Prof Karen Bryan  
European Institute of Health and Medical Sciences  
University of Surrey  
Guildford  
GU2 5XH.

Tel: 01483 682507  
email: k.bryan@surrey.ac.uk

Dr Jane Maxim  
Human Communication Science  
University College London  
Chandler House  
Wakefield Street  
London  
WC1N 1PF.

Tel: 020 7679 4227  
email: j.maxim@ucl.ac.uk
Dear Editor,

This letter is intended to stimulate a debate on Speech and Language Therapy (SLT) services for people with dementia and to highlight the need for change. SLT services for older people with mental health problems vary widely across the UK. Many older people with communication difficulties arising from conditions such as dementia who might benefit from referral do not receive speech and language therapy intervention. Yet we know that the ability to communicate is an important component in maintaining quality of life for both clients and carers (Bryan and Maxim 1996). Efficacy studies support intervention to maintain and improve communication but speech and language professionals do not always seem confidant of their role and may not always lobby vigorously for their inclusion in such provision. The National Service Framework (NSF) for Older People now provides a unique opportunity for the profession to address variability and quality in this area of service provision.

The NSF for Older People focuses on:

- rooting out age discrimination
- providing person-centred care
- promoting older people’s health and independence
- fitting services around people’s needs”.

It also sets out specific standards for the health and social care of older people with a mental illness focusing particularly on dementia and depression. The NSF for older people states that good mental health services should be comprehensive and multidisciplinary. Speech and language therapy is listed as a
service where a contractual arrangement for service provision needs to be in place.

Many of the challenges for speech and language therapy exist in common with other professional groupings. Murphy (2001) highlighted the need for change within mental health services for older people and the lack of impetus for change from the professions themselves.

Demographic changes mean that the older population is increasing which may put further pressure on inadequately resourced services. The number of people in the UK over the age of sixty is rising with projections of an increase from 12 million (20% of the population) in 2001 to 18.6 million in 2031 (30%). The population of older people with chronic disease and disability are also projected to increase two to threefold (Khaw 1999). One area of difficulty for service provision is defining the population for that service. SLT services may, for example, be targeted at a disease group, as is the case for stroke, while another service may be targeted at older versus younger adults. Such service labels may mean that a particular population (such as people with a dementia) may not be explicitly targeted in service provision.

Rehabilitation is specifically addressed in government initiatives such as the NSF older People and the NHS Plan (2000). The NHS Plan makes provision for £900 million to be spent on establishing intermediate care for older people, an increased emphasis on access to rehabilitation for people in residential care and calls for more research on care at home and rehabilitation effectiveness. Implicit (admittedly not explicit) is that more rehabilitation and therapy will be made
available for older people across the country. What should the expectations for
greater numbers of therapists and planning strategies be for improved SLT
services within these initiatives? As a profession, are we ready to embrace these
service improvements (no doubt involving great effort and skill on behalf of SLT
managers in getting a share of any monies)?

In the last ten years, there has been only a small increase in SLT’s specializing in
the area of dementia. A survey, commissioned by the SLT Specific Interest
Group in Old Age and supported by the Royal College of Speech and Language
Therapists, shows that service levels remain low, with existing services
commonly being ad hoc in nature and only 30% of the existing services involve
specialist SLT’s (Ponte 2001). 78% of respondents reported a lack of specific
service standards within their service. Only 40% of SLTs working in elderly
mental health work within a multi-disciplinary team. Modest improvements in the
number of therapists and in the number of specialist posts have to be balanced
by the population increases over the ten-year period since a previous survey.
This is depressing for those who are committed to working with older people with
mental health problems but should not be allowed to detract from the islands of
excellent services that are available in some places. Indeed, it is important to
consider why such islands of excellence develop and how to extend that
development to other areas?

Service provision and the SLT’s role have been described in detail (Stevens and
Ripich 1999, Barnes 1999, Riffiths and Baldwin 1989, Tanner and Bryan 1996,
Walker 1996). We appear to be fully aware of the service that might be offered to
older people with dementia who have communication difficulties, but perhaps less willing to advocate more widespread provision of such services?

We are suggesting that as a profession we need to be more committed to improving services for older people with dementia and to eradicating the variations in service provision which currently exist. That is not to say that the profession is currently uninterested, but to suggest that debate (and disagreement) are likely to result in dementia being more of a priority area. It is timely to do this because:

- the government is showing more interest
- older people themselves are becoming more aware of health issues
- there are relevant advances in the understanding of dementia
- the body of evidence to support intervention is increasing.

Let us examine each of these factors in turn:

THE POLICY AGENDA

Reference has already been made to the government’s interest in improving services for older people generally, with specific references to rehabilitation (NHS Plan 2000) and services for older people with mental health problems (NSF Older People 2001). Access to specialist such as SLT’s was deemed important to achieving high-quality care for older people in hospital (HAS 2000).

Specifically in relation to older people with mental health problems, the Forget-Me-Not Report (Audit Commission 2000) stresses the need for comprehensive services for older people with dementia that include access to specialist staff.

The need for therapeutic approaches to managing people with dementia is
emphasized in order to promote a greater level of well-being. The SLT profession needs to ensure that it is included in service developments resulting from policy initiatives.

SERVICE USER INVOLVEMENT

The need to include service-users views and requirements in healthcare planning is now widely acknowledged (Wheeler and Grice 2000). Older people are concerned about the care they receive or are likely to receive when they are older and when or if they need to enter long-term care provision. ‘Each generation is different, but we’re all increasingly used to being consumers with voices. I don’t see why I won’t be heard at 80 if I expect to be heard at 50’ (pp17) (Easterbrook 1999).

A Help the Aged report entitled Our Future Health (HOPE Group 2000) can tell us a lot about what older people want from services. Within the top ten priorities are ‘preventing and responding to sensory impairments’ and ‘access to active rehabilitation’. We also know that carers rate communication difficulty as one of the most difficult problems to cope with in caring for someone who has dementia (Gilleard 1984, Greene et al 1982).

ADVANCES IN THE UNDERSTANDING OF DEMENTIA

The traditional clinical view of language ability in AD is that all areas are compromised starting from word finding ability and running through to total inability to communicate (terms such as mutism being used). This gave us a bleak outlook and is entirely 'deficit' based. A number of recent areas of research
have challenged that view and support a more positive interventionist stance in relation to maintaining function in the dementias.

a) There is greater recognition of different types of dementia, with developments in early and reliable clinical diagnosis (Garrard and Hodges 1999, Vuaoinen, Laine and Rinne 2000). Diagnostic decisions can lead to specific interventions such as
- appropriate drug treatments in Alzheimer's disease (Forette and Rockwood 1999).
- prompt interventions to prevent further strokes in vascular dementia (Herrman et al 1997).
- advice to carers on managing possible behavioural problems in Lewy Body or frontotemporal dementia (Lindau et al 2000).

Even dementia of the Alzheimer type is now recognised as an umbrella term with several sub-groupings such as early onset AD, familial AD, AD associated with Downs syndrome (Florette et al 1992)

b) Research studies are yielding valuable information on the breakdown of language in different forms of dementia. (For a detailed review see Bryan and Maxim (1996). Research also suggests that different dementias need to be managed in different ways. For example, communication in semantic dementia can be maintained and enhanced by specific interventions such as utilising the beneficial effects of personally relevant autobiographical memory and re-training concepts within a personally relevant context (Snowdon and Griffiths 2000).

c) Acknowledgement of individual variation in both disabilities and abilities, which will influence the effects of whatever 'sub-type' of dementia is present (Maxim,
Bryan and Zabihi 2000). As well as differences in exact type and location of pathology, variables such as language and education history, psychological state and sensory impairments will influence the impact of language deficits. Therefore detailed individual assessment of language and communication is important. Language assessments specifically designed for use with older people are becoming available (Bryan et al 2001).

d) There are indications that processing constraints in some dementias may be due to difficulty in access rather than to storage problems (Hodges, Salmon and Butters 1992). Recent work shows that access to the semantic system can be maintained in AD despite disease progression (Maxim, Bryan and Zabihi 2000, Bell, Chenery and Ingram 2000)

e) A more person centred approach to dementia (exemplified by the work of Kitwood and others in the Bradford Dementia Group UK) promotes treating people with dementia as valuable individuals who can achieve an optimal level of functioning if they receive the help and encouragement that they need (Kitwood 1997). This suggests a key role for speech and language therapists in training other professionals to achieve maximum communication.

g) There is a realisation that even people with advanced dementia have something to say and that if we communicate in the right way they can achieve effective communication (Frank 1995). This has come about largely through application of techniques such as conversation analysis to individuals who have dementia (Hamilton 1994, Penn 2000). In other words the approach is one in which language is seen as an integral part of human life. Recent work by Le Dorze, Julien,
Genereux et al (2000) suggest that viewing caregivers as communicative partners who can take on a greater share of the communicative burden as deterioration progresses is a positive way to encourage communication by direct intervention with carers.

Taking into account the body of research outlined above, it is now possible to suggest a very much more positive definition of language change associated with dementia: a person-centred approach to the individual who has dementia emphasising preserved abilities and their utilisation for maximum communication gain.

The role of therapists, including SLT’s is recognised beyond the profession. The HAS report ‘Not because we are old’ examining the treatment of older people in general hospitals states that:

“where they were present, therapists are highly valued and seen as making an important contribution. In addition to their own specialist skills, they had an important role in training and supporting others….These specialist staff also played a very important role in shaping the overall ‘philosophy’ of the ward team and in emphasising goals of maximising independence”. (pp 33)

RCSLT has documented the service that should be provided for people with dementia but these remain ideals that few services can sign up to (Communicating Quality 2, 1996). Similarly, service models such that outlined by Walker (1996) are available. It is beyond the scope of this paper to advocate any particular service model, but as a profession, we need to debate issues such as:

- Are ‘assessment only’ services for people with dementia acceptable?
- Do services for older people with dementia move seamlessly from acute care, through to home care and into the residential care sector?
- How can equity of service provision based on clinical need alone (as required in the NSF for Older People) be achieved?
- Should services for older people be separate from services for younger adults?
- How should service provision for younger people with dementia be organised?
(There are about 17 000 younger people with dementia in the UK (Alzheimer’s Society 1996))

We could go on detailing such questions, but the important point is to ask that such debate needs to take place both within and across professions as these issues and dilemmas are not unique to SLT. We might also think about future planning- does work with older people with dementia receive enough emphasis in clinical training? Only 22% of the MHE services in Ponte’s survey reported that they took students, yet we know that actually working with older people promotes a positive attitude towards such work (Bebbington 1991).

EVIDENCE TO SUPPORT EFFECTIVENESS

a) Effective service delivery. Research has shown that speech and language therapy (SLT) can be effective for people with dementia. Heritage and Farrow (1994) and Griffiths and Baldwin (1989) found that the work of the SLT was most effective when the SLT was a permanent and specialist member of the multi-disciplinary team. As well as specific benefits for clients, the whole team benefit from heightened awareness of communication problems and advice and training on how to deal with them.
b) Effective programmes for patients. What of effectiveness of therapy? Powell (2000) and Bourgeois (1991) have reviewed the evidence for the value of communication interventions (not all of which are SLT mediated) and discusses efficacy issues. Powell states that:

“an overall aim of intervention should be to improve ‘quality of life’ – a notoriously complicated outcome to measure”. While this may be desirable, it may not always be necessary and failure to live up to this ideal should not preclude evaluation research proceeding.

Direct SLT intervention has been shown to enhance communication with evidence from intervention studies (Clark 1995, Shadden 1995, Orange, Ryan, Meredith and MacLean 1995). Evidence suggests that SLT’s have a role in assisting other professionals to achieve effective communication with patients who have dementia (Orange and Ryan 2000).

c) Effective programmes for patient and carer communication. Family carers benefit from intervention to preserve communication (Muir 1996) and such intervention has been shown to be cost-effective in avoiding respite and residential care costs (Brodaty and Peters 1991). Hart and Wells (1997) showed that modification of communication can reduce agitation. Training for carers within the residential setting has been shown to be effective (Jordan et al 2000) and the role of SLT’s as trainers has been outlined (Maxim et al 2001). Lubinski (1995) has been a consistent advocate of the need for sustained carer training and all the evidence points to carers themselves appreciating training.
We therefore have at least an initial body of evidence to justify intervention with people who have dementia to improve communication. Not all of this intervention necessarily requires a speech and language therapist, but we have an important role in advising others and in reviewing the support available. We may claim a more specific role in diagnosing and understanding communication problems and in working with other professionals and carers to ensure that people with dementia who have communication problems can communicate to the best of their ability within the limitations of the disease process.

Much debate is also needed around ‘how’ changes will be embraced. Murphy suggests that ‘Increasingly the specialist services are going to become true ‘consultants’, educators and travelling salesmen peddling expertise to colleagues in primary care, the independent sector and the general public’. We may or may not agree with her but she goes on to state that ‘communication skills and expertise in teaching are going to be increasingly important for community mental health professionals working in the field’, suggesting that speech and language therapists may be very well placed to embrace the challenges set out in the policy initiatives.

We hope that the services opportunities provided by the NSF for Older People can be utilised effectively to provide improved services for older people with dementia who have communication difficulties.

K Bryan and J Maxim.

(2704 words)
BIBLIOGRAPHY


Murphy, E (2001) Mental Health Services for Older People: Time for Change. The Mental Health Review, 6 (2), 3-5.


Prof. G Conti-Ramsden
Editor, IJDL.
Human Communication and Deafness (HCD)
School of Education
University of Manchester
Oxford Road
Manchester
M13 9PL.

Dear Prof. Conti-Ramsden,

Re: LCD/2001/0021 When we are very old….

Thank-you for your email of 22.11.01. I enclose two copies of the text and a disc with a copy of the file in word and a text only format.

Best wishes.

Karen Bryan
Professor of Clinical Practice
Speech and Language Therapist.