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To cite this article: Roberta J. Elman , Jennifer Ogar & Sidney H. Elman (2000)  
Aphasia: Awareness, advocacy, and activism, *Aphasiology*, 14:5-6, 455-459, DOI:  
[10.1080/026870300401234](https://doi.org/10.1080/026870300401234)

To link to this article: <http://dx.doi.org/10.1080/026870300401234>



Published online: 31 Aug 2010.



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# Aphasia: Awareness, advocacy, and activism

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## Abstract

To the public and the media, aphasia is an unknown disorder. In this paper we argue that the ramifications of being 'unknown' are far more than philosophical, with resulting economic, psychosocial, and political consequences. We compare aphasia to other neurological disorders and to other historically disenfranchised individuals. We offer some preliminary ideas for media and political action plans to raise awareness, increase funding, and reduce psychosocial isolation for those living with aphasia. The need to inform and unite is great. Only then will those impacted by aphasia begin to receive the resources to which they are entitled.

Does something exist without a name? Although this question certainly has philosophical interest, our purpose in the present paper is to outline the day-to-day impact of 'aphasia' being relatively unknown. We argue that the ramifications of being 'unknown' are far more than philosophical, with economic, psychosocial, and political consequences.

Few people know about aphasia. Is it because few stories have been written about it? It is estimated that aphasia affects more than 1 million individuals in the United States alone. For the purposes of the present paper, we decided to compare aphasia to other health conditions and communication disorders with either similar or lower US incidence rates (listed in parentheses here): Parkinson's disease (1 million); stuttering (2.5 million); multiple sclerosis (350,000); autism (125,000); and muscular dystrophy (250,000). Appreciating the inherent differences and difficulties in comparing health conditions and communication disorders, we conducted a Lexis-Nexis search in June 1999 to determine if aphasia has been adequately represented in the print media. The top 50 newspapers (by circulation) in the United States were searched for the number of times a newspaper article used the words 'aphasia', 'Parkinson's disease', 'stuttering', 'multiple sclerosis', 'autism', and 'muscular dystrophy'. Table 1 displays the results of this search.

Our newspaper search indicates that the word aphasia has been used with much lower frequency compared to other health conditions or communication disorders having either a similar or a lower incidence rate. However, these data do not provide us with information regarding *why* the word aphasia has been used less frequently.

We also looked at the content of the stories that had used the word 'aphasia'. We randomly selected 50 stories from the previously described search in order to determine the type of usage for 'aphasia'. Stories were sorted into three possible categories of usage: word only provided, definition provided, or content provided. This descriptive analysis

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**Table 1. Results of a 1999 Lexis-Nexis search of the top 50 US newspapers (in circulation) for the numbers of stories that used the terms aphasia, Parkinson's disease, stuttering, multiple sclerosis, autism, and muscular dystrophy**

Terms	Number of newspaper stories		
	Past 5 years	Past 90 days	Past month
Aphasia	352	19	7
Parkinson's disease	1000+	686	219
Stuttering	1000+	239	69
Multiple sclerosis	1000+	1000+	299
Autism	1000+	418	137
Muscular dystrophy	1000+	368	131

revealed that 20 of the 50 stories used the word 'aphasia' alone without providing a definition or any additional content, such as 'we had our aphasia picnic'. A further 17 of the 50 stories provided a short definition of aphasia within the story. These short definitions included: '... expressive aphasia—she could think of the words she wanted to say but couldn't say them.' The remaining 13 stories used the word aphasia with significant content about the disorder of aphasia and typically focused on the impact of the disorder in people's lives. These 'content' stories, however, included many aetiologies in addition to stroke for aphasia including Alzheimer's disease, AIDS, brain tumour, traumatic brain injury, and mental retardation.

The results of this search indicate that the word aphasia is used infrequently in major US newspapers, especially when compared to other health conditions or communication disorders having similar or lower incidence rates. When the word 'aphasia' is used, it is often used out of context or in association with many different aetiologies. These data substantiate the notion that 'aphasia' has been inadequately described, at least in the print media, and may explain why so few people have heard of the disorder.

If you mention AIDS or Parkinson's most people's faces will light up with instant recognition. If you mention aphasia, you may very well be met with a blank stare. On the surface, this public ignorance may seem merely regrettable. In reality, without public awareness a vicious cycle is set into play—there is less funding for research, less money for services and, perhaps most serious of all, less empathy and understanding for people with aphasia who are trying to reintegrate themselves into the community. 'Name recognition is imperative,' says Sharon Klisser, of the American Parkinson's Disease Association. 'If the disorder doesn't have a name, how will it ever be understood?' (S. Klisser, personal communication, July 1998).

A myriad of organizations fight for a pool of limited financial resources. When people involved with well known disorders like Parkinson's, multiple sclerosis, or muscular dystrophy go looking for money, they rarely have trouble convincing funders that they are fighting for a worthy cause. People involved with aphasia aren't so lucky. After all, what foundation or institution wants to invest in a disorder they've never heard of? Most important, being 'known' does appear to correlate with grant funding. A search of the grants given by the 1000 largest private and public foundations from 1994 through 1997 indicates a dramatic disparity for the funding of aphasia related programmes/research compared to other health conditions and communication disorders. Please refer to table 2.

Private and corporate foundation grants are not the only sources to keep in mind when trying to raise funds. Although foundation assets are sizeable, the vast majority of

Table 2. Grants given by the 1000 largest foundations in the United States from 1994–1997 for the disorders of aphasia, Parkinson's disease, multiple sclerosis, and muscular dystrophy (grants over \$10,000 only)

Aphasia	\$202,700
Parkinson's disease	\$1,684,400
Multiple sclerosis	\$4,201,153
Muscular dystrophy	\$631,400

money given to charitable organizations comes from *individual* donations. In 1998, 77% of philanthropic contributions in the United States were made by individuals. Foundations gave a mere 9.8%, bequests amounted to 7.8%, and corporations gave 5.1% of the \$175 billion given that year (AAFRC 1999). We argue that because aphasia is largely unknown, it is extremely difficult to raise money either from foundations or individual donors.

Without knowing that there are other people out there with aphasia—people struggling with the same health, family, social and readjustment issues—many individuals feel isolated. As they are unlikely to have previously heard of aphasia, individuals with aphasia mistakenly believe that they have a rare disorder that impacts few others. Besides the profound psychosocial implications of feeling totally alone, individuals with aphasia and their loved ones are less likely to realize that a variety of community and treatment services might be available to them, because other community agencies are not as aware of the disorder or available services.

People with other disorders such as AIDS can and do advocate for themselves—frequently with a militant passion. People with cancer or heart disease can lobby for more research funding or better services from health care insurers. But people with aphasia can't always be such vocal advocates. Unlike other ailments or disorders, aphasia disturbs language. It's difficult to go out and raise public awareness when words are a jumble. But someone has to do it. In the words of many seasoned health care advocates, 'awareness is everything'. Without it, we can expect to see more cutbacks, fewer services, and meagre public support. Mentioning the word aphasia will continue to draw blank stares.

Gross, Anderson, and Powe (1999) report the relationship between funding by the National Institutes of Health and the 'burden' of various conditions or diseases. They conclude that there is no relation between the amount of funding and the incidence, prevalence, or length of hospital stay attributed to various conditions or diseases. They do find a strong correlation between the number of disability-adjusted life-years and funding; however, some diseases receive significantly more funding than would be predicted. Diseases receiving disproportionate funding are the same ones that have the most vocal advocates: AIDS, breast cancer, diabetes mellitus, and dementia.

We must learn to apply those techniques used by other disadvantaged and disenfranchised individuals who ultimately achieved public awareness and equality. We can learn much from their lessons. The questions to be asked include: How are people with aphasia to be heard? How do they tell their story? How can those with aphasia re-enfranchise themselves and make sure that their rights are upheld?

We can learn much from groups who have gained rights outside the health care arena. In the United States, women and minorities have used the political process successfully

to increase public awareness, government protection, and financial support. These groups have used the following methods to achieve their goals: activism, legislation, and judicial action. A systematic and strategic campaign must be provided on many different fronts by all those affected by aphasia, including speech-language pathologists. Publicity in many forms can both energize and pressure politicians and insurers. Publicity will also serve to alert both foundations and prospective individual donors to the disorder of aphasia. Health care professionals and community organizations will become better acquainted with the disorder. Judicial action needs to be taken when appropriate as it is precedent setting and therefore far reaching. We must consider taking cases to court under the Americans with Disabilities Act or other laws when those with aphasia are denied basic services or guaranteed rights.

To start raising awareness, increase funding, and reduce psychosocial isolation, we must make a name for aphasia. But how? We must build awareness of aphasia through advocacy along with political and judicial activism.

We need to become media-savvy and find ways to turn the media's attention towards aphasia. *Giving USA*, the annual philanthropic report, found that hearing or reading a news article was the third most cited reason why people give. (The first reason was that they were asked to donate by a loved one and the second was that they were asked by a member of the clergy.) The power of the media in this modern age is undeniable. 'I think media attention is incredibly important,' said AIDS Foundation Associate Director of Development Clay Jones. 'The media has trained us to look to them for what's important. Unfortunately, they have a lot of pull in this day and age.' In the age of sound-bite journalism, stories are often driven by what titillates or shocks. As they say in the newsroom, 'if it bleeds, it leads' (C. Jones, personal communication, July 1998).

Approaching an editor of a newspaper's health or science page may be one way to find a forum for stories about aphasia. But don't come with ho-hum press releases or flyers. 'You've got to try and find a way to make aphasia sexy,' advises veteran *Los Angeles Times* Contributing Editor Robert Scheer. 'Approach an editor or writer, a booker on a TV program. Figure out who's really interested at a newspaper and emphasize the human interest aspects of your story. Find someone who's afflicted, who's making progress, either famous or not—that could be a good story' (R. Scheer, personal communication, July 1998).

Celebrities are sexy, which means that celebrity spokespeople are the ones who are most often written about. 'A lot of people know that Annette Funicello has MS,' says Mary Lou Torre, development director for the Northern California branch of the MS Society. 'It certainly helps. People look at muscular dystrophy and they think "Jerry's kids," and they automatically have that association,' she says. 'It really makes a difference. Anything that you can do that makes it easy for people to understand what it is, and to make it personal to them when they don't have a connection is always a good thing' (M. Torre, personal communication, July 1998).

Aphasia does not yet have a Jerry Lewis or Annette Funicello, but that doesn't mean non-celebrities can't do the talking. If there is a physician, therapist, person with aphasia, caregiver or anyone else who is eloquent when speaking about the disorder, put them in contact with the booker for a radio programme that has health-related shows, suggests Klisser whose primary job for the Parkinson's association in Los Angeles is to promote public awareness. There are a number of resources that speech-language pathologists can already use to prepare for beginning in an advocacy role (ASHA 1996, 1998a,b, 1999). The American Speech-Language-Hearing Association also provides excellent information on its web site to help professionals advocate [[www.asha.org](http://www.asha.org)]. In addition, ASHA's

Special Interest Division 2—Neurogenics has recently assembled an advocacy sub-committee to increase awareness of neurogenic communication disorders.

In lieu of a full-page *New York Times* story on aphasia, what else can be done to raise awareness? A relatively cheap and effective way to get the word out is to do a public service announcement. Radio and television stations in the USA are bound by law to reserve a certain amount of time for PSAs. If you send a tape, there's a good chance it will be on the air in no time. 'My advice to you would be to get a PSA on the radio,' said Klisser, who said the total cost of creating, copying and sending a radio PSA about Parkinson's disease was only \$1,500. 'It makes a huge, huge, difference, I cannot tell you what it did for us,' she said. 'It's the best spent \$1,500 of my life. I just thank God that we did it. We were able to help so many people this way.'

We must also facilitate self-advocacy skills for all those impacted by aphasia. In the USA, the National Aphasia Association provides a basic structure for this work. However, there is much more work to be done. Penman and Pound at the City University of London found direct and indirect benefits of fostering self-advocacy skills within groups of those with long-term aphasia (Penman 1998). Other innovative programmes include the Action for Dysphasic Adults self-help groups in the United Kingdom (Coles and Eales 1999) and the Pat Arato Aphasia Centre Peer Support and Leadership Training Program (Cohen-Schneider 1996).

We must unite all those impacted by aphasia: stroke survivors, families, friends, and professionals. Working together we can increase awareness and give aphasia a name. And with a name, those impacted by aphasia may receive the resources to which they are entitled.

### Acknowledgements

Portions of this paper were presented at the 1999 British Aphasiology Society Conference. The authors thank Kathryn Yorkston, Kevin Kearns, and two other reviewers for their helpful comments on a previous version of this manuscript.

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