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Research Report

Reconciling the perspective of practitioner and service user: findings from The Aphasia in Scotland study

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Abstract

Background: It is widely accepted that service users should be actively involved in new service developments, but there remain issues about how best to consult with them and how to reconcile their views with those of service providers.

Aims: This paper uses data from The Aphasia in Scotland study, set up by NHS Quality Improvement Scotland to identify the direction of the development of services for people with aphasia in Scotland. It examines the views both of those who provide and of those who receive those services.

Methods & Procedures: The study integrated findings from a questionnaire to all speech and language therapists treating people with aphasia across Scotland with findings from focus groups with service users and aphasia practitioners.

Outcomes & Results: Three themes were identified: (1) public and professional awareness of the impact of aphasia on the individual and their family; (2) current service provision and gaps in services; and (3) directions for the future development of services and barriers to change. Although the impact of aphasia is well recognized amongst most professionals (that is, not just speech and language therapists), considerable concern was expressed about the level of knowledge amongst professionals who do not specialize in stroke care and about public awareness of aphasia. Service providers indicated a shift in the model of service delivery of which the service users were largely unaware. Although the majority of speech and language therapists spend most of their time providing one-to-one therapy, and this is valued by service users, there is undoubtedly an emerging shift towards a focus on broader social function and the inclusion of the person with aphasia in supportive social networks. This creates tensions because of the existing pressure for individualized models of delivery. Concern was expressed by practitioners, although not echoed by patients, about the transition from the acute sector to primary care. Practitioners also expressed concern about the introduction of more recent services like NHS 24 and e-health initiatives, which rely on means of communication that may be particularly challenging for people with aphasia.

Conclusions & Implications: The findings from this study indicate that although there are clearly common perspectives, the views of people with aphasia about services do not necessarily coincide with those of service providers. This is an important consideration when initiating consultation and highlights the need for clarity on the part of practitioners in identifying the aims and objectives of their ervices as far as people with aphasia are concerned.

Keywords: aphasia, speech and language therapy, stroke, qualitative, practice.

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What this paper adds

What is already known on this subject

There is extensive research into the value of patient consultation. Recently we have come to know about the concerns of people with aphasia about the impact that aphasia can have on their lives and about the services they receive.

What this study adds

The study is one of the first to address service change from the perspective of both practitioner and service user. Although Speech and Language Therapy practice is moving towards a more functional approach emphasising social inclusion as much as one-to-one language therapy, this is not reflected in the expectations of service users whose concerns often focus on the level of public awareness and professional knowledge of aphasia. Practitioners expressed concerns about the impact on people with aphasia of transitions between services and of new developments in care for people with long term conditions.

Background

The nature of services for people with aphasia has been a subject of considerable discussion over recent years. Widespread variability in service delivery has long been identified at a local (Jordan 1991), national (Mackenzie *et al.* 1993), and international level (Katz *et al.* 2000). Decisions about the organization of services appear to vary across localities although the majority of studies conclude that service levels are well below that recommended by the literature and that there has generally been a shift of resources away from aphasia provision altogether towards dysphagia services (Code and Heron 2003). There has been marked shift in the outcomes measured from 'utilitarian functional communication' towards outcomes denoting social and psychological functioning (Holland and Thompson 1997), although the focus largely remains a function of practitioner choice (Greener and Grant 1998). Indeed outcome measurement often serves as a proxy for the intervention approach adopted, practitioners adopting measures which they consider to best map on to the aims of their therapy (Petheram 1998, Hesketh and Hopcutt 1997, Simmons-Mackie *et al.* 2005).

One of the key questions in the delivery of services is the role played by the service user. Participation in external activities of any sort can prove to be a real challenge to people with aphasia (Howe *et al.* 2008) and this can be particularly problematic when it comes to accessing healthcare generally (Hartley 2003) and primary care more specifically (Law *et al.* 2005). Nevertheless, most of the barriers and facilitators are similar across context. They include respect, time, supplementary communication support, etc. We know less about the precise nature of the services which people with aphasia value most although attempts have been made to develop methods to do this (Horton *et al.* 1998).

The policy context

In recent years there has been a pronounced shift in the way in which policy-makers have come to look at the management of chronic conditions such as stroke and specifically the pressure for much of the care to be delivered in the community and at home (Scottish Executive 2005a, 2005b). This shift has been driven by the rising number of people with long term chronic conditions, the democratization of medicine, the pressure for the individual to manage their own care and, more generally, the better integration of services (Scottish Executive 2005b). The focus of services Thus, changes from treating individuals to providing individuals with the right sort of information and support to best help them look after themselves. 'Person-centred care' suggests a renegotiation of the relationship between service user and professional. It emphasizes both the need for individuals to make decisions about their own care and the supportive role of social inclusion, for example, in the role that family members and those in other social networks (church, clubs, etc.) can play in supporting the person with the disability (Innes *et al.* 2006). This is a relatively easy concept to advocate but one which is much more difficult to realize from the position of both the service user and the professional, especially when the communication between the two is affected, which, by definition, is the case for people with aphasia. This shift in emphasis has become a focus of many of those working with people with aphasia (Pound *et al.* 2000).

Within this context, The Aphasia in Scotland study was commissioned by NHS Quality Improvement Scotland (QIS) in early 2006 to look at both the impact of aphasia on the individuals with aphasia and their families, and emerging models of practice for the management of aphasia following stroke. The research questions addressed by the present paper are as follows:

- To what extent are recent shifts in evidence-based policy and practice reflected in speech and language therapists' (SLTs) practice in aphasia?

- To what extent were recent changes in service development reflected in the expectations of service users and other practitioners?

Methods

The study adopted two different approaches to data collection; a survey of current and emerging practice amongst SLTs and a series of focus groups with aphasia practitioners and with people with aphasia. The survey, which is not the main focus of this report but is available in full elsewhere (Law *et al.* 2007a), focused on current speech and language therapy practice and on where speech and language practitioners saw the field developing in future. The two elements were linked in the original study to examine the impact of current and emerging practice in speech and language therapy on both other professional groups and on the service users themselves. The different methodologies were adopted to reflect the nature of the enquiry and the communication needs of the target groups. Thus, the survey methodology was appropriate for a large data collection exercise of a standard set of practice parameters where the majority of the responses were clear-cut. Experience of aphasia and service delivery particularly do not necessarily lend themselves to this type of enquiry because the parameters may be much less transparent and a survey is likely to present challenges for people with aphasia. The focus group provides additional value for the practitioners because they were able to interact with one another, discussing scenarios, etc. Qualitative methodologies have been widely used in health services research for many years now and are particularly well suited to the type of inductive exploratory enquiry needed in the present study (Shi 2008). It is important to stress that the survey and the focus groups were linked. The topic

guides for the focus groups were based on the findings from the survey and discussion with the project steering group and the experienced service user group. The topics included were the experience of living with aphasia, the experience of services both in hospital and in the community, why services are important (which elements were well received and what was missing), how family and friends are involved, and future changes and improvements to services).

Participants

A range of different participants involved and these are summarized in Figure 1. Three categories of respondents were as follows:

- The survey of SLTs.
- The 'aphasia professionals' or professionals specializing in working with people with stroke in general but with experience of people with aphasia such as speech and language therapists, physicians, nurses, social workers, physiotherapists, occupational therapists and therapy assistants.
- The service users (people with aphasia).

There were three focus groups of aphasia professionals ($n = 21$) drawn from across Scotland. They were self-selecting according to expertise, interest and availability. Commonly they were associated with a single service and included those working in acute facilities and in the community. These three groups met on one occasion. There were three focus groups of service users. These were set up with the help of local voluntary organizations and a local speech and language therapy service. A purposive sampling approach was used to tap into the experience of stroke from the perspective of people of different gender, age, health board and geographical setting (for example, rural, urban). Each
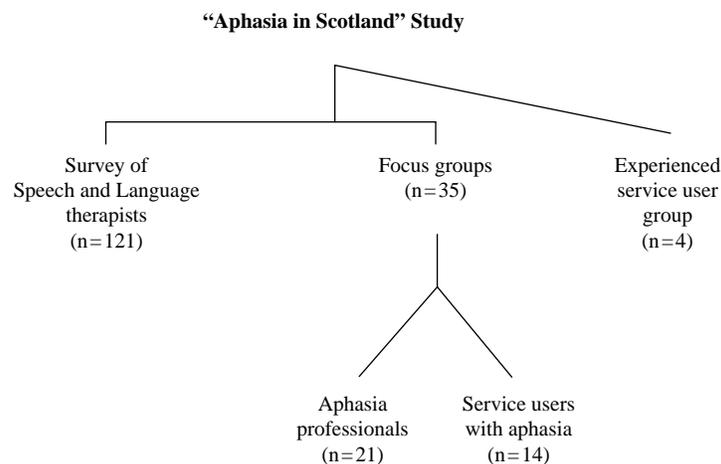
Figure 1.   Participants in The Aphasia in Scotland study.

group met for one hour on three occasions to discuss predetermined topics. Each group was held in a different health board area in Scotland. Group members came from both urban and rural locations, with one group concentrating on experiences of rural care. In total, fourteen service users attended the three focus groups: eight men and six women. There were two women in each group. Participants were aged between 33 and 76 years old. The group ranged from being 9 months post-stroke to 14 years post-stroke. There was a range in severity of aphasia in each group. Four carers provided communication support for their spouses. The majority of participants were recruited through known charity groups, with only two participants being recruited through NHS speech and language therapists.

The Experienced Service User Group

Four additional service users with aphasia were termed the 'experienced' service users because they had all been involved in representing the views of service users with aphasia in the past. They were recruited through the voluntary sector and contributed to the development of materials, advised on recruitment and the detail of the focus groups. The Experienced Service User's Group was not part of the focus groups but contributed by overseeing and validating the work of the project. 'Aphasia friendly' materials were used throughout the discussions of this Group, as they were in the focus groups, to provide supplementary information prior to and during discussion groups.

Ethical approval

The project received ethical approval through the NHS COREC approval system and through the Research Ethics Committee at Queen Margaret University.

Analysis

Responses to the questionnaire were coded and analysed in SPSS v14. Free text was also included and analysed thematically. The focus groups were transcribed and coded by two of the research team (A. B. and C. H.) using a coding frame agreed with the project management group and the experienced service users group. Codes were then analysed thematically (Ritchie and Spencer 1994).

Results

Three principal themes were identified:

- The impact and implications of aphasia for the individual and their family.
- Current service provision and gaps in services.

- Directions for the future development of services and barriers to change.

The practitioners and service users consulted exhibited differences in their prioritization of issues, reflecting their different relationship to the service system. For example, the service users focused on their experiences of stroke and specific services that they had accessed, while the SLTs emphasized the services that they provided in terms of the issues they faced and skills they needed. We did not explicitly test for differences between speech and language therapists and the other aphasia professionals.

The impact and implications of aphasia for the individual and their family

Unsurprisingly, service users highlighted the challenges associated with the experience of aphasia following stroke, particularly on their well being.

> I had a lot of trouble asking where I wanted to go on the bus, because I didn't know how the bus pass system worked. I just got on the bus and walked up past the driver and got a seat, and he shouted down the bus. Is he shouting at me? Your mind is all jumbled up and you can't take it in that you have done something wrong. Um … and eventually a woman sitting in front of me said you have got to get a ticket from the bus driver. I mean it was difficult because you couldn't … at least I couldn't ask … tell the driver where I wanted to go. I just said [location] but I didn't say where I was wanting to go in [location] …. (person with aphasia)

There are a number of such comments and these are broadly in line with the developing body of literature on the subject (Parr *et al.* 1997). These can be separated into three further subthemes, those that are communication specific and those that are rather more generic:

- The ability to understand the communication of others, for example keeping up with conversations, watching television and following jokes;
- The ability to express themselves, for example asking for things, talking on the telephone, telling a story, etc.
- The ability to carry out everyday tasks associated with literacy and numeracy.

When asked to identify the major changes to their lives, people with aphasia cited everyday activities such as difficulties associated with doing crosswords, reading and watching television etc and they stressed the changes to social aspects of their lives and particularly friendships (keeping in touch through telephone or e-mail) and on their relationship with their partner and family. Many of their concerns could be considered an indirect effect of their communication difficulties, for

example on their work, their finances and on family life generally.

Among the aphasia professionals, regular support from SLTs for other professionals was still seen as an invaluable aspect of services both to the service users and to service providers.

> I don't think I could do my job without it (joint working with SLTs), for people with aphasia, not do it effectively. (social worker)

One of the most striking concerns expressed by both those with aphasia and the aphasia professionals was the lack of public and professional knowledge about aphasia and the effect that this has on the individual's behaviour. This affects access to services but also impacts on the response people with aphasia get in some care settings. For example, a number felt that hospital nursing staff often did not know about aphasia or were too busy with tasks and were not able to spend time communicating with them. This tended to have a negative effect on their experience of care and their ability to express their basic needs. This was even more pronounced amongst the public. Simply put, too few people know anything about aphasia, increasing the risk of social stigma.

Current service provision and gaps in services

The service user's perspective

The service users were generally very positive about the SLT and other services that they had received and the role that these played in their recovery.

> I cannae speak highly enough of the [SLT service] because when I came out of hospital I got speech therapy three times a week, once at the hospital, twice a week they came out to me … and they do everything with you … you do sums … you do reading … that was through the outreach rehabilitation services. (person with aphasia)

That said, the availability and timing of provision were of concern, with services perceived by many to be provided at the convenience of those delivering the therapy services, not the service users themselves. Many service users expressed their anxiety about the way in which they had initially accessed services and specifically the fact that they and their families found it so hard to find out what was wrong with them.

> I didn't get a lot of information, no. I would have liked to have been told if there was anything I could do to help. (carer)

This is not simply a matter of providing information but of making it available when it can best be used and when service users and their families are 'ready' for it.

Some service users indicated that they felt that therapy should be available when people are able to make use of it and commented that they may not have been ready for it at the time it was offered.

> There is just the whole thing that was four and a half years and now can let's go.

> It's taken you four and a half years to get to the point of being ready for some of that (therapy input)? (research team)

> Aye, aye. (person with aphasia)

Some respondents discussed the way that therapy was delivered, for example, in groups or one to one. Those who had experienced both forms of therapy provision indicated that, while they had enjoyed both, they felt that they benefited more from the latter.

> I would like to see more one to one Speech Therapy. The classes (group work) were good but now that I am looking from where I am, I just see how much more I could have got out of one to one. (person with aphasia)

There were more mixed views on the way in which services were introduced and withdrawn and the extent to which service users were included in the decision making process. Many people indicated a preference for therapy provided within the home as this eased pressure on them and also on their family to take time off work and attend appointments, especially for those living in rural areas. Finally, it was a relatively common experience amongst our respondents for people with aphasia not to feel included in their overall care management.

Many service users were very positive about their experience of a wider range of facilities provide by public and third sector (voluntary) services provided. This applied to both social support, that is, meeting other people in the same situation and practical support such as having access to cards carried by the person with aphasia which explain to others about aphasia and widely considered a helpful way of improving routine communication. These are the size of a credit card and are produced by a number of different agencies. They are often made up specifically for the individual concerned. There was a preference for aphasia specific groups rather than more generic stroke support groups, and. where feasible, for balancing groups in terms of age. That said, it is important to acknowledge that we recruited people for our focus groups through these more specialized groups and this may have affected this interpretation.

The professional's perspective

The speech and language therapist perspective is best captured in the result of the survey carried out as a part of this project. The reporting here picks out elements of the findings from the questionnaire to reflect the foregoing discussion. The full results are reported in (Law *et al.* 2007a).

The majority of the responses of those SLTs working in the acute sector (78%) indicated that therapists saw patients two or more times a week while the majority of responses for those in the community sector (84%) indicated that therapists saw patients once a week or less. By far and away the most common form of work is individualized one to one work with 92% of respondents saying that they frequently used this approach. Group work was less common with only 4% reporting this activity frequently and 76% of respondents indicated that they sometimes or rarely used this approach and 9% never using it. In contrast, delivering therapy through other family members and other professionals, was reported to be used frequently by 49%, seldom/rarely by 39%. Other therapeutic approaches, such as that focusing on the communication skills of the family, functional communication tasks, life issues, emotional support and giving advice or educating practitioners, were also cited.

Two other indices of the shift towards a broader more 'social' model of therapy were adopted, namely the use of referrals to the charitable sector and the involvement of the patient in personal goal setting within the clinical context. When asked to indicate to what extent they actively linked their patients up to charitable organizations such as Speakability, Chest, Heart and Stroke Scotland/Association, etc. 19% of SLTs said that they did so frequently, 45% sometimes but 29% indicated that they rarely or ever did this, suggesting that this is by no means a routine procedure. The survey explored the use of goal setting, key to the active involvement of service users in their care. Eighteen per cent indicated that they involved their clients in goal setting most of the time and only 9% said they rarely or never did so. Asked to comment on factors that determine whether an individual would be involved in goal setting, SLTs cited level of communication difficulty as the most common factor (60%). One respondent mentioned that severe communication difficulties, especially related to receptive language skills could 'make it difficult to discuss what they would like to work on'. A 'lack of insight', 'knowledge of prognosis', 'awareness of own difficulties' and 'insight into communicative abilities' and motivation were also cited. By contrast, respondents noted that 'eagerness to participate in therapy', 'level of interest and commitment to therapy' and

understanding of what was meant by 'goal setting' increased the likelihood of it being effective as a strategy. Characteristics of individual service users played a considerable role in the development of all aspects of service delivery. Twenty per cent of respondents felt that therapy intervention may vary in response to the differing needs and lifestyles of people of different ages, including being of working age and wishing to return to work or a desire to drive again. Many expressed concern about the level of support available for family members. Some professionals felt that they did not have adequate time and resources to support families fully.

> I think we struggle as well, even in hospital, to support carers and to give the carers adequate information and advice about communicating with their partners, mothers, fathers, with aphasia. (speech and language therapist)

Finally, the aphasia professionals and the SLTs commented on the value of 'aphasia friendly' materials for communicating with service users e.g. for appointment letters, discharge information and the type of 'easy to use' information cards the size of a credit card referred to above. The benefits of specific resources such as the *Stroke Talk Book* (Cottrell and Davies 2006) to explain hospital procedures and the *Stroke and Aphasia Handbook* (Parr *et al.* 2004) for more general issues pertaining to stroke. Interestingly, the service users did not comment on the use of such materials and it was not obvious whether they had not experienced these resources, did not value them or simply took them for granted.

When asked to identify barriers to the introduction of services, resources were one of the most commonly identified by SLTs as affecting the provision particularly of intensive therapy, training and equipment. Time was cited by 17% of respondents as a barrier to the introduction of service change, where many felt that 'there is insufficient time to take forward developments' and that time was necessary to 'allow SLTs to carry out audits or projects that would lead to change' or to 'review the evidence base, plan changes, evaluate changes, listen to service users and carers'. Resource pressures were also identified from the demand for dysphagia services. For their part, the aphasia professionals highlighted the importance of structural boundaries between hospital and community services which meant that some professionals based in hospitals could not visit people at home, often leading to a gap following in-patient discharges or a sharp discontinuity in service provider. They stressed the limitations of working within an in-patient setting in terms of providing for the service users' wider needs and the specific challenges of a very rural caseload, where caseload numbers can fluctuate and access can be a challenge.

Directions for the future development of services and barriers to change

Our findings suggest that there are moves towards increasing service user participation in service development. But this is not true everywhere. For example, only 16% of SLT respondents indicated the increasing emphasis on patient centred service provision with more time spent 'discussing patient needs, expectations and wishes in therapy' and 10% highlighted a shift to working more commonly on aspects of functional communication and the provision of support to families. Similarly, some respondents mentioned a shift towards an 'impact'-based model of treatment, looking at the consequential impact of the resulting difficulties and on 'living with aphasia' and especially the increased inclusion of family members in the treatment process rather than treatment of the existing symptoms. Other examples of recent changes identified by respondents were increased working with other professionals, increased links with outside organizations and increased inclusion of people with aphasia in service planning and training.

When asked what would make the greatest difference in the next five years, a fifth of SLT respondents indicated that increased staffing levels (SLTs and support staff) would make the greatest improvement in services. Many indicated the need for a more relevant evidence base. Given that a substantial proportion of our respondents (just under fifty percent) reported that they had been involved with a project or new initiative concerning people with aphasia this seems feasible. Others felt that more specialist services were needed, such as 'local SLT leads in aphasia specifically' or 'creation of specialist posts that are specific to stroke'. Improvements in service provision within the community and for longer term provision was also mentioned, with many respondents feeling that an increase in care once the person is at home is a necessary improvement. Increased support groups, outside organizations and support for everyday living, such as accessible college courses and giving advice to workplaces were similarly highlighted as important developments. Interestingly only 10% of respondents identified access and equity of services was as important, such as improving transport and providing equal service provision across differing geographical areas and therapy settings. A slightly smaller proportion (8%) felt that increased awareness of aphasia across service users, professionals and the general public would be an important service development. Service user choice regarding service development was also identified as a need by some. Of course, one of the key issues when it comes to change is who is in a position to make such

changes. Over 90% of respondents indicated that individual SLTs made such decisions, closely followed by SLT managers with only a third saying that others outside the profession had input into the decision making process. The potential for a change in practice would, therefore, appear to rest in the hands of the SLT practitioners.

The aphasia professionals stressed the need for increasing the capacity of stroke services more generally to ensure that all people with aphasia are treated within environments with a good understanding of stroke and aphasia. This was thought to be a more feasible option than training staff members in non-specialist settings. Service specific recommendations were also made, for example, for greater flexibility in the provision of appointments and the points at which individuals could access and re-access services and a greater degree of continuity of professionals across settings to ease transitions and fill current gaps that exist between services. Greater emphasis needed to be placed on training families about aphasia and on the provision of psychological and complimentary therapies to assist with concomitant mental health problems such as anxiety, stress and frustration.

Discussion

The findings have allowed us to address the research questions generated for the study namely: To what extent are recent shifts in evidence-based policy and practice reflected in SLT practice in aphasia? and To what extent were recent changes in service development reflected in the expectations of service users and other practitioners? To the former, the answer is clearly that practitioners are aware of recent shifts in practice and, while there has been a general movement towards, for example, more functional outcomes, practice has not changed substantially in most cases. To the latter there are clear indications that the aphasia professionals had developed an appreciation of the role of speech and language therapy as a profession supporting other staff in their communication skills as well as providing intervention to the individuals with aphasia themselves. As far as those with aphasia are concerned the picture is more complicated. They did not seem to be aware of services changing and indeed appeared to favour the more traditional one to one model. They greatly valued the input they received from their speech and language therapist and other members of the rehabilitation team and were generally very positive about what they had received, only concerned about the amount of contact they had and the way that it was introduced and withdrawn rather than the nature of that input or the way that it was delivered.

The findings confirm the serious, pervasive and long term impact of aphasia following stroke on the individual, on their families and those in their immediate environment—from their spouse, their friends and their grandchildren through to those providing care in the health and social care sectors and to the person who serves them in their local shop. If practitioners, whether they be in the health, social or charitable sectors, cannot communicate effectively with their clients they are likely to find the provision of effective intervention and support difficult. To this extent, aphasia is similar to a number of other conditions which have associated communication support needs (Law *et al.* 2007b). The impact of aphasia is not, of course, confined to speech, language and communication skills. People with aphasia often feel depressed and distressed and are commonly in need of psychological services to assess and treat issues associated with mood, cognition and psychosocial concerns (Townend *et al.* 2007). Inevitably the complexity of the impact has considerable implications for those providing services.

This study focused on the expectations of service provision from the perspective of both service user and practitioner. SLTs are aware of the pressure to involve service users more fully in the services that they provide although the number of those who had substantively changed their practice in this direction remained comparatively small. Our data also points to a real dilemma for both practice and policy in aphasia care. On the one hand, there is evidence that many SLTs are aware of recent changes in approaches to service delivery, particularly the use of functional assessments and therapy which emphasizes social functioning. On the other, there continues to be an emphasis on language rehabilitation delivered on an individual basis,. This is particularly true within the hospital context but it is also true in the community and is broadly supported by the service users who personally favour one to one work. A real tension emerges between the practitioners, who sometimes deem one-to-one work as a less than efficient use of resources for patients with 'unrealistic expectations' about their recovery potential, and patients' expressed priority of this form of therapy when asked their opinion.

For SLTs, another tension arises between sustaining a high level of one to one contact and the time pressures created by supporting the family, improving collaboration with agencies in the community and facilitating 'access' more generally. Traditional models of practice comprising direct behavioural intervention fostering speech and language skills in individual or group contexts continue to co-exist alongside the newer, perhaps more person centred, approaches which emphasize the planned re-integration of the person with aphasia into their communities (Duchan and Byng

2004). Although it is evident that this means more of the latter, it is not so obvious that there is a corresponding reduction in the former. This suggests that, while there is an awareness of the value of the shift, therapists often find it difficult to reconcile these competing interests. While SLTs often indicated that they were aware of these issues there was less evidence that this was reflected in their practice. In fact, to a great extent, SLTs appeared to be adhering to an individualized model of therapy provision, adding activities to that model and then expressing concern that they were not able to manage their caseloads. They maintained that one solution is to increase the number of therapists although another is obviously to do less one-to-one work and place greater emphasis on training and other more indirect models of service provision. Many service users were also committed to this one-to-one model and were wedded to the idea of getting better, an expectation that the SLTs often recognized as unrealistic. Given the professional autonomy expressed by therapists, the need to reconcile these pressures would appear to come down to individual rather than managerial decision-making.

We found relatively little reference amongst the service users to an awareness of these more functional and indirect forms of service delivery. This may reflect a bias in the experience of those involved in the study or that they were simply not aware of the additional activities that are being provided and may subsume them all under 'one to one therapy'. Thus, it may be that our focus groups did not pick up this shift in activity or that, when service users indicate that they were receiving one to one input, this was in fact along the lines of the social model, that is, about building social networks.

The one factor which all contributors appeared to be united over was the lack of public and professional awareness of aphasia.. Greater awareness would almost certainly reduce the individual's experience of disability, but it also has legal implications. Under the Disability Discrimination Act 2005 (H. M. Government 2005) all service providers have a duty to provide a 'reasonable adjustment' to enable a disabled person to access their services. This refers not only to making changes to the physical environment (the installation of ramps, rails, etc.) but also to adapting the ways that services are delivered. The latter has a direct consequence for people with aphasia who, as our focus groups show, experience considerable difficulties in accessing the services that they need. In the light of this legislation, and in line with the views of a number of service providers and people with aphasia, there is a case for making communication access training compulsory for all staff working in the public services in a way that training associated with 'moving and

handling' and 'child protection' have become obligatory over recent years. Such resources are already available for those working with people with aphasia (Parr *et al.* 2006) but have, to date, tended to be directed towards health and social care staff. Clearly the issues associated with communication access go far beyond the needs of people with aphasia and are equally relevant to the training needs of a wide variety of service providers. Communication access has already been accepted as a right for those with sensory conditions, for example in the provision of a wide variety of statement of intent in the state legislatures in the United States and elsewhere, although few are as inclusive as that for the government of Victoria in Australia (Department of Premier and Cabinet 2009). The implications of such a move would be considerable for people with aphasia but would be equally relevant for those working with people with a host of other communication related conditions for example those with learning disabilities, mental health problems and those who are not able to communicate readily in English.

Limitations of the present study

This study was set up to explore the nature of developing practice with regard to the provision for people with aphasia following stroke with a specific emphasis on the provision of speech and language therapy. It drew upon three different sources of information (SLT, patients and other practitioners) using two different methodologies (survey and focus groups). Although the number of respondents to the questionnaire was relatively high, those for the focus groups were much lower and their comments should be seen as indicative rather than representative of the populations from which they were drawn. For example, care needs to be exercised in assuming that the recommendation of one-to-one therapy holds for all people with aphasia. Although a range of respondents was identified the numbers were too small to be able to separate out further the views of sub-groups of participants. Thus, we cannot readily identify the needs of those who had their strokes many years ago from those that had them recently or those who have had more severe aphasia from those with less severe manifestations. It is also important to note that the study did not focus on the views of carers except in so far as they contributed to the views of their partners with aphasia. This would have been interesting but impractical given the nature of the study. The present report focuses on the consistency of the views of service providers and users and in particular looks to reconcile what the different groups say about the needs of the latter. The fact that we did not use an identical

methodology means that the comments made are not necessarily in response to the same questions, at times making interpretation difficult. Survey methodology would not have been appropriate for many of the service users given the nature of their communication and cognitive skills. Although it is possible to be reasonably confident about the response of the SLTs, given the way that the sample was constructed, it is always possible that there would be another set of responses which could be derived from focus groups constituted in a different way.

Conclusion

The impact of aphasia is now well-documented but there remain issues about the way that services are delivered. A series of societal and professional drivers are currently impacting on practice. There is a general awareness of new roles as a feature of future service delivery, especially for those working in the community, but, for many, individual practice has yet to reflect this change. One of the key issues in judging changing practice is the identification of the levers for that change. On the one hand the literature may point in a particular direction, while on the other there may be pressure from other clinicians and services users to function in a recognizable and familiar fashion. Our evidence suggests that SLT practitioners consider that they are largely responsible for their own decisions in this respect. This has all sorts of positive consequences in terms of the autonomy of the professional and their response to the needs of their clients. However, it does require the practitioner to manage the pressure to both change and to stay the same, to focus on social exclusion while providing one to one therapy, to take on new tasks while not dropping the old ones. Thus, the practitioner is left trying to please all parties often without sufficient institutional support. Professional autonomy, especially for therapists who are not working closely with teams of other professionals, may potentially be quite isolating and may militate against the introduction of innovative service-wide developments.

Acknowledgements

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