

Social exclusion of people with marked communication impairment following stroke

Aphasia is a communication impairment that commonly follows stroke. It affects people's ability to talk, understand, read and write. Some are so profoundly affected that any form of communication is minimal. Aphasia seems poorly understood and relatively unrecognised, perhaps because it is invisible; people with aphasia describe being overlooked. The experience of those with profound communication difficulties has never been documented before, partly because of methodological difficulties. This study by Susie Parr, Sally Byng, Colin Barnes and Geof Mercer found that:

-  People with severe aphasia had little access to employment, educational, training or leisure opportunities. Many were long-term recipients of a wide range of statutory and voluntary care services. Health, social and residential care workers did not have training or information about aphasia, and did not know how to support fragile communication.
-  Health and social care services often failed to address important issues, such as employment, or financial concerns, and there was little connection and communication between the various agencies.
-  People with severe aphasia were often excluded from the benefits of health, social care, residential and nursing services because information and instructions were inaccessible, activities inappropriate or unachievable, and there was continuous communication breakdown in interactions. For these people, services became 'hard to reach'.
-  Service providers, family and friends may have unintentionally excluded people with severe aphasia by using idiosyncratic, unmonitored communication strategies. People with aphasia were talked about, patronised, teased and given orders.
-  Particularly in residential and nursing care settings, people with severe aphasia were in danger of losing their identity as staff often knew very little about them and didn't know how to find out.
-  Maintaining friendships and social contacts was difficult for people living with severe aphasia, resulting in isolation and boredom. Relatives described experiencing similar restrictions.
-  People with severe aphasia mostly exercised little choice and control in their day-to-day lives.
-  The researchers conclude that social exclusion is a common, though not inevitable, experience for people with aphasia. Training and support for communication are urgently needed for carers and service providers.

Background

People who have aphasia as a result of stroke find that their ability to understand and to express themselves through speech and writing is suddenly compromised, and communication becomes difficult. Some experience such severe communication impairment that it becomes extremely difficult for them to understand others and to express their thoughts and wishes in any form. Aphasia commonly follows stroke, and it is estimated that many thousands of people in the UK are faced with major long-term difficulties in communicating.

Despite the large numbers of people affected, aphasia remains poorly understood and unrecognised, possibly because it is invisible. While the perspectives of some people with aphasia have been explored through interview, the experience of those with very profound communication impairment has never been documented, partly because of the methodological problems involved. This study combined ethnographic, survey and supported interview methods to document the day-to-day experience of people with severe aphasia in a variety of domestic, rehabilitation and care settings.

The gap between needs and provision

The study found that many people with severe aphasia became long-term recipients of a wide range of health, social care, welfare and voluntary services. Social networks associated with previous work, family and leisure activities were often replaced with extensive new networks, mostly comprising care and service providers.

Within these care networks, people with severe aphasia had little access to employment, training or leisure opportunities, and their needs or wishes concerning such opportunities were often not recognised. Services often failed to acknowledge and address matters of great concern and importance to people with aphasia. These areas of concern included dealing with communication breakdown, returning to work, maintaining financial stability in the absence of employment, making decisions regarding the family, dealing with troubled relationships and countering boredom and isolation. There was a lack of relation between what services offered and the matters of concern to people with aphasia. In

addition, there seemed to be little connection and communication between different agencies such as rehabilitation therapies, employment and benefits agencies and those in the home or care setting.

Services often seemed inaccessible or inappropriate to people with severe communication difficulties. Information, when available, was often unclear and sometimes hurriedly delivered. Activities such as quizzes and question and answer sessions highlighted rather than circumvented the impairments of those taking part.

Communication breakdown characterised interactions in all the service settings studied, even when highly qualified professionals were involved. Service providers typically did not know what to do, how to deal with difficulties or how to maximise understanding and expression. As a result, consultation and choice were rarely in evidence. In some cases, clients with severe aphasia were described as 'non-compliant' or 'unmotivated' when perhaps the problem was that they could not understand what was going on, nor could they express their wishes and concerns or negotiate services.

Service providers who indicated a desire for more information and support in communicating with people with severe aphasia commented that none was forthcoming. Physical needs, rather than communication needs, were prioritised in their training. These features made the services themselves, rather than those with communication impairment, 'hard to reach'.

Difficulties in supporting communication

Service cultures were often unsupported, and within these services there was much evidence of idiosyncratic and unmonitored methods of trying to support communication. Although developed with the best of intentions, these strategies often consolidated the exclusion of people with aphasia – they were sidelined, issued with strings of instructions, made to perform, chastised, teased and patronised. Many people were talked about in their presence as if they were not there; for example, volunteer workers at a stroke club said of David, who was listening: *"He has a lovely wife."*

Difficulties in supporting communication were

not just in evidence among service providers. Family members described the continuous and exhausting pressure of trying to resolve misunderstandings and determine the meaning of what was being expressed. None could recall receiving any advice about how to deal with communication breakdown; most acted instinctively, with idiosyncratic outcomes and varying degrees of success. Family members often stuck by the person with aphasia, and dealt with the communication difficulties as best they could. But friends either fell away, pointedly avoiding any contact, or developed well-meaning strategies such as teasing the person with aphasia and telling them to speak properly.

These communication difficulties meant that people with aphasia were distanced by and from others. In many cases, their individual identity was lost: their memories, history, experience, associations, aspirations, fears and stories were unexpressed and unexplored. This was particularly apparent in respite and residential care settings, where nursing and care staff commented that they knew little if anything about the person who could not speak. In these situations, there were no relatives to supply background information. Often, people with severe aphasia sat silently, isolated, excluded, and perceived as one-dimensional beings.

Lack of choice, control and engagement

Boredom was an issue for many people with aphasia, who found themselves faced with hours of enforced leisure time. While some family members made huge efforts to involve and engage the person with aphasia in various leisure activities and household responsibilities, the most common pastime was watching the television. For some in residential and respite care settings, even television and radio became inaccessible because remote controls were either not available or did not work. People with aphasia may not be able to communicate their requests to have the TV switched on or off, to change channel, or to 'channel-hop', just as they cannot ask for a light or a radiator to be switched on or off. Rarely were these wishes anticipated.

Some care environments were shabby and poorly maintained. Day-to-day routines, seating

arrangements and background noise often consolidated the isolation of a person with aphasia, even when surrounded by other people. The authoritarian and inaccessible nature of some environments was also conveyed through the tone and organisation of notices, posters and written information.

In day-to-day life, at home and in different service settings, there was little evidence of people with severe aphasia being involved in decisions and choices, other than the most basic selection of menu and clothing options. Some exerted some control over their circumstances by staying put and refusing to leave their room or house, others by closing their eyes and blocking everything out. Many expressed a sense of profound depression and hopelessness, through sighs, gesture and facial expression.

There were examples of people with aphasia being supported in making choices and decisions, in expressing their thoughts, wishes and desires and being engaged in pleasurable pursuits and interactions. However, such examples were few and far between, and often depended on the skill, sensitivity, humour, hard work and persistence of one or two family members.

Conclusion

The study found that people with severe aphasia experienced profound social exclusion, but that this was neither a constant nor inevitable outcome of communication impairment.

It is possible to make communication work and to overcome the barriers to enjoyable interaction, conversation and engagement. With the right level and type of support, it would be possible for people with aphasia to express their choices, wishes and concerns, represent the subtleties and details of their identity and experience, and engage in enjoyable and productive activity. This would depend largely on time (a scarce resource, particularly in service cultures) and the sustained efforts and skills of other people: family members, friends and service providers. They in turn would need huge amounts of training, information and support.

The need for training and support for communication is every bit as important as training to meet physical needs, but is not generally perceived

in this light. Although communication is rarely prioritised over physical issues, its importance is fundamental. It is the means through which choice and autonomy are exercised, social and emotional life maintained, and identity expressed.

About the project

The project combined information from three sources:

- a survey of speech and language therapists, voluntary-sector workers, self-help groups and organisations of disabled people;
- interviews with family members and paid carers;
- an ethnographic study of the day-to-day lives of 20 people with severe aphasia in the UK.

The participants with aphasia were sampled to ensure a range of relevant experience and were aged between 33 and 91. Each participant was observed three times in different settings: for example, at home; in a residential or nursing home, respite care or day centre; in stroke clubs and support groups; shopping or engaged in a sporting activity. In each case, the environment, activities, interactions, routines, artefacts and exchanges were described in minute detail. In all, 60 transcribed and annotated sets of field notes were analysed. Prominent themes were identified and considered in terms of social exclusion and inclusion. Findings were discussed with some participants and their responses fed into the dataset. The project advisory panel comprised researchers and people with aphasia, some with severely impaired language. This raised many challenges to the research process and revealed insights into the structural and temporal changes required if research is to be inclusive of the people it is about.

The study was carried out by Susie Parr of City University, Sally Byng of Connect, the communication disability network, and Colin Barnes and Geof Mercer of the University of Leeds. Susie Parr can be contacted by phone (0117 921 1192) or email (susiepparr@btinternet.com).

How to get further information

The full report, **Living with severe aphasia: The experience of communication impairment after stroke** by Susie Parr and edited by Sally Byng, Carole Pound and Alan Hewitt, is published for the Foundation by Pavilion Publishing (ISBN 1 84196 126 4, price £15.95).