmes of care.
2. Health and Social Services Commissioners and Providers must have in place a detailed analysis of the demographic detail of their respective rapidly expanding older populations to effectively assess need and plan for current and future provision for those older people with mental health issues. This analysis should include identification of older people from ethnic minorities.
3. Health and Social Services Commissioners and Providers should undertake a scoping exercise of current service provision for older people with mental health issues, identifying shortfalls in provision, unmet need and the service provision anticipated for the next 10 years.
4. Realistic tariffs for residential and nursing care, which reflect the particular needs of older people with mental health issues, should be agreed.
5. A Policy and Practice Development Centre for Mental Health Services for Older People should be established which would provide information, training, consultation and research and help secure comprehensive and relevant dementia service provision.
6. Public education programmes, focusing on promotion of good mental health and prevention, should be developed.
7. The DHSSPS should ensure from a strategic point of view, that health promotion in relation to mental health issues is given the same priority as for other service user groups.
8. Dementia and mental health issues in older age should be included in all training programmes for health and social care staff (including those working in the independent sector). This should be undertaken on an inter-agency and multi-disciplinary basis where possible. Training and education programmes for carers should also be provided.
9. Independent, specialist advocacy services should be available for older people with mental health issues. These should be commissioned on a regional basis to ensure equity of access and service delivery to agreed standards.
10. Health and social care professional education and training at undergraduate and postgraduate level should include more training in the area of dementia and functional mental illness. This education should include experience of dealing with these conditions in the community.
11. Primary care staff should receive more training in the early detection of dementia and

functional mental illness and recognise the benefits of doing this. The use of standard assessment tests should be encouraged.

12. Systems which are sensitive to the particular needs of carers should be in place within GP surgeries, e.g. flexible access.
13. Clear, local protocols should be drawn up jointly between primary care and specialist services.
14. Dementia care and care of older people with functional mental illness in the community should be considered as a Locally Enhanced Service (LES) within the GMS contract.
15. Specialist domiciliary care services for older people with mental health issues should be developed. These should be available over a 24-hour period. Continuity of service delivery is vitally important and every effort should be made to ensure this is central to any new care plan.
16. Good quality domiciliary care requires adequate resources to be made available to attract good staff and allow for proper training. Trusts must identify the appropriate resources to develop specialist domiciliary support services. These services must be supplemented by assistive technology and multi-disciplinary crisis/rapid response.
17. Support for older people with acute mental health issues should be available on a twenty-four hours a day, seven days a week basis. Support should be available both for those with dementia and functional illness.
18. A person with dementia in the community who develops acutely increased confusion/agitation should have an urgent medical assessment to check for delirium.
19. Older people should only be admitted to hospital if their medical or psychiatric condition requires it. No-one should be admitted to hospital solely to provide a place of safety when what is needed is an increased level of care in the community.
20. Older people with dementia and FMI should have access to similar crisis/home treatment teams as younger people with mental health problems or those with physical illness. Crisis/Rapid Response Services should include older people with FMI and dementia and be sensitised to their specific needs.
21. A range of models of day-time support which are responsive to user and carer need and which promote social inclusion, should be developed. Particular consideration should be given to people in rural settings and the need to develop creative responses to their needs.
22. Respite care provision should be a clear and identifiable part of any commissioning or service planning process. A range of models should be delivered. It should be provided locally, be flexible, responsive and of benefit to older people with mental health issues and their carers.

23. Providers and commissioners must contribute to NIHE strategic planning in order to ensure that the needs of the increasing population of people with mental health issues are fully considered. Future planning must guarantee a range of housing options, internal design solutions, adaptations and use of assistive technology which promotes people's independence both in their own homes and in supported housing settings.
24. Providers must ensure that support models promote empowerment, independence and social inclusion.
25. Department for Social Development (Housing Division) funds should prioritise the provision of 2 bedroom bungalows for one person in order to encourage a carer and/or family to live with the individual on a permanent or regular basis (including overnight and weekend stays).
26. Assessment processes should include consideration of the potential to use assistive technology. The use of assistive technology should be promoted and extended. This will require adequate resourcing and clear assignment of budgetary responsibility.
27. Organisational structures should support restraint-free/minimal restraint care and provide the required staff education, consistent staffing levels and the equipment and technology necessary to support this care strategy. Audit frameworks to monitor employment of restraint policies should be in place within all care settings. A regional directive that is dementia specific should be developed.
28. Older people with mental health issues who are resident in care homes should have the same access to all primary and community care services as those living independently in the community, e.g. dental, podiatry and optical services, rehabilitation, falls prevention services and day care services if that is their choice. This should also include regular medical review by a GP.
29. Standards of care in all care homes should reflect not only high quality nursing care, but also a culture that promotes a positive and enjoyable quality of life, including appropriate activities, enjoyable and appropriate food and promotion of independence. This should be regularly reviewed.
30. Staffing levels should adequately reflect the high level of needs of older people with mental health issues.
31. There should be adequate induction, supervision and ongoing training for staff, particularly in the management of dementia and mental health needs.
32. There should be effective and rigorous monitoring and reporting of standards and quality, including the quality of life and lived experiences of residents, within care homes by the Regulation and Quality Improvement Authority.
33. Users and carers should be fully involved in all decisions about care and care provisions.

34. Interim care challenging behaviour facilities should be developed. These must be appropriately staffed and funded.
35. Commissioners should seek proposals on how a palliative care approach for people with advanced dementia can be rolled out to all care settings.
36. Older people with mental health needs should have access to suitable intermediate care services.
37. Specialist teams should provide the necessary support to staff working in mainstream intermediate care services. This may include in-reach by link staff from specialist teams to provide support, training and coaching.
38. Anyone with a diagnosis of dementia or long-term severe functional mental illness should have a key worker for the duration of their illness.
39. Specialist Multi-disciplinary Teams for Older People with mental health issues should be introduced where not currently in place.
40. Pilot projects which include the development of enhanced practitioner roles should be set up and monitored.
41. Pre- and post-diagnostic support should be available for people with dementia and their carers.
42. Consideration should be given to moving towards a single point of entry for referrals to specialist services with multi-disciplinary allocation of referrals as suits local circumstances.
43. In-patient facilities for those with functional mental illness should be located within a function-specific unit for older people, alongside other psychiatric admission facilities within a local general hospital site. Strong links are required with the professional staff within the district general hospital.
44. Older people should have access to all evidence-based treatments according to need, including psychotherapeutic services.
45. Access to appropriately staffed Day Treatment Units with flexible opening hours for those with severe mental illness should be seen as a priority.
46. Protocols for the management of common psychiatric conditions and referral to the Psychiatry of Old Age Liaison team should be introduced in to general and specialist hospital wards supported by education and training delivered by a dedicated multi-disciplinary Old Age Psychiatry Liaison team.
47. Care pathways for older people with mental health needs in the acute hospital setting should be developed.

48. There should be an appropriately qualified designated person to co-ordinate discharges for older people with mental health issues.
49. Where possible, decisions about long-term care should be made in the community, in a setting familiar to the older person.
50. Services for younger people with dementia should be located within either the mental health programme or older people's programme of care. There must be a clear policy in place and a dedicated lead for the planning and delivery of services for young people with dementia. Services must also be appropriately funded given the complex needs of this group.
51. There should be adequate financial support for young people with dementia and their carers to enable them to meet the extra costs of caring. Employers and the Social Security System should adopt practices which recognise dementia as grounds for early retirement and which protect a person's entitlement to pension rights and other benefits.
52. Residential respite is important for short breaks and could have links with an assessment/rehabilitation unit. There may be opportunities for joint developments with the Brain Injury service for assessment facilities, respite care and specialist units for extreme behavioural problems.
53. People with a learning disability should have access to good quality dementia care. Those individuals who develop dementia and are already known to learning disability services should remain within this programme of care for the purposes of continuity of care. "In-reach" expertise and support should be available as required. People with a mild learning disability who develop dementia should be cared for within mainstream services, if that is their choice.
54. A report should be commissioned to establish the extent of ARBD in Northern Ireland. This could form part of the overall scoping exercise and needs assessment proposed in recommendations 2 and 3.
55. At around the age of 65 years (or an age agreed within the local service) individuals with enduring or relapsing mental illness should have a comprehensive review of their health and social care needs. The individual's ongoing care should be provided by the team which is best placed to meet their identified needs. However, if someone has significant physical health problems, complex care requirements or significant cognitive impairment, then a transfer of care to the specialist old age service should be considered. It is important that the person's GP is kept fully informed of any transfer of responsibility.

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Expert Working Committee**

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Legislative and Policy Context

Community Care

1. **People First: Community Care in Northern Ireland in the 1990s** continues to provide the policy focus for actions designed to ensure that all users of community care services have access to high quality and responsive care in the setting most appropriate to their needs. These services should optimise choice, promote independence and ensure fairness and equity.

Dementia Policy Scrutiny

2. The DHSSPS' general policy covering community care provides a policy framework that embraces dementia. However this overarching policy had only limited impact on the development of coherent dementia services. In commissioning the **Dementia Policy Scrutiny Report**, the Department sought:
 - to make good the identified policy deficit;
 - to establish a strategic direction for the development of dementia services; and
 - to provide helpful guidance on good practice for purchasers and providers.
3. A Scrutiny Action Team drawn from a variety of relevant backgrounds and professions undertook the Scrutiny from 1 March to 30 June 1994 on the basis of the following remit:

“the policy scrutiny will review the health and social services needs of dementia sufferers and their carers, identify the components of an appropriate and effective dementia policy and make recommendations.”
4. The Scrutiny Action Team's major recommendations were grounded on the need to establish dementia services on a sound and regular footing, with a clear administrative base; ensure the development of effective and well-targeted services, identifying and meeting need in a timely and appropriate manner; and contribute positively to enabling people with dementia and their carers live full and independent lives, ideally in a community setting.
5. These objectives are fully in line with the general objectives of the health and social services in Northern Ireland. The recommendations were split into two groups:
 - i. those which should be implemented immediately (20 in all), generally with limited resource consequences which should be met within existing resources (including People First monies); and
 - ii. those which would be implemented progressively as part of a dementia strategy, commencing now but covering the period of the next Regional Strategy (13 in all).

The latter were recognised as possibly having more substantial resource consequences.

Review of Community Care

6. An extensive consultation exercise was carried out from July to September 2001 taking on board the views of statutory and independent sector providers, voluntary organisations and the health and social care professions. The objectives of the consultation exercise were to identify barriers to the delivery of good community care services, to identify good practices across the region and to bring forward recommendations for improvements in the shorter term. **The Review of Community Care–First Report** was published in May 2002 and contained seven recommendations which were:
 1. enabling people to live in their own homes;
 2. spreading best practice;
 3. developing services to provide practical support for carers;
 4. care management processes and assessment tools;
 5. promoting the development of a flourishing independent sector alongside good quality public services;
 6. accountability of agencies; and
 7. funding structure for community care.

A number of project groups have been set up to take these recommendations forward, including one tasked with developing a Single Assessment Tool for Older People which can be applied to all Trusts within Northern Ireland. This project is now at the start-up stage.

Carers' Issues

7. The contribution of informal carers to the effective delivery of personal social services has been recognised and the needs of carers, to help them continue in their caring role, are being addressed in a number of ways by the DHSSPS. The Minister commissioned a strategy for carers in October 2000 with the aim of identifying practical measures that will make a real difference to the lives of carers. In drawing up a draft strategy, the Department consulted a reference group of carers and organisations representing carers to find out what they saw as solutions to the difficulties carers face in carrying out their caring role. The outcome of this consultation was reported in **Valuing Carers** and was published in April 2002.
8. The **Carers and Direct Payments Act (Northern Ireland) 2002**, which commenced in part on 31 March 2003, gives carers a legal right to an assessment for services in their own right. The carer's assessment looks specifically at the impact of the caring role on the health and well-being of the carer and concentrate on what is needed to support the carer in his or her own role. The Act also makes it possible for carers to receive services in their own right and allows them to be considered for receipt of direct payments as an alternative to direct service provision.
9. The Act also places a requirement on Trusts to identify carers, to provide them with information on services available and to offer assessment of their need for services.

Protection of Vulnerable Adults

10. All Health and Social Services Boards have had policies and procedures for the protection of vulnerable adults in place since the mid 1990s, following the issuing of draft guidance by the DHSS in 1995.
11. Most policy documents have adopted the Law Commission (1995) definition of a “Vulnerable Adult”, i.e. “any person aged 18 or over who:
 - is, or may be, in need of community care services or is resident in a continuing care facility by reason of mental or other disability, age or illness; and who
 - is, or may be, unable to take care of him or herself or unable to protect him or herself against significant harm or exploitation.”

The policy covers all forms of abuse and is applicable to all sectors and settings.

12. The **Protection of Children and Vulnerable Adults (Northern Ireland) Order 2003 (POCVA)** commenced in April 2005 and provides a legislative basis for the maintenance of a list of individuals who are considered unsuitable to work with vulnerable adults.

Ensuring Quality

13. **Best Practice – Best Care** (DHSSPS, April 2001) set out proposals to put in place a framework to raise the quality of services provided to the community and tackle issues of poor performance across the Health and Personal Social Services. The aim is to provide a high quality system of health and social care which is easy and convenient to use, which is responsive to people’s needs and which provides a service that instils confidence in those who use it.
14. The quality agenda is underpinned by the **Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003** which has two main dimensions:
 - regulation of individual establishments and agencies; and
 - inspection of clinical and social care governance in the HPSS.
15. Key elements of the programme of change initiated by Best Practice – Best Care include:
 - a statutory duty of quality on Boards, Trusts and Agencies;
 - minimum published standards of care;
 - wider and stronger regulation of services;
 - creation of an HPSS Regulation and Improvement Authority (RQIA); and
 - links to national bodies in standard setting, training and support.

16. The RQIA will be responsible for:
 - regulating services;
 - conducting reviews;
 - undertaking investigations; and
 - carrying out inspections.

17. **A Healthier Future: A Twenty Year Vision for Health and Well-Being in Northern Ireland 2005-2025** is the new regional strategy for health and well-being and presents a vision of how health and social services will develop in Northern Ireland over the next 20 years. The five main themes addressed include:
 - investing for health and well-being;
 - involving people – caring communities;
 - responsive combined services;
 - teams which deliver; and
 - improving quality.

18. The strategy places a special emphasis on promoting health and well-being among vulnerable groups, including older people, for whom preventative measures could have the greatest effect. It also offers a commitment to offering immediate access to community-based and emergency services, where these are required, and to increasing choice for people near the ends of their lives about how and where they receive services.

19. A further policy direction is concerned with protecting and promoting a “full life” for carers, people with mental health problems and older people amongst other groups.

20. The need to break down the barriers between services delivered in communities (primary and community-based care) and services delivered in hospitals (secondary, acute or tertiary care) is also highlighted.

21. The strategy acknowledges that the demands for hospital services will grow over the next years and endorses the wide-ranging programme of modernising hospitals set out in **Developing Better Services (DBS)**. Two of the key directions being pursued as part of the DBS agenda are:
 - greater provision of generalist services, including primary care services, within communities or on a day-patient or out-patient basis; and
 - greater specialisation, particularly within acute hospital services.

22. The role of hospitals is increasingly being seen to support community based care services, requiring a whole systems approach to be adopted to ensure an appropriate balance of investment in services, both in the acute sector and in the primary and community care sectors, and innovative ways of working, which will share good practice and resources to the benefit of the patient, for example, Managed Clinical Networks.

23. **Ageing in an Inclusive Society** (OFMDFM) strategy document was launched in March 2005 as part of the Promoting Social Inclusion and Targeting Social Need initiatives. It sets out the approach to be taken by Government to promote and support the inclusion of older people in Northern Ireland. Strategic aims include the promotion of an enabling environment which gives older people choice and control over the services that influence their lives and the need for integrated action to provide more effective economic, health and housing support to the older community. To monitor the delivery of the strategy, a Champion for Older People at Senior Civil Service level has been established.
24. **Caring for People Beyond Tomorrow**, A Strategic Framework for the development of Primary Health and Social Care for Individuals, Families and Communities in Northern Ireland, DHSSPS, 2005, sets out how primary care services should be developed and provided over a 20 year time span. The emphasis is on the development of consistently high quality and seamlessly integrated services delivered in the community, close to where people live, which will provide the great majority of services, achieve high levels of health and social well-being and minimise the need for hospitalisation or residential care.

Funding Long-Term Care

25. The Royal Commission Report on Long-Term Care which was published in March 1999, recommended that the costs of long-term care should be split between living costs, housing costs and personal care, with the personal care component being paid from general taxation and the rest being subject to a co-payment according to means.
26. One of the key principles underpinning the recommendations of the Royal Commission was equity. The Report states:

“Care needed by people with Alzheimer’s Disease is directly analogous to the kind of care provided for cancer sufferers. The latter get their care free. The former have to pay.... The situation must be put right.” (*para 6.33-64*)
27. While there was much initial support in principle for the Royal Commission proposals, the additional monies made available by Government were targeted more at intermediate than long-term care. Free nursing care was only provided up to a limit of £100 per week and then only if provided by a registered nurse. The House of Commons Health Committee Report (April 2005) comments:

“Over six years after the Royal Commission reported, and nearly ten years after concerns were first raised by a predecessor Health Committee.....elderly people...still find themselves subject to a bewildering funding system which is little understood even by those who administer it, and which few patients or carers would describe as fair, or as guaranteeing their security and dignity.”
28. In Northern Ireland, there has been support in principle for the Royal Commission proposals. In October 2002, the Northern Ireland Assembly introduced a weekly HPSS contribution towards nursing care in nursing homes. This payment is intended to pay for

the professional care given by a registered nurse employed in a nursing home. There is a flat weekly payment of £100, payable by Trusts to homeowners on behalf of residents with assessed nursing needs who pay privately. Alternatively, it is discounted from the charges raised by Trusts for people who are required to refund Trusts at the full rate. Those residents in a nursing home who fully fund their care may be entitled to a contribution of £100 a week towards the cost of a Nursing Needs Assessment where the client's nursing needs are identified. Any further implementation of the policy has also been delayed by the political situation in terms of the suspension of the Northern Ireland Assembly.

29. Some of the key issues which are yet to be resolved are the distinctions between health and social care and between nursing care and personal care. The definition of "personal care" adopted by the Royal Commission, which is based on an internationally recognised definition of nursing, precludes care given by other carers. This is particularly significant for older people with dementia whose care is mostly provided by informal carers and unqualified staff. June Clarke, Professor Emeritus, University of Wales, comments:

"On every issue, older people with mental health problems (especially dementia) fare worse than other older people."

Therapeutic Activities

Kitwood (1997) identifies six needs which we all have as human beings, including the need for identity, occupation and self-expression. These needs are equally important for the older person with dementia or FMI although will often need to be nurtured and facilitated by others such as carers or care staff. One way of achieving this is through offering “expressive outlets” in the form of therapeutic activities or through the use of the arts.

Activities can be linked to a person’s previous life experiences and interests or may offer new opportunities for creativity and self-expression. Occupation needs to be personally significant and to draw on the person’s abilities. Activities can target all sensory levels, which is of particular importance where verbal communication ability is impaired.

Some of the interventions highlighted below are primarily used with people with dementia; others will be appropriate for use with both dementia and FMI service user groups.

1. COMPENSATORY INTERVENTIONS

These are techniques that compensate for the level of disorientation associated with dementia.

Cognitive management and rehabilitation approaches are aimed at supporting memory function by reducing cognitive load and encouraging the use of external memory aids.

Reality orientation programmes – in these programmes, various cues and prompts are used extensively as external memory aids, to reduce load on the memory. The technique aids orientation by unobtrusively repeating facts about day to day life, current events etc. It can provide the individual with a structured environment to help them to adjust and function to the best of their ability. Environmental cues and prompts need to be obvious if they are to enhance the quality of life. The person must usually learn to associate the cue with the information its retrieval is meant to prompt. Research findings indicate that there is some evidence to suggest that reality orientation is effective in improving cognitive ability, with a demonstrable long term gain (Bates J. et al. 2004).

2. ENGAGEMENT INTERVENTIONS

These techniques use long-term memory as a means of engaging the person. Long-term memory appears to be much less affected in the early stages of dementia than short-term memory and so offers “a fertile ground for recall of past learning and past experience”(Gibson, 2006)

Reminiscence therapy involves the recollection of past activities, events and experiences with another person or group of people. This may be achieved by using tangible prompts such as photographs, familiar items from the past as well as music etc. The evidence

relating to reminiscence therapy and life review is more equivocal. Positive effects were found by Baines S. et al. (1987) who found that treating confused older people firstly with reality orientation and subsequently with reminiscence therapy, led to significant improvements on measures of cognition, communication and behaviour even at four weeks post-treatment.

Recent research by McKee et al. 2005, found that reminiscence enjoyment was associated with positive psychological health while high frequency of reminiscence and regrets was associated with negative psychological health. This study highlights the need to choose participants carefully and to be aware of individual needs and differences. However, Spector et al. in their Cochrane review (2003) found there was insufficient data to reach firm conclusions about the effectiveness of reminiscence therapy for dementia and highlighted the need for further research.

Life Review/Life Story Work typically involves individual sessions, in which the person can be guided through life experiences, encouraged to evaluate them and produce a life story book. Life story material is anything that is relevant to the individual (it is not simply life history) and reinforces the person rather than the dementia.

Recent research carried out by Gibson, Haight & Michel (2006) in Northern Ireland seeks to evaluate the use of life review and a life story book project as a psychosocial intervention in long stay care settings (forthcoming publication).

Best Practice Example

The Northern Ireland Reminiscence Network, which has a membership drawn from health and social care agencies across all sectors, libraries, museums, arts, education and community organisations, encourages people of all ages to recall, share, value and preserve memories of their personal life experience for the enrichment of themselves, their families and communities. The Network undertakes reminiscence education and training, promotes good reminiscence practice with individuals and groups and engages in projects in partnership with Health and Social Services Trusts, libraries, museums, voluntary agencies, schools and colleges.

3. COUNSELLING INTERVENTIONS

Elements of person-centred counselling are used in these approaches.

Psychosocial Interventions – are the treatment of choice, in preference to drugs, in managing behaviour and mood disturbance in people with dementia. (NSF, 2001; SIGN Guidelines, 1998; Moniz-Cook, 1998; McGrath and Jackson, 1996) Awareness of the various psychosocial interventions for tackling difficult and challenging behaviour assists staff with person-centred approaches to care, thus providing a positive alternative to pharmacological therapies. This is important in the light of evidence concerning the overuse of medication in patients with dementia in nursing homes. It is essential there is a multi-disciplinary team approach with cross-disciplinary discussion of service users who present with complex issues.

Psychotherapy and Cognitive Behavioural Therapy

There have also been exciting developments in the application of dynamic psychotherapy (Hausman, 1992; Sinason, 1992) and cognitive behavioural therapy (Thompson et al. 1990) to older people with dementia. These developments reflect the earlier recognition and diagnosis of various types of dementia, resulting in a growing number of individuals with a much clearer awareness of what is happening to them.

Studies also report that CBT has produced beneficial effects in the treatment of depression and late-life anxiety (Cuijpers, 1998; Stanley and Howarth, 2003) with improvements noted not just at the post-treatment stage, but at one year follow-up.

Resolution Therapy

This therapy strives to achieve effective communication by demonstrating that people with dementia “have something to say”. It entails paying attention to all attempts at communication by focusing on what is heard, seen and emotionally expressed to try to understand the world from the point of view of the person with dementia. (Stokes and Goudie, 1994). It is difficult to assess the effectiveness of resolution therapy and there is limited research in this area.

Validation Therapy

Feil developed this approach in the early 1980s. (Feil, N.1982). Feil’s Validation approach is underpinned by a belief that all behaviour, no matter how bizarre, has a rational explanation, the guiding principle being that factual inaccuracies should not be allowed to impede effective communication. Various techniques are suggested, including rephrasing speech, matching the emotion displayed, linking behaviour and unstated need.

4. CREATIVE MEDIA

Art Therapies – including Dance Therapy, Art Therapy and Dramatherapy

While there is limited research on the effects of these therapies, there is optimistic belief of the benefits achieved in self-esteem, participation in activities of daily living, mobility, communication and general quality of life (Howarth and Ketteringham, 1995). Killick and Allan, 2001 suggest that fantasy and imagination play key roles for people with dementia, “allowing them to escape from the realities of predictable, institutionalised life, and providing a welcome relief from an otherwise inhospitable environment”.

Best Practice Example

Elderflowers Project run by the Hearts and Minds Charity in Edinburgh – Professional actors are trained specifically in communication with people with dementia and deliver programmes using drama and humour to elicit participation and response.

Music Therapy

It has been noted by many that music occupies a special place in the lives of many people with dementia. Bright (1992) highlights that musical memories appear to be better

retrieved than verbal memories, although these music memories may lead to some verbalisation. Music therapy sessions allow people to express emotion in a supportive atmosphere. They can be undertaken on an individual or group basis.

Ryszcak (2003) highlights that comparisons of music therapy sessions with discussion-led programmes have revealed significant improvements in the music therapy groups in relation to orientation, social behaviour and verbal participation, with an accompanying decrease in non-social behaviour. A study by Burke 1995, as cited by Ryszcak (2003) found that active participation in group music experiences impacted positively on self-esteem and depression in older people. Music therapy can be of benefit even to those in the advanced stages of the illness who can often seem unreachable.

Best Practice Example

“Respond to Music” Video produced by Age Concern Northern Ireland and Dementia Services Development Centre in Stirling demonstrates how music can enhance opportunities for communication with people with dementia.

5. SENSORY THERAPEUTIC ACTIVITY

This approach is aimed at sensory rather than cognitive engagement and is probably most helpful in the later stages of dementia when cognitive faculties have declined. The emphasis with such approaches is on relaxation, decreasing anxiety and improving well-being.

One such approach to emerge from the Netherlands is **Snoezelen**, which involves multi-sensory input in the form of music, projected images, bubble tubes and aromatherapy. This approach has its origins in the field of learning disability. Baker et al. (1997), conclude that multi-sensory environments led to increased happiness and interest, with a reduction in socially disturbed behaviour.

Sonas is another approach which provides a multi-sensory experience using a variety of activities to stimulate all the senses in a group setting. This therapy has been found to have a positive impact on the person’s well-being both during and immediately after the group sessions (Parrish et al. 2005).

Modality Specific Stimulation targets one sense in particular, for example, the use of “white noise”, which involves playing an untuned radio to people with dementia to reduce agitation or bright light therapy which has been used quite successfully for those with disturbed sleep patterns (Lyketos et al. 1999) or behavioural disturbances (Koss and Gilmore, 1998).

6. COMPLEMENTARY THERAPIES

There is a growing body of literature to support the use of various complementary therapies with people with dementia. With appropriate attention given to issues of safety and the

importance of informed consent, these therapies may have much to offer when seeking to improve the sense of well-being and quality of life of both the individual and their carers.

Some examples of these are:

Aromatherapy

Reflexology

Acupuncture

Current research is limited. However, benefits reported include decreases in challenging behaviours, improved verbal and non-verbal communication and improved mental state.

7. PHYSICAL ACTIVITY PROGRAMMES

The benefits of physical activity for older people with depression are well-documented (Blumenthal et al. 1999; Singh et al. 1997). A randomised control study by Mather et al. 2001 found that 55% of the exercise group experienced a greater than 30% decline in depression. In people with dementia, physical activity has been shown to promote better sleep patterns, aid elimination and reduce constipation, help retain motor skills and reduce agitated pacing. (Tielis, infoaging.org. 2003). Physical activity can be incorporated in to the person's normal routine and should be appropriate to their general level of mobility and fitness. Even gentle exercise programmes, such as armchair aerobics can be of benefit.

Best Practice Example

“Oh dear, what can the matter be?” – a video produced by Dementia Services Development Centre, Stirling which focuses on encouraging people with dementia to stay active.

8. GROUP WORK PROGRAMMES

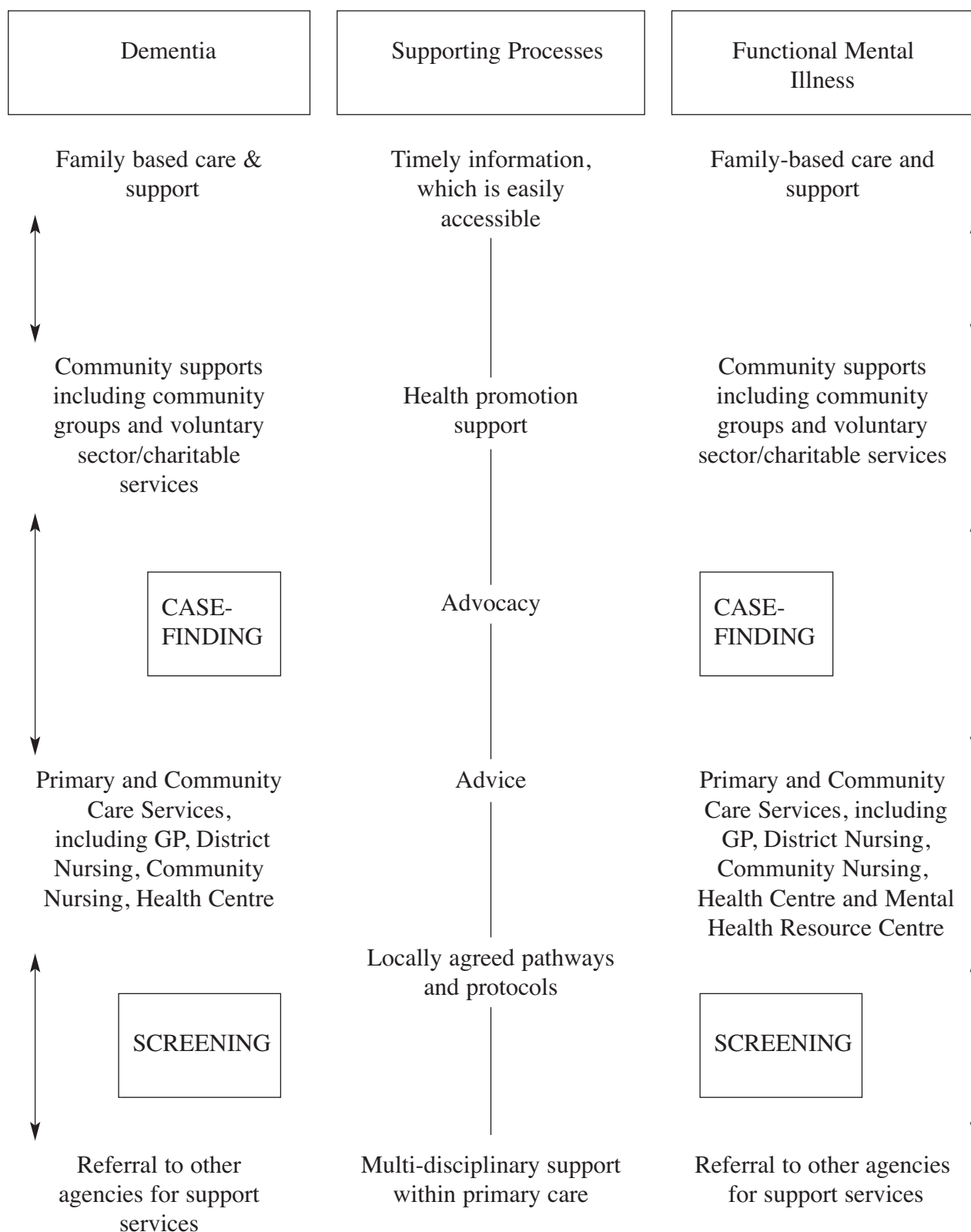
These may be of particular benefit to people in the early stages of dementia or for those with FMI. The group can provide a useful forum for offering mutual support, self help, advice and information or for promoting the development of new skills and coping strategies, e.g. relaxation, coping with depression or memory difficulties.

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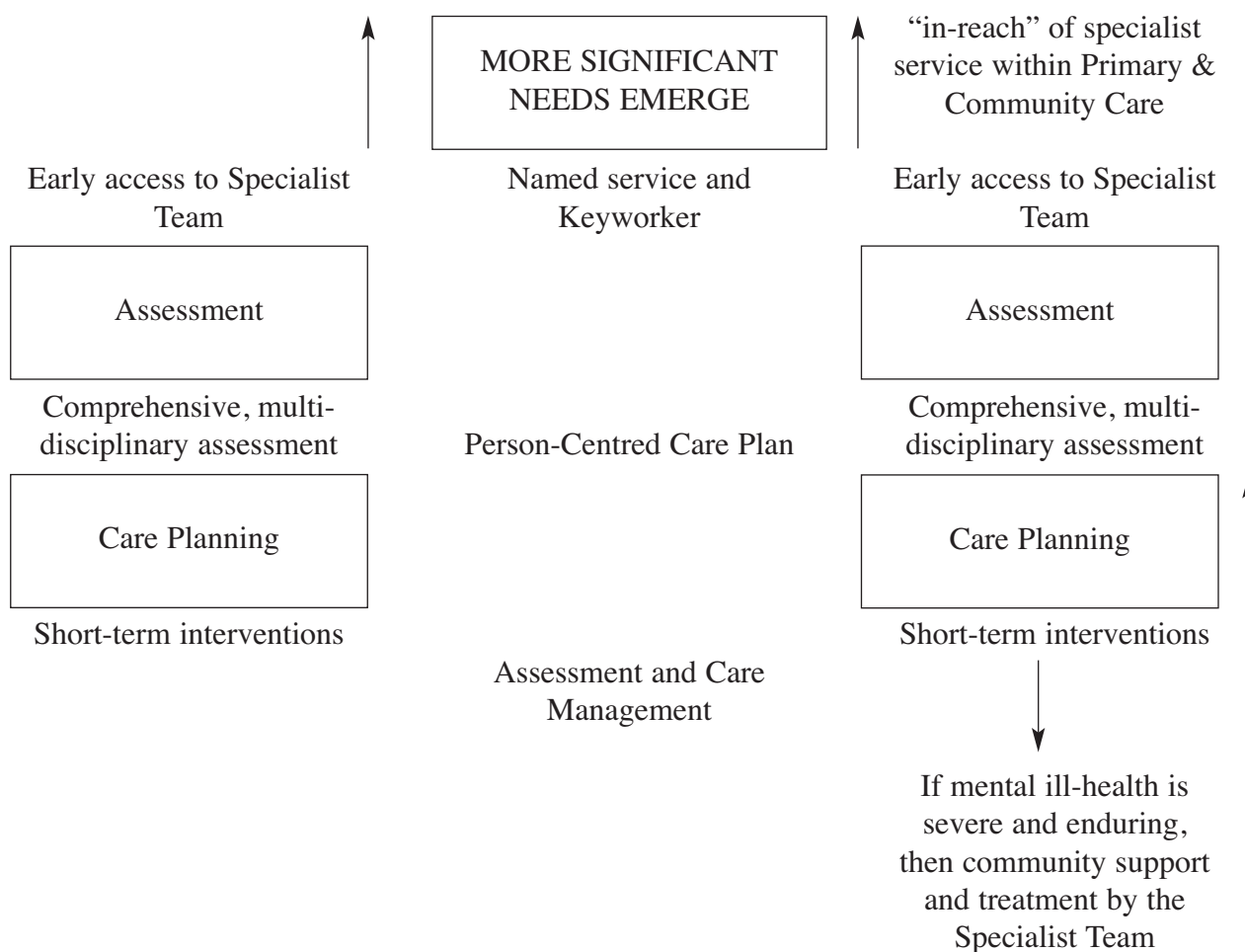
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A Flow Process for The Mental Health Care System for Older People



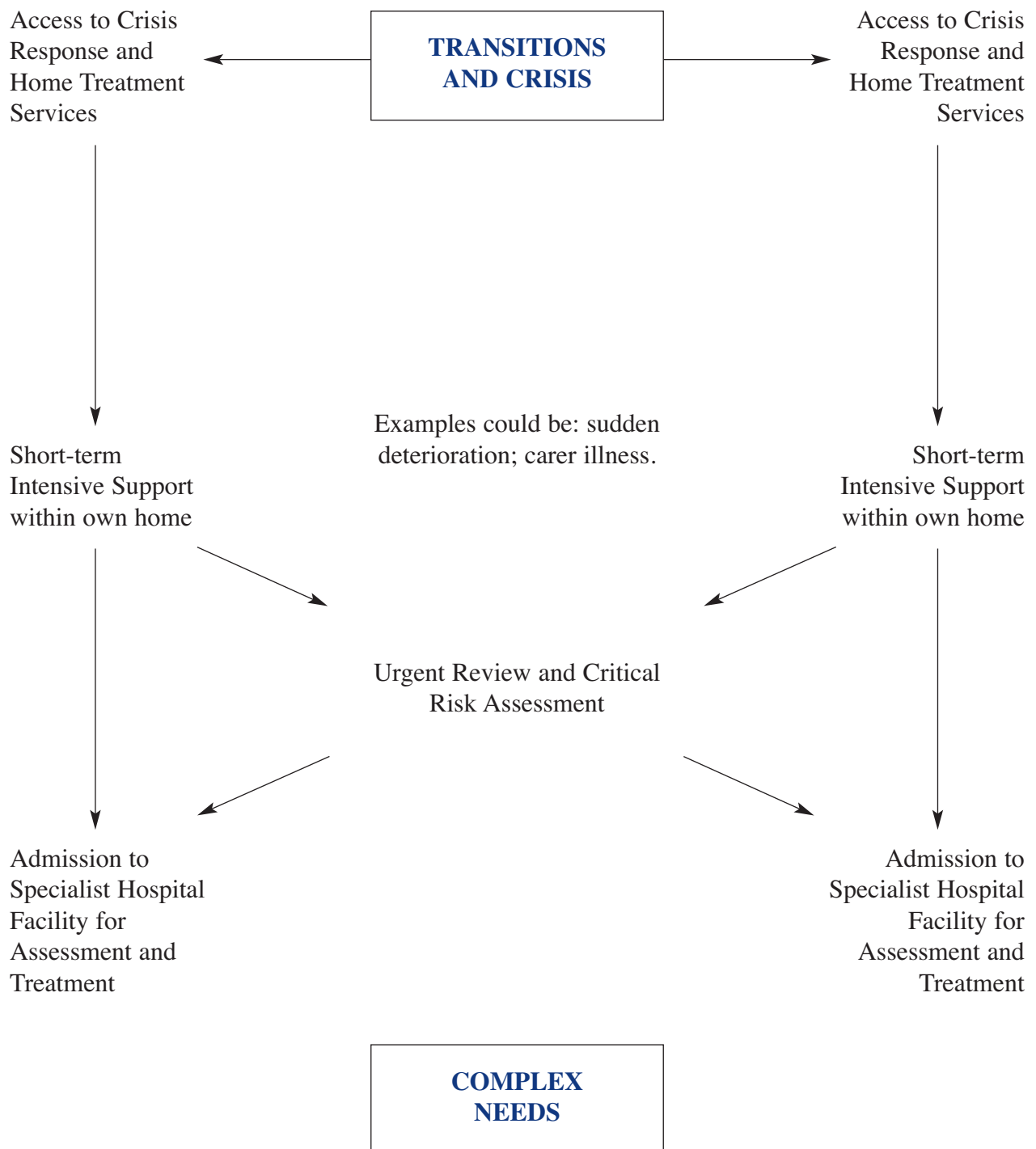
KEY ISSUES AND THEMES AT INITIAL STAGES:

- The vast majority of those presenting with depressive illness and anxiety disorders should be effectively treated and supported within primary and community care services.
- Those identified as developing dementia should be assessed and treated within primary care, with in-reach from specialist mental health services as appropriate. They should be supported at home with primary care supports for as long as possible.



KEY ISSUES AND THEMES AT THIS STAGE:

- Locally agreed protocols to support effective interface and joint working between primary and secondary care services.
- Flexible supports developed within the policy context of direct payments and personalised care budgets.
- Focus on achieving positive outcomes, effective monitoring.



- Challenging behaviour
- Unpredictability and risk
- Risk vs public safety
- “Palliative care” requirements
- Legal intervention
- Other medical conditions

- Severe and ongoing mental illness, eg Schizophrenia, Bi-polar Affective Disorder, severe depression
- Unpredictability and risk
- Risk vs public safety
- Alcohol misuse/co-morbidity
- High risk of suicide/self-harm

Multi-disciplinary Team Members and their Individual Roles in Mental Health Services for Older People, Including Dementia

Psychiatrists

Provide the medical input to the service, diagnostic and clinical expertise, treatment prescribing and assessment and information to service users and carers. They will also contribute to the development of clinical protocols and participate in research or clinical trials.

Social Workers

Provide assessment of the social situation, explore relationship issues, offer counselling support, facilitate the development of coping strategies for carers and individuals with dementia/mental health problems as appropriate, offer benefits advice. They also often act as gatekeepers to a range of support services and resources.

Nurses (including Community Psychiatric Nurses)

Nurses play a lead role in needs assessment, provide diagnostic and clinical expertise, monitor medication and provide care and support for people with mental health problems and dementia and their carers. They carry out assessments of people at home and can advise patients and carers on ways of coping and improving their health and quality of life.

Pharmacists

Pharmacists are aware of drug interactions and can advise on use of medication and possible side effects and undertake reviews of medication both for individuals in the community and in care homes.

Clinical Psychologists

A Clinical Psychologist can carry out a full neuropsychological assessment of individuals who complain of forgetfulness or who are thought to have dementia. This is sometimes warranted where the routine cognitive screening employed by Psychiatrists is inconclusive or where it reveals little in the face of considerable concern on the part of the person or their carer/family. Such an assessment will shed more light on the unique pattern of the person's strengths and weaknesses and counselling may be offered to help them explore how to cope with any apparent deficits.

Neuropsychological assessment can also help to make sense of challenging behaviours and can act as a basis for advice to those who live with and care for people who exhibit such behaviours as to how best they can be managed.

People in the early stages of dementia often suffer concurrently from anxiety or mood disorders and a Clinical Psychologist can offer psychological therapies that address these difficulties.

Occupational Therapists

Occupational therapy interventions may improve, restore or maintain function, promote participation in activities that optimise physical and mental well-being and self-care ability. Assessments are used to help establish a diagnosis, to establish a baseline of function, to monitor

change over time, to plan useful intervention strategies, to advise family/carers and to determine the efficacy of treatment and intervention strategies.

A significant feature of dementia is the functional decline demonstrated by the increasing loss of ability to perform various daily living activities and later on this generally leads to the need for increased level of assistance and care. Being aware of the rate and impact of functional decline is helpful in planning for both the present and the future.

Historically, occupational therapists in dementia care have worked with people in the middle to late stages of the disease. Recent developments in medication have led to the need for an earlier diagnosis of dementia and it is suggested that referral to services at this early stage would enable people to learn coping strategies and would therefore enable people to function better for longer into their illness.

Physiotherapists

Physiotherapy input can contribute to encouraging and helping people with dementia and FMI to remain active and maximise their physical potential. Physical activity can promote better sleep, more regular bowel habits and has been shown to be effective in reducing the amount of agitated pacing a person with dementia may do. Access to physiotherapy services for musculo-skeletal, neurological problems, chest conditions etc. is as important for this service user group as for any other and it is important that such access is facilitated where necessary.

Speech and Language Therapists

Communication is of critical importance in the assessment and management of dementia. It is often the area which carers find most difficult to cope with as its breakdown affects relationships, causing distress for all concerned. Developing communication skills of professionals and carers can enhance the quality of life for the person with dementia. There is a need for increasing involvement of speech and language therapy in the assessment and management of older people with mental health problems, including dementia and related disorders, helping to maintain functional communication for as long as possible.

Dieticians

Dementia and FMI can often result in changes in a person's eating habits and ability to eat. Dieticians can provide advice on issues such as poor appetite, weight loss or weight gain and food supplements.

Podiatrists

Healthy, pain free feet are important in maintaining mobility. Many older people will have significant pedal problems due to neglect, poor circulation, diabetes and access to a podiatry service is important.

Opticians

Problems with sight can add to confusion. Sight should be regularly checked by an optician who can examine the eyes for signs of glaucoma, cataracts and other eye and medical conditions.

Dentist

Regular dental care is essential to wellbeing and may be easily ignored in the older person with communication difficulties. It is important to ensure that teeth and gums are healthy and that dentures, where worn, are comfortable.

GLOSSARY

| | |
|---------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Acute Mental Health | Care provided within the hospital setting to Inpatient Care those individuals who require admission for purposes of assessment, treatment and/or rehabilitation |
| Care Pathways | Ensuring that patients with certain conditions have access to standardised basic forms of care and treatment |
| Continuum of care | The range of services and supports required to care for a person throughout the course of his or her illness |
| Dementia | A clinical syndrome characterised by a widespread loss of mental function which can result in memory loss, language impairment, disorientation and changes in personality and/or behaviour |
| Early Onset Dementia | People who develop dementia before they are 65 years of age |
| Functional Mental Illness (FMI) | A term used to refer to a number of mental health disorders, the most common of which is depression |
| Graduates | Those individuals who have suffered enduring severe mental disorder (or episodes of) in adulthood and who have reached the age of 65 and are transferring to older people's services |
| Intermediate Care | Short-term care provided to either prevent admission to hospital or to facilitate early discharge. This care can be provided in a residential or nursing care context or within the person's own home. |
| Interim Care | The provision of residential/nursing care to those individuals who present with challenging behaviour |
| Mainstream | Those services which are generally available to everyone in the community |
| Mental Health Issues | The "summary" term adopted by the Review to refer to both dementia and functional mental illness |
| Multi-disciplinary | A term used to refer to staff from different professions, e.g. nurses, social workers working together to plan and provide care and services to individual service users |
| Palliative Care | Those services offered to people with life-limiting illnesses |

| | |
|------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Primary/Community Care | Those health and social care services which act as the first point of contact and as a gateway to other services and which are generally provided within the context of the person's own home |
| Specialist Services | Services which are designed to meet the specific needs of a service user group. Such services are generally offered where there are complex levels of need |

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Chapter 9

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