

## WHAT DO SERVICE PLANNERS AND POLICY-MAKERS NEED FROM RESEARCH?

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### ABSTRACT

Nine policy preoccupations have been identified in a recent study of dementia care policies in all European countries. These are used to structure a set of issues which researchers might usefully address to assist service planners and policy-makers. Areas where there is already a research literature are identified. Some description and commentary on the application of current policies in the UK is provided to illustrate the need for research. It is suggested that service planners and policy-makers march to some distant drum which is only remotely related to research, if at all. However, the importance of a research base is stressed with the suggestion that research in related fields could usefully be transferred. Copyright © 1999 John Wiley & Sons, Ltd.

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Dementia Services Development Centres (DSDCs) exist to extend and improve services for people with dementia and their carers. The DSDC at the University of Stirling in Scotland was the first to be established (1989). They now exist all over the UK, in Norway, Ireland and New South Wales. This paper is based on the experience of working with service planners and policy-makers in Scotland, who usually work for the Scottish Office, local authorities or health boards. They have achieved a great deal in improving dementia care over the last decade. It is from their perspective that I have addressed the question: what do service planners and policy-makers need from research?

There are two ways of looking at this question: first to wonder where to start because there is so little research in the field of dementia care, and second to wonder if service planners and policy-makers need any research at all, since planning and policy-making is usually only vaguely related to research. Indeed, service planners and policy-makers might inhabit a parallel universe that goes about its business regardless of research. The Dementia Services Development Centre has an important role in interpreting these two worlds to

each other. An example of how this is achieved is the SNAP report (Scottish Needs Assessment Programme, 1997), which attempts to distil research findings to inform staff responsible for commissioning services. Currently in the UK there is an emphasis in clinical practice on the need for evidence and in services on 'best value' (Filkin, 1997), which presupposes a more explicit rationale, so there may be a demand for more research. In this paper I propose to take a middle way and to suggest some research which would be useful given current policy preoccupations. This will only be in the most general terms since priorities vary enormously both between different agencies in this field (health, housing, social work) and geographically.

Since the Maastricht Treaty, the EU has been able to undertake work on public health. The three 'scourges' it has prioritized have been heart disease, AIDS and cancer. Dementia was not on the agenda until Directorate-General V (DGV) decided to make a short-term investment. Applications have been solicited over the last three years and there has been a burgeoning of interest and expertise. One of the most interesting projects is the ETAS (European Transnational Alzheimer Study) project run by Professor Morton Warner based at the Welsh Institute for Health and Social Care, University of Glamorgan, which has systematically studied the official documents relating to policies and practice

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Table 1. Key principles which have emerged to inform national policy frameworks

Principles emphasized by all Member States	Principles emphasized by most Member States
<ol style="list-style-type: none"> <li>1. People with dementia should be enabled to remain at home for as long as possible</li> <li>2. Carers should receive as much help as possible in order to facilitate 1 above</li> <li>3. Sufferers should retain maximum control over the support they receive</li> <li>4. All relevant services should be coordinated at the local level</li> <li>5. Sufferers in institutional care should live in surroundings which are as 'homely' as possible</li> </ol>	<ol style="list-style-type: none"> <li>1. There should be a systematic attempt to equate service provision with need</li> <li>2. Categorical care should be replaced by care which addresses the general needs of sufferers</li> <li>3. Early diagnosis of dementia should be encouraged</li> <li>4. The needs of people with dementia are not addressed separately from the needs of older people in general at the national level</li> </ol>

on dementia in each European country. They have identified nine key principles which have emerged to inform national policy frameworks, five emphasized by all Member States and four by most of them (see Table 1).

These principles will provide a structure for this paper since they are the best evidence possible of the current preoccupations of policy-makers and planners in this field. Under each principle the paper will address the kind of issues which, in my view, need research. This paper will assume that there are three different types of research: blue sky research, research which tests and clarifies the detail, and studies which pull together and rigorously appraise existing knowledge, often from related fields. Dementia care needs contributions from all three.

Policy-makers and planners will always say that the information they need most and which is most often not available is about the relative costs of services. Much policy is based on assumptions about costs, for example the belief that community care is cheaper than institutional care. It is rarely based on systematic longitudinal research. The DGV funds have been given to several projects concerned with costs yet the information available, the methodological problems and the difficulties of comparisons render it almost impossible to produce little more than generalizations. This paper is no different. Indeed, beyond these few remarks the issue of costs will not be addressed.

#### POLICY PRINCIPLES ESPOUSED BY ALL EUROPEAN COUNTRIES

##### 1. *People with dementia should be enabled to remain at home for as long as possible*

Enabling people with dementia to remain at home for as long as possible is a central policy

preoccupation internationally and is in many countries a response to large-scale institutionalization of people with psychiatric disorders in the past, which was expensive as well as unpopular. It has proved difficult to identify the key factors which make staying at home more or less likely. They are generally seen to include:

- The presence of a relative
- The relationship between the carer and the cared for
- The motivation of both parties
- The assistance available
- The nature and extent of symptoms of the dementia such as memory loss, behaviour and concomitant physical and psychological illness
- The health of the carer both psychologically and physically, and their morale.

This is well-trodden turf as far as researchers are concerned, although clear evidence for helpful interventions is sparse. However, policy-makers still work in a vacuum for several reasons. These include the fact that research is not sufficiently clear, for example it often fails to specify how much of a service is required and at what stage. Another reason is that the interventions for carers studied are not those which are generally available. Professor Mittelman's research (Mittelman *et al.*, 1996), for example, clearly demonstrates the value of psychosocial interventions with carers in extending their capacity to keep people with dementia at home, yet few policy-makers in the UK understand what psychosocial interventions are. It is also very difficult to specify a flexible, individually responsive service in our contract culture.

Evaluative research is usually undertaken on innovative services that have occurred for very specific reasons. Evaluation may tell us what has benefited people with dementia and their carers. It

rarely takes account of the 'newness' phenomenon (the fact that staff are highly motivated to succeed in the first phase of any project) or of the people involved and the local culture in which they operate. Replication is therefore problematic. Policy-makers often want to be seen as innovators. This can be a higher priority than learning from research.

Dementia is a complex disease, the reactions of each individual and their family vary and policy cultures vary both geographically and in terms of current policy trends or 'fashions'. In the UK at the end of the twentieth century, we live in a culture which seems to demand simple quantifiable answers to problems. Dementia must be 'cured' with a tablet, measurable indicators such as shorter waiting lists are seen as indicative of a better health service, and there must be one service answer which will keep people out of longstay care. This is within a wider explicit social policy of social inclusion and cost containment and an implicit one, sadly, of continuing ageism. The intervention chosen for attention seems to be as much a matter of fashion in policy circles as anything else.

There are also numerous new policy interventions, too new to have been subjected to research.

One of these new policy interventions is the design and modification of individual houses and the use of technology in them. Disorientation is proving difficult to incorporate into everyday thinking about disability. Thus most guides to barrier-free housing (Martin, 1992; Smith, 1997), a concept also known as lifetime homes, focus on the possibility that all of us at some time or other will have impaired abilities such as mobility and reaching, and that designing a house to take account of this will help us remain independent. Rarely do they mention that many of us will at some time be disorientated through illness or, most commonly, through dementia. If houses were orientating or had the potential to be easily and cheaply modified, would it be possible for people with dementia to remain in them for longer? Design guides are being produced all the time for housing for older people. Research into the specific design characteristics which might assist people with dementia would be invaluable.

Technology has a greater 'imperative' about it and there is a great deal of interest in incorporating technology into the houses of people with dementia to assist them to remain independent. Not surprisingly, given the current western preoccupation with

risk (Alaszewski and Manthorpe, 1998), the main interest is in safety devices. These include passive alarm systems which relate to sources of risk such as cookers, fires, baths and front doors. There is also huge potential in equipment which promotes independence such as reminder devices and environmental control devices, and equipment which either stimulates or relaxes people with dementia. These devices are receiving rather less attention. Policies in health, social care and housing are going to be formulated and plans made over the next year or two with very little research evidence of the impact of these new technologies on the lives of people with dementia living at home.

## *2. Carers should receive as much help as possible in order to facilitate the above*

This is an area where there has been a great deal of research. Preventing people with dementia from entering institutional care is often seen as a desirable outcome for interventions to help carers. Quality of life for both the person with dementia and their carer and prevention of disability are rarely considered as key outcomes. The research on preventing admission to longstay care needs to be constantly reviewed and presented in digested form for policy-makers since this is a fundamental policy. There are often unsubstantiated assertions in planning documents justifying expenditure on particular interventions. It is often asserted, for example, that more home helps or more day care or new services such as night care are required to keep people at home. Remaining at home or entering institutional care may have more to do with waiting lists and cost containment than any intervention. Dissemination of existing research would go some way to create a better understanding of the complexity and constantly changing nature of this disease in its family context and the constellation of needs which arise.

## *3. Sufferers should retain maximum control over the support they receive*

It is surprising that this third policy strand should appear in all European documentation given the dearth of expertise on how to achieve it. One can only assume it is a transfer from policies for people with disabilities, older people generally or from policies for disabled people generally. In the case of the latter, there has been a very strong move in the UK towards greater control by the

people themselves, exemplified by the move towards being given cash to buy services rather than receiving services directly. Interestingly, this direct payments system does not so far include older people. When we undertook our European Alzheimer Clearing House (EACH) (1997) survey of services and asked service providers about empowerment of people with dementia, we obtained a very scant response. However, all the indications are that this will be a major area of policy development in the next few years. Malcolm Goldsmith's (1996) book *Hearing the Voice of People with Dementia* on the topic has been a best-seller and there are numerous British initiatives and research studies related to hearing the voice of people with dementia, such as that by Keady *et al.* (1995).

What do service planners and policy-makers need from research into giving people with dementia and their relatives control over the support they receive? Interestingly, in strictly policy terms I do not think they need research at all. The principle fits in with a current preoccupation with the user voice which can be seen in every current health and social care policy document. 'Best value', for example (Filkin, 1997), is a set of UK government policy objectives in which the satisfaction of the user is a key component. Of course, user satisfaction and user control are by no means the same thing, but they are closely related. There is an important and much neglected research literature on older people's satisfaction with long-term care which emphasizes the importance of autonomy (Sinclair, 1988), a finding that is borne out again and again in other research (Murphy, 1998). This literature could do with a wider airing and application to the field of dementia care. The principle that 'what suits fit older people should guide our thinking on people with dementia unless there are clear indications otherwise' is insufficiently accepted.

Policy-makers in the UK therefore currently promote the principle of user control and want to know from research how best to achieve this for people with dementia and their carers. There is very little research. There have been policy initiatives which have given relatives control over the apportioning of resources. These include getting a group of carers to allocate access to a respite bed between them. However, this kind of initiative needs to be properly evaluated. There is a strong groundswell of exasperation in relatives in the UK at the moment of which the formation of the Relatives

Association (1998) is an illustration. They are demanding greater involvement in services. It is my impression that this is matched by greater openness by staff, that they sometimes find relatives really difficult. The Scottish DSDC is producing a practice guide to assist staff to involve relatives as a response to this pressure. It would be useful if there was research into techniques for achieving greater autonomy for relatives in ways which do not undermine staff.

The DSDC in Stirling is currently researching a set of techniques which might assist staff to hear the views of people with dementia about the services they receive. What is lacking is research on when and how people with dementia can make choices in every aspect of their lives. We need to know whether advance directives made at the point of an early diagnosis can include choices about treatment, care options and participation in research studies as well as resuscitation. We need to know when and how people with dementia, with varying levels of disability, can make day-to-day choices as well as major decisions. This is not straightforward. There has also been too little attention paid to some of the consequences of greater autonomy for people with dementia, such as the inevitable conflicts of interest that arise with other people like their carers, both paid and unpaid. We know little about the extent to which these arise, how serious they are and how best they might be resolved. This is surprising given the widespread recognition of the vulnerability and powerlessness of people with dementia. Another dimension needing greater attention is that of risk assessment. It is a buzz word on every social worker's and community psychiatric social nurse's lips, yet there is little research on how to perform it with people with dementia and how to base decisions on risk assessment. Supposing, for example, that there was a one in a hundred chance of a fire in a counter kitchen in a dementia unit (which provides a real opportunity for autonomy in terms of undertaking well-learned tasks). Is this a sufficiently high probability to condemn the whole idea, to make special suppression arrangements or to ignore the risk? The knowledge to make this judgement does not exist. Risk assessment and dementia is often still in the realms of folklore for both health and social care staff.

Advocacy for people with dementia has only recently been seen as both possible and desirable. We know little about the best way to achieve it for people with dementia at different stages through

the disease. It is a particularly important issue for minority ethnic groups, whose needs are so poorly understood and about whom we know so little. We also need to know what skills are needed by advocates in terms of techniques of communication and also of choice. More imaginative approaches such as the use of life story books may be particularly significant when people with dementia become very disabled.

Ethical issues are receiving increasing amounts of attention from policy-makers and service planners. Research would be valuable on the whole process of decision-making in relation to people with dementia, especially when decisions are made which infringe their normal civil liberties. Who makes them at present? On what basis? Would ethical protocols assist?

#### *4. All relevant services should be coordinated at local level*

There is a very strong move in the UK at present, exemplified by the current White Papers on the health services for England and Wales, and Scotland (Department of Health (England and Wales), 1997) and Scottish Office DOH (1997), to shift decision-making and allocation of funds as close to the person as possible. The policy buzz words are all about partnership, integrated care, holistic assessment. This is clearly not unique to the UK. The trouble is that there is a lot of exhortation on how this objective is to be achieved, but little guidance. Joint work between health and social care staff is still not customary in the UK. The move towards increasing decision-making at the family doctor level may or may not make it happen more often. If it can be made to work, it will expose other boundaries such as the one between primary and secondary care, or that between the acute and chronic sector. At a macro policy level, the boundary between policies for dementia that are rightly those of mental health and those which are more appropriately aged care is unclear. There will always be boundaries. We need to know which ones are best overcome by structural changes and which can be overcome by other mechanisms such as joint training or procedures.

A phenomenon which has existed in the UK for a number of years is the mental health team for older people, and sometimes specifically for dementia. Numerous descriptions of their functioning have been written up over the last 10 years or so, the most recent being the publication by

Sheard and Cox (1998). The overriding impression is that these teams are much liked and apparently very successful, although systematic evaluations are rare (Mountain, 1998). Yet they are not sustainable. To survive, they seem to need clarity of objectives and membership, as well as strong leadership and management support and strong personal trust and liking between participants. They rarely have all of these for any length of time.

Coordination is an elusive goal. In the UK we embarked on a policy of assessment and care management in our community care legislation which placed the role for coordination firmly with the local authorities without much clarity as to how health personnel were to be involved. Given the major role of health services in the lives of people with dementia, coordination was going to be problematic, and so it has proved. There is a widespread view that coordination has not worked very well. For some people with dementia who are perceived as having complex and enduring mental health problems, the Care Programme Approach has been instigated, which is basically a return to horizontal coordination from the hospital outward into the community, with health taking the lead. The key issue is who should be responsible and the extent to which they are resourced in both skills and time to do it. Coordination is not an easy by-product: it requires motivation, time, systems, meetings, knowledge and skills. The obvious locus for coordination in the UK is the local health centre and all current health policies are towards the centrality of the family doctor in all aspects of care. In Scotland this has gone as far as the formation of Primary Care NHS Trusts. The difficulty in the field of dementia care is the history of lack of interest by most GPs. Models of locality planning and provision of services do exist and researchers should ensure that the impact of these is monitored for people with dementia. It is possible to take the view that if these new models of service coordination successfully integrate the medical and the social model of care for people with dementia, they will work for everybody, since dementia is the most complex biopsychosocial disease.

The DSDC has produced a 'continuum of care' in a report written to inform planning and commissioning staff (SNAP, 1997) as to what range of services should exist in any locality for people with dementia and their families. It is based on research inasmuch as it existed when it was written. The key characteristics are that help should

be available locally from the earliest stages of the disease to the end, that there should be both coordination and continuity of care and that services should be seen as independent of specific buildings. As far as possible, help should move to the person and the family rather than requiring them to attend or move. Continuity is not mentioned in the ETAS list, yet for people with dementia and their families it seems crucially important. We need research to assist us to understand the relative importance of continuity versus appropriateness. Is it more important that people with dementia and their families receive help from the same people or is it more important that the person has the precisely appropriate skills at the right time? The answer is always going to be a bit of both, but we need greater understanding of the way to judge the relative merits, particularly when crucial decisions have to be made about moving people to more appropriate services or putting in more support at home.

This issue becomes very significant indeed around the issue of long-term care: how do we weigh up the relative merits of a home for life versus care for people in a setting where the needs of the residents are homogeneous? This might be in relation to key characteristics, usually challenging behaviour or need for physical care but sometimes issues of age, lifestyle and cultural background. Without research and effective dissemination, decisions on these matters are made on the basis of fashion or pragmatism.

Finally, a very neglected aspect of coordination across another, and possibly the most difficult boundary: that within and between the acute health sector and the rest. Older people are high users of the acute sector, and for many of them it fails to follow through their care into the community. There has been a great deal of research (Dalley and Denniss, 1997, for example) and practice guidance (Department of Health, 1989; Henwood, 1994) in the UK into problems around discharge from hospital, an issue which has become more significant as convalescence and rehabilitation beds have been phased out. As ever, the picture is even more unsatisfactory for people with dementia, who are often disabled by the experience of acute care itself, which can fail to maintain their remaining competence for a variety of reasons. People with dementia form a significant proportion of the 'blocked beds' (patients awaiting discharge who no longer require acute care) and cause much resentment. The research on discharge from hospital has

not addressed this issue of excess disability in acute settings and the implications for discharge. It is sorely needed, both to identify appropriate interventions and to stop people with dementia being blamed for clogging up the system, with all the guilt and poor decision-making that result from such an attitude.

This policy theme above all the others raises a very central issue for this paper, which is the time lag in research. Service interventions rarely wait until there is evidence for their efficacy. Research tends to follow wide implementation of policies rather than precede it as in pharmaceutical research. By the time findings are available, policies have often moved on. Service interventions are much more often influenced by politics and policy fashion trends across a very wide field. Macro shifts in thinking create waves that affect every aspect of service planning and policy, with research playing a relatively small part until well after the wave has passed. We need to be a great deal more skilful in learning from research in related fields (eg learning disability) and in identifying approaching trends in social policy so the research is ahead of its widespread application.

##### *5. Sufferers in institutional care should live in surroundings which are as 'homely' as possible*

Great strides have been made in the last 10 years in changing the vision of institutional care. Nightingale wards with beds down each side for people with dementia are now relatively rare. It is generally assumed that people with dementia need smaller units and to share bedrooms with small numbers if at all. This change is not confined to people with dementia: indeed, it has been much more radical for people with learning difficulties, where principles of normalization have had enormous impact. We are still at the stage in dementia care of needing to know more about the impact of the size of groups rather than promoting the concepts of independent living, as is happening in learning disability.

The key issue is, 'what does homely mean?'. It means different things in different countries. In Sweden, and increasingly in other parts of Scandinavia, it means group homes, usually in normal housing. In the UK and Australia, it more usually means units of eight or 10, purpose-built as residential or nursing homes. In the USA, it generally means nursing home units, though recently assisted living dementia care has been getting a lot of attention. In all countries the trend

is to more domestic furniture and fittings, and more single rooms in all facilities. For most of us without dementia these features have little to do with our homes, because they all presuppose group care. Few of us live with groups of other people, especially in old age. Very few communal settings enable people to sustain the routines of home.

There is a remarkable international consensus on design for dementia (Calkins, 1988; Cohen and Weisman, 1991; Cohen and Day, 1993; Judd *et al.*, 1998), which emphasizes either key characteristics or key principles (Table 2).

There is a need for a great deal of research in this field, since the consensus is not based on research except in the sense of consultations with staff in this field and project development. As Lawton (1987) points out, there is an astonishing range of professionals involved in design and they all have their own approach to research. Architects see research as trying out designs (which appears wholly unscientific until you grasp the complexity of a building and the way every aspect is inter-linked), behavioural scientists struggle with the fluid and multifactorial nature of living environments, clinicians are deeply cynical of research in this field without experimental studies but rarely try them (a small, honourable exception being Wilkinson *et al.* (1994) in New Zealand, who tested toilet door signs), interior designers are more concerned with user satisfaction than research into efficacy as far as outcomes for people with dementia are concerned. We seem to have had a research stalemate for a number of years, during which time this consensus has developed.

Two trends can be observed which may be highly significant and will potentially rock the consensus. Both could be researched in time to inform further developments. The first is an increasing awareness of diversity in cultural background. A home for the rural aboriginal people of Australia or for people from the Bangladesh delta will be very different as, on a smaller continuum, will be the home of an inner city Afro-Caribbean elder from the Bronx and a prairie farmer. We need to know the key design characteristics which really help people with dementia from these communities to feel at home and to function at the highest levels possible. The second is the trend towards keeping people with dementia in their own homes or providing normal single-person or family dwellings which have been modified or purpose-built for dementia. We need to know what design characteristics are important here too.

Table 2. The consensus on principles and key design features

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The consensus on principles of design includes:

- Design should compensate for disability
- Design should maximize independence
- Design should enhance self-esteem and confidence
- Design should demonstrate care for staff
- Design should be orientating and understandable
- Design should reflect a balance of safety and autonomy
- Design should reinforce personal identity
- Design should welcome relatives and the local community
- Design should allow control of stimuli

The consensus on design features includes:

- Small
- Familiar, domestic, homely in style
- Plenty of scope for ordinary activities (unit kitchens, washing lines, garden sheds)
- Unobtrusive concern for safety
- Different rooms for different functions
- Age-appropriate furniture and fittings
- Safe outside space
- Single rooms big enough for lots of personal belongings
- Good signage and multiple cues where possible, eg sight, smell, sound
- Use of objects rather than colour for orientation
- Enhanced visual access
- Controlled stimuli, especially noise

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#### PRINCIPLES EMPHASIZED BY *MOST* MEMBER STATES

##### 1. *There should be a systematic attempt to equate service provision with need*

The principle of assessing need was central to the community care policies in the UK and we have learned how very difficult it is to achieve. It seems to make very little sense to staff doing the assessment and to the people being assessed. It is much easier to see assessment as a process of assessing eligibility rather than need, but unless need is assessed we will not get away from static models of provision. A good form helps, such as the CarenapD promoted by the DSDC (McWalter *et al.*, 1994), which directs the person completing it to met and unmet needs. One of the problems is that we are living in a time of resource constraint, which means that staff feel their main task is rationing rather than developing fresh responses to new or newly recognized needs. Indeed, the guidance from the Scottish Office at the time stressed that need was to be identified only within the resources available (Scottish Office, 1991). In a

sense, at a time when we were attempting a change of culture, the environment in which it was happening reinforced traditional practice. When the history comes to be written it will, I think, be clear that we failed to provide time, space and training for staff doing assessments to learn how to assess need and match services to this need. It will be very interesting to see how the rest of Europe is grappling with this policy, given that most of them have espoused it.

There has been a considerable amount of research into the changes in practice resulting from the changes in community care policy in the UK, for example that undertaken by the Social Work Research Centre at the University of Stirling (Petch *et al.*, 1996). There have also been more flexible responses to the meeting of needs which rely less on current services and more on individual preferences. The most well developed is person-centred planning (Svanberg *et al.*, 1997; SHSIA, 1997), which is best developed in relation to learning disability. We need to know more about practice with people with dementia.

One of the problems in most countries in the world is the division of professional and organizational boundaries into health and social care. This works well for acute care but is really unhelpful for people with chronic and progressive conditions, especially if they are related to brain function. Here the distinction between health and social is really impossible to make. The Australian model of multidisciplinary aged care assessment teams would seem to be a lot more appropriate, if rather health-driven. Other international comparisons would be very valuable indeed.

## 2. *Categorical care should be replaced by care which addresses the general needs of sufferers*

There is increasing awareness in the UK and clearly throughout Europe that people with dementia are not just receiving special health and social care but are moving about in our towns and cities like the rest of us. This realization has led the Ministerial Task Force on Dementia Services in Victoria (1997) to the view that dementia is a public health issue. Making our communities 'dementia-friendly' is the challenge. To an extent, it could be said that we have the expertise in our field and we now have to share it. We have to make sure that our shopping centres are dementia-friendly, our emergency services are sufficiently knowledgeable, our transport systems are as comprehensible as

possible, our general facilities for older people able to cope with all but the most extreme difficulties experienced by people with dementia, and so on. If our communities are dementia-friendly they can enhance independence and self-esteem, and if not they can increase dependence and lack of confidence.

Research can help planning and policy across this broader canvas by evaluating what works and what does not work. Our knowledge and skills from the world of dementia care are under-researched, but the transfer of them to the wider world will not wait. They will be modified in transfer too. Some relevant research (O'Brien *et al.*, 1993) probably exists in the field of disability, especially learning disability. But on the whole it seems unlikely that disorientation will have had anything like enough research attention.

If we take the acute hospital wards as a case study, we know that the first area needing attention is admission and assessment systems. To take an example: in the UK, to ensure the highest possible levels of bed occupancy, patients are often moved around the wards. This is very unhelpful to people with dementia. We need to know if studies have been done on the impact of these policies on people without dementia, or people with acute confusional states. We need to know if there are systems anywhere for identifying patients for whom this policy is contraindicated and how these work.

The second area needing attention is the skill of frontline staff both in dealing with challenging behaviour and in preventing it. It seems likely that there is a literature on this issue. Does it make any difference if staff are aware and trained? Can we reduce excess disability? Another area needing attention is design modifications. Can we make acute hospital wards more orientating? How? Answers to these questions would have a huge impact on very substantial numbers of people with dementia as well as other patients. It is a truism that 'dementia-friendly' equals more 'friendly' for everyone.

Raising general levels of awareness about the unnecessary disabilities associated with dementia is an urgent task for policy-makers for several reasons, one of which will be covered in the next section. It would seem likely that there is research on how best to achieve this goal from the disability literature. There are many parallels with mobility problems. People in wheelchairs have had long and hard experience of raising public awareness, some of which must have been the subject of research.



We need to learn from this and then identify how to proceed for dementia.

*3. Early diagnosis of dementia should be encouraged*

This is an illustration of how policies race ahead of research. We know little about the advantages and disadvantages of early diagnosis (and some authors take opposing views) except in the sense that the new cholinesterase inhibitors seem to be most effective in the early stages of Alzheimer's disease. I suspect the policy has little to do with research and more to do with a user-centred principle: that people should have an early diagnosis so that they can be given the diagnosis when they are still able to understand it and make some decisions (Fearnley *et al.*, 1998).

In this area of dementia care there is considerable attention from researchers, in the sense of how early diagnosis is made and by whom. The accuracy of diagnosis is improving, which removes some of the particular dilemmas arising from uncertain diagnosis in our field (Jobst *et al.*, 1997). The issue of sharing the diagnosis is also attracting research attention, not least from the Centre for Social Research in Dementia. There is a great deal we need to know. There is probably a literature about sharing diagnoses of terminal illnesses in fields such as cancer and the neurological diseases. How do we know whom to tell and how? What kind of help is needed at these times? What do patients want to know? Is this the best time to write advance directives? Issues of terminal care need to be addressed.

There has been far too little research on memory clinics. It seems likely that they could have a central role in dementia care, providing not just a diagnosis but a link to sources of help and advice. They would appear to be able to cut across a whole set of boundaries such as age and access arrangements. We need to know more about the most efficacious arrangement for these clinics. Should they be integrated into social as well as health care systems? What professionals are necessary and what are their respective roles? Are they better as a roving resource which goes to the place most acceptable to the patient or do they need an identifiable location? What about access arrangements, especially for the less proactive patient? Should they have open access or access via the family doctor? By whom and how should

the diagnosis be shared? What is their role in management, for example in decisions like whether or not the person with dementia should be allowed to drive?

*4. The needs of people with dementia are not addressed separately from the needs of older people in general at the national level*

This Eurospeak phrasing is raising the old chestnut of segregation versus integration. The reality is that in every country most people with dementia will be cared for in mixed settings: the need is for these settings to be geared up to provide adequate dementia care. Segregation is only ever going to be available for a minority, and the key question is: which minority? Generally speaking, specialist dementia care is more expensive so it tends to be for people who have high levels of challenging behaviour. But it might equally be for people in the terminal stages. Specialist care also often exists for groups of younger people with dementia, although here too it is rare. There are a few units for people with Korsakoff's dementia and units planned for those with Down's syndrome. The unit for people with HIV-related cognitive impairment in London has recently closed. The need for specialist home and day care for younger people with dementia, both Alzheimer's disease and vascular dementia, seems well appreciated even if it is yet to be a reality in much of the UK. We need to know a great deal more about when segregation is useful and when it is not.

A theme of this paper has been the need to know more about meeting the needs of people with dementia wherever they are. We learn from specialism and apply it both to services for older people generally and to society as a whole. It might be more helpful to write all policies for older people as if they had dementia. It would certainly help all older people if this was the case and would go a long way to a more socially inclusive policy. There are useful parallels from other parts of the disability movement. For example, if all buildings are accessible for people in wheelchairs it also helps those of us who are a bit stiff. We know far too little about the relative impact of separate versus general policies, and indeed formal policies may have little to do with service development and practice on the ground unless the users are skilled in demanding implementation. There is an urgent need for more user-driven outcomes in research.

## CONCLUSION

Evidence-based practice has become a mantra which often excludes debate. There is a need for more debate about the nature of evidence; it is much easier with pharmaceutical or surgical interventions than it is with services. There is also a danger of doing nothing because there is no or poor evidence. As serious is the way that lack of evidence can be used to justify ageist practice. The lack of evidence for single rooms rather than double rooms which is used to justify the latter, for example, would never be used with young disabled people who expect to be treated like normal adults. Related is the issue of the limitations of policies that focus on the measurable, to which I have drawn attention. It is very difficult to measure motivation, for example, which may often be the key determinant of outcome.

I have also drawn attention to fashion and trends in policy-making where the ripples of some distant stone thrown into world thinking finally reach dementia care. Where does the push for a locality focus come from? Is it related to policies of subsidiarity in Europe? Is there an inevitable swing of a pendulum between central and local control? Is it fundamentally about reducing costs of public expenditure and therefore related to major international economic trends? User involvement is another 'hot' policy imperative, the origins of which are far from clear. Does it relate to the increasing power of the disability movement? Does it relate to the increasing value given to autonomy over collective provision?

The time lag issue has been mentioned and is so central an issue that it needs no further emphasis. I have mentioned the need to identify key issues on the horizon so research might better run ahead of policy. Having done this we could make much better use of research findings from other fields or from other countries. My judgement is, for example, that a public health approach will soon be seen as sensible for dementia and we can learn from numerous other fields and from other countries.

The need to learn from other fields is a recurring refrain in this paper, in part because it seems so wasteful of time and effort not to. We could, for example, learn from child psychiatry about the efficacy of close professional collaboration and a consistent approach in that field. We can learn about the problems that arise for specialist services for people with dementia with challenging

behaviours, which are well known in the field of learning disability.

## REFERENCES

- Alaszewski, A. and Manthorpe, J. (1998) Welfare agencies and risk: The missing link? *Health Soc. Care Commun.* 6(1), 4–15.
- Calkins, M. P. (1988) *Design for Dementia: Planning Environments for the Elderly and the Confused*. National Health Publishing, Maryland.
- Cohen, U. and Day, K. (1993) *Contemporary Environments for People with Dementia*. Johns Hopkins University Press, Maryland.
- Cohen, U. and Weisman, G. D. (1991) *Holding on to Home: Designing Environments for People with Dementia*. Johns Hopkins University Press, Maryland.
- Cox, S. and Sheard, D. (Eds) (1998) *Teams, Multi-disciplinary and Interprofessional Working and Dementia*. Dementia Services Development Centre, Stirling.
- Dalley, G. and Denniss, M. (1997) *Patient Satisfaction: The Discharge of Patients from Hospital*. Centre for Policy on Ageing, London.
- Department of Health (1989) *Discharge of Patients from Hospital*. HMSO, London.
- Department of Health (England and Wales) (1997) *The New NHS: Modern and Dependable (White Paper)*. HMSO, London.
- Department of Health, Social Services Inspectorate (1989) *Homes are for Living in*. HMSO, London.
- European Alzheimer Clearing House (EACH) (1997) *Report on Workpackage 2: Examples of Good Practice in the Continuum of Care*. Dementia Services Development Centre, Stirling.
- Fearnley, K., McLennan, J. and Weaks, D. (1998) *The Right to Know? Sharing the Diagnosis of Dementia*. Alzheimers Scotland—Action on Dementia, Edinburgh.
- Filkin, G. (1997) *Spotlight on Best Value* LGIU, London.
- Goldsmith, M. (1996) *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. Jessica Kingsley, London.
- Henwood, M. (Ed.) (1994) *Hospital Discharge Workbook: A Manual on Hospital Discharge Practice*. Department of Health, London.
- Jobst, K. A., Barnetson, L. P. D., and Shepstone, B. J. on behalf of OPTIMA (1997) Accurate prediction of confirmed Alzheimer's disease and the differential diagnosis of dementia: The use of NINCDS-ADRDA and DSM-III-R criteria, SPET, X-ray CT and ApoE4 in medial temporal lobe dementias. *Int. Psychogeriatr.* 9(1), 190–223.
- Judd, S., Marshall, M., Phippen and P. (Eds) (1998) *Design for dementia*. *J. Dementia Care*. p. 12.
- Keady, J., Nolan, M. and Gilliard, J. (1995) Listen to the voice of experiences. *J. Dementia Care*. 00, 15–17.

- Lawton, M. P. (1987) Strategies in planning environments for the elderly. *J. Ind. Living*. Fall, 000–000.
- Martin, F. (1992) *Every House You'll Ever Need: A Design Guide for Barrier Free Housing*. Edinvar Housing Association, Edinburgh.
- McWalter, G., Toner, H., Corser, A., Eastwood, J., Marshall, M. and Turvey, T. (1994) Needs and needs assessment: Their components and definitions with reference to dementia. *Health Soc. Care Commun.* 2(4), 213–219.
- Ministerial Task Force on Dementia Services in Victoria (1997) *Dementia Care in Victoria: Building a Pathway to Excellence—Final Report*. Department of Human Services, Victoria Government, Victoria.
- Mittelman, M., Ferris, S., Steinberg, G., Shulman, E., Mackell, J., Ambinder, A. and Cohen, J. (1996) An intervention that delays institutionalisation of Alzheimer's disease patients: Treatment of spouse caregivers. *Gerontologist*. 33(6), 730–740.
- Mountain, G. (1998) The delivery of community mental health services to older people. *Ment. Health Rev.* 3(1), 7–15.
- Murphy, C. (1998) *Evaluation of Town Break Befriending Scheme*. Dementia Services Development Centre, Stirling.
- O'Brien, J., Pearpoint, J. and Forrest, M. (1993) *PATH: Planning Alternative Tomorrows with Hope—A Workbook for Planning Possible Positive Futures*. Inclusion Press.
- Petch, A., Cheetham, J., Fuller, R., MacDonald, C., Myers, F. with Hallam, A., Knapp, M. (1996) *Efficiency and Effectiveness in the Delivery of Community Care*. Stationery Office, Edinburgh.
- Relatives' Association (1998) *As Others See Us*. Relatives' Association.
- Scottish Needs Assessment Programme (SNAP) (1997) *Dementia*. Scottish Forum for Public Health Medicine, Glasgow.
- Scottish Office (1991) *Community Care in Scotland: Assessment and Care Management*. Scottish Office, Edinburgh.
- Scottish Office (DOH) (1997) *Designed to Care: Reviewing the National Health Service in Scotland*. (White Paper). Scottish Office, Edinburgh.
- Sheard, D. and Cox, S. (1998) *Teams, Multidisciplinary and Interprofessional Working and Dementia*. Dementia Services Development Centre, Stirling.
- SHSIA (1997) *People, Plans and Possibilities: Exploring Person Centred Planning*. Washington Court, Edinburgh.
- Sinclair, I. (Ed.) (1988) *Residential Care: The Research Reviewed*. HMSO, London.
- Smith, A. (1997) *What Does 'Barrier Free' Mean for People with Dementia in Designing New Housing: Discussion Paper*. Dementia Services Development Centre, Stirling.
- Svanberg, R., Stirling, E. and Fairbairn, A. (1997) The process of case management with people with dementia. *Health Soc. Care Commun.* 5(2), 134–139.
- Wilkinson, T. J., Henschke, P. J. and Handscombe, K. (1994) How should toilets be labelled for people with dementia? *Austral. J. Ageing* 13(4), 163–165.

