



Experiences of Welsh-speaking People with **Aphasia**

**Stroke Association/
Cardiff Metropolitan University Project 2023**

Authors: Dr Katherine Broomfield and Carys Williams

Cymdeithas
Strôc | **Stroke**
Association



Cardiff
Metropolitan
University

Prifysgol
Metropolitan
Caerdydd

Contents

Foreword - Stroke Association	4
Rhagair - Comisiynydd y Gymraeg	6
Foreword – Welsh Language Commissioner	7
Foreword – Royal College of Speech and Language Therapists	8
Recommendations	10
Background	11
Stroke and aphasia	11
Welsh language	13
The challenge	15
The research project	18
Method	19
Public involvement	20
Ethical approval	21
Participants and recruitment	21
Data collection	23
Data analysis	24
Researcher background	26
Results	27
Access to speech and language therapy	28
Theme 1: Service	28
The experience of being a Welsh speaker with aphasia	30
Theme 2: Identity	31
Theme 3: Emotionality	34
Discussion	36
Policy	37
Speech and language therapy	39
Stroke Association	41
Limitations	42
Conclusion	43
Recommendations	44
References	47
Acknowledgements	49



Every five minutes
stroke destroys lives.

We help to rebuild them.

Foreword - Stroke Association

A stroke happens in the brain, the control centre for who we are and what we can do. The impact varies depending on which part of the brain is affected. It could be anything from wiping out your speech, to a physical disability or affecting your emotions.

Many people who have a stroke are affected by aphasia, a language and communication disorder. Aphasia can affect a person's ability to understand speech, speak, read, write, and use numbers. However, it doesn't affect a person's intelligence.

At the Stroke Association, we know how important it is to support people with aphasia to rebuild their lives after stroke. This has particular significance here in Wales, where we continue to make a dedicated effort to improve our Welsh language offer to stroke survivors; working to ensure that language is never a barrier to accessing the help they need.

Navigating health and social care is complex and it is critical that we can receive care and support in our language of choice, particularly when facing life-changing health conditions like stroke. It's important that stroke professionals actively seek to address the diverse needs of those affected by stroke. As you will see from this report, language is not merely a means of communication but a fundamental aspect of identity and culture in Wales. We need to reflect and respect that diversity.

The Stroke Association is funded to deliver specialist Communication Support alongside our Stroke Recovery Service in some parts of Wales. However, not every health board commissions this service, meaning not all stroke survivors are routinely offered Communication Support, leading to a postcode lottery.

Under the current Welsh language requirements, people working in stroke should consider the use of Welsh and the specific needs of Welsh speakers throughout the recovery process. Language plays a crucial role in rehabilitation, as well as fostering a sense of belonging and empowerment for survivors.



Plans to transform stroke services in Wales must include a focus on a comprehensive Welsh language provision. By incorporating Welsh language services, we can ensure that every stroke survivor in Wales has the option to receive care and support in Welsh if that is their preference. This inclusive approach will not only deliver quality services but will also promote equity and dignity for all.

As we look to the future, it's essential to consider how we can attract and cultivate a Welsh-speaking workforce, particularly in areas like stroke rehabilitation and therapies.

Thank you to all those dedicated to delivering and improving stroke care and support in Wales. Together, we can strive for inclusivity, accessibility, and excellence in services for people affected by stroke.

Katie Chappelle
Associate Director, Wales

Rhagair - Comisiynydd y Gymraeg

Mae cyfathrebu yn hanfodol i ni fel pobl. Mae iaith yn ein galluogi i fynegi ein hunain a datblygu a chynnal cyfeillgarwch a pherthynas o fewn ein teulu, ein cymuned a thu hwnt. Gall hefyd fod yn rhan greiddiol o'n hunaniaeth.

Gall affasia effeithio'n andwyol ar bobl yn yr holl gyd-destunau hyn gan ei fod yn gyflwr sy'n effeithio'n uniongyrchol ar allu unigolyn i fynegi ei hun. Mae angen cymorth arbenigol a chefnogaeth ar bobl ag affasia i'w cynorthwyo i wella eu gallu i gyfathrebu, codi ansawdd eu bywyd a lleihau unigedd. I siaradwyr Cymraeg, gall gwasanaethau cyfrwng Cymraeg fod yn hanfodol i'w hadferiad.

Mae'r Gymdeithas Strôc a'u cydweithwyr ymchwil ym Mhrifysgol Metropolitan Caerdydd wedi amlygu profiadau negyddol siaradwyr Cymraeg ag affasia na dderbyniodd y cynnig rhagweithiol o wasanaethau Cymraeg sy'n egwyddor ganolog i Mwy na Geiriau, fframwaith strategol iechyd a gofal cymdeithasol Llywodraeth Cymru. Nid yn unig y bu rhaid i siaradwyr Cymraeg ofyn am y gwasanaethau hynny, ond nid oeddent ar gael ym mhob achos, diffyg a allai danseilio adferiad.

Mae'r adroddiad yn tanlinellu pwysigrwydd gwasanaethau cyfrwng Cymraeg addas ar gyfer siaradwyr Cymraeg ag affasia. Cyflwyno argymhellion gwerthfawr ynglŷn â gwella dealltwriaeth o'u hanghenion a datblygu'r ddarpariaeth ar eu cyfer. Gallai gweithredu ar yr argymhellion hyn arwain at gynorthwyo siaradwyr Cymraeg ag affasia a'u cefnogi i wella ansawdd eu bywyd, gan sicrhau parch ac urddas iddynt trwy ofal sydd wir yn ateb eu hanghenion.

Hywel Iorwerth
Uwch Swyddog Polisi

Foreword – Welsh Language Commissioner

Communication is essential to us as humans. Language enables us to express ourselves and develop and maintain friendships and relationships within our family, our community and beyond. It can also be a core part of our identity.

Aphasia can have an adverse impact on people in all these contexts as it's a condition that directly affects an individual's ability to express himself or herself. People with aphasia need specialist assistance and support to help them improve their ability to communicate, enhance their quality of life and reduce isolation. For Welsh speakers, services through the medium of Welsh can be essential to their recovery.

The Stroke Association and its research colleagues at Cardiff Metropolitan University have highlighted the negative experiences of Welsh speakers with aphasia who did not receive the active offer of services through the medium of Welsh, which is a central principle of More Than Just Words, namely the Welsh Government's strategic health and social care framework. Not only did Welsh speakers have to ask for those services, but they were also not even available in all cases, a shortcoming that could undermine recovery.

The report underlines the importance of appropriate services through the medium of Welsh for Welsh speakers with aphasia. It presents valuable recommendations for improving understanding of their needs and developing provision for them. Acting on these recommendations could help Welsh speakers with aphasia and support them in improving their quality of life, and ensuring respect and dignity for them through care that genuinely meets their needs.

Hywel Iorwerth
Senior Policy Officer

Foreword – Royal College of Speech and Language Therapists

We welcome the publication of the research on Welsh-speaking people's experiences of aphasia and the debate that this raises. Speech and language therapy plays an important role in the rehabilitation and reablement of stroke survivors by assessing their needs and providing appropriate strategies to support their speech, language, communication and swallowing needs. The Royal College of Speech and Language Therapists guidelines state that Speech and Language Therapists should provide intervention in the individual's mother tongue and support the family in their use of mother tongue when necessary/appropriate. There is a clear clinical rationale for the availability of Welsh language speech and language therapy and as a college, we are committed to supporting improvements in this area.

Since the publication of the Welsh Government More than Just Words Strategic Framework for the Welsh Language in Health and Social Care in 2012, we have seen significant developments to improve the availability of Welsh language speech and language therapy services. These include the appointment of lecturers through the Coleg Cymraeg Cenedlaethol to ensure undergraduates are able to study through the medium of Welsh and the introduction of quotas for Welsh speakers within commissioning figures for the profession.

The report raises important questions about access to speech and language therapy provision through the medium of Welsh and the need for ongoing action in this area. We will study the recommendations in the areas of policy, practice and research carefully and look forward to working with key stakeholders such as the Stroke Association, higher education institutions, the Welsh Language Commissioner and local health boards to drive further progress.

Pippa Cotterill
Head of Wales Office, Royal College of Speech and Language Therapists



Recommendations

For policy (epidemiological data and policy adherence):

- 1) Data collection and access that provides insight into the prevalence of aphasia following stroke in Wales and the need for post-stroke communication support in Welsh.
- 2) Evaluation of the Active Offer in health and social care.

For Speech and Language Therapy (professional practice):

- 3) Clearer understanding across statutory and voluntary organisations about the pathways for SLT support for aphasia when Welsh is a person's choice language.
- 4) Education and training about the nature of aphasia for bilingual people and how therapy needs to target choice or both languages rather than the majority language.

For the Stroke Association (research and outreach services in Wales):

- 5) Enhanced aphasia services that support the communication needs of mono- and bilingual people in Wales – building Welsh-language communication support offer to enhance existing aphasia services and provide community-based intervention (e.g. groups) in areas where there is a deficit.
- 6) To foster a culture that supports greater engagement with research about stroke in Wales.

Background

Stroke and aphasia

'Stroke' is a term used to note a cerebral vascular event. This can lead to impairment of motor, sensory, and cognitive function, depending on the location and severity of the damage to the brain. The Stroke Association estimates that 100,000 people have strokes each year and that there are 1.3 million stroke survivors in the UK¹. The Welsh Government² identifies stroke as the fourth leading cause of death in Wales and recognises its long-term impact on the survivors of stroke. It is estimated that 7,400 people in Wales have a stroke each year and that 70,000 stroke survivors live in Wales².

The National Aphasia Association defines aphasia as "an impairment of language, affecting the production or comprehension of speech and the ability to read or write"³. The most common cause of aphasia is stroke. The Stroke Association estimates that 350,000 people in the UK have aphasia. Of the 70,000 stroke survivors in Wales, it is estimated that up to 40% may have aphasia (Berthier, 2005); of these, an increasing proportion are likely to be Welsh- speakers.

Speech and language therapists support people who have aphasia. "The primary aim of speech and language therapy (SLT) in aphasia management and rehabilitation is to maximise individuals' ability to communicate. Speech and language therapists are typically responsible for the assessment, diagnosis and, where appropriate, rehabilitation of aphasia arising as a result of stroke" (Brady *et al.*, 2012).

¹ <https://www.stroke.org.uk/what-is-stroke/stroke-statistics#:~:text=Key%20statistics%3A,people%20have%20strokes%20each%20year>

² <https://www.gov.wales/quality-statement-stroke-html>

³ <https://aphasia.org/what-is-aphasia/>



Aphasia therapy strives to improve an individual's ability to communicate through multiple strategies; to help people use residual communication abilities, restore language function, develop compensatory strategies, learn other methods of communication, or support communication partners to adapt to the person with aphasia's communication needs⁴.

The Stroke Association provide communication support services to enable people with communication disability following stroke to achieve the best level of communication possible through providing targeted support to individuals and their families or carers. The aim of the Stroke Association Communication Support service is to improve communication and quality of life, and to reduce social isolation⁵.

⁴ <https://www.rcslt.org/members/clinical-guidance/aphasia/aphasia-guidance/#section-5>

⁵ <https://www.stroke.org.uk/professionals/life-after-stroke-services/communication-support>

In Wales, the 2021 Census⁶ estimated that 538 000 usual residents in Wales aged 3 and over could speak Welsh (17.5% of the population), and that approximately 14% of people over 45 speak Welsh. The Annual Population Survey⁷ for the year ending March 2023, identified a larger proportion, 29.2% (889,700), of the population speaks Welsh. There is no county in Wales that has no Welsh speakers and there are some areas where the Welsh language is spoken by the majority.

English and Welsh have both had equal legal status in public services, business and justice since the Welsh Language Act of 1993. The Welsh Language Measure (2011)⁸ gives the Welsh Language official status in Wales which engages the general principle that the Welsh language should not be treated less favourably than the English language in Wales and that opportunities to use the Welsh language should be facilitated and promoted. Public sector bodies in Wales, including health boards, local authorities, and other key agencies in the field of Public Health are subject to statutory duties under the measure to use the Welsh language in all facets of their work. Since 2016 local authorities have been required to comply with Welsh language standards and since 2019 health bodies have also been required to comply with standards. These standards set out clear expectations about the responsibilities of health and care bodies to provide access to services in Welsh. Despite legal parity

of Welsh and English, a report prepared by Care Council for Wales and Welsh Government in 2012, “Welsh Speaker’s Experiences of Health and Social Care Services”⁹, captured many examples of the impact of receiving, or not receiving, Welsh language healthcare services. The research was used to contribute towards the strategic framework for the Welsh language in Health and Social Care services in Wales – Mwy na Geiriau/ More than Just Words in 2012, and three follow-on frameworks were launched in 2016, 2019 and 2022¹⁰. One of the core principles of Mwy Na Geiriau is the ‘Cynnig Gweithredol/Active Offer’. This principle requires health and care workers to establish whether a person would like to receive services in Welsh. Speech and language therapy is highlighted as a priority area within the strategic framework and a key action under the section Welsh language planning and policies includes ‘establishing Welsh language care pathways for vulnerable

⁶ <https://www.gov.wales/welsh-language-wales-census-2021-html>

⁷ <https://www.gov.wales/welsh-language-data-annual-population-survey-july-2022-june-2023>

⁸ <https://www.welshlanguagecommissioner.wales/about-us/the-welsh-language-measure>

⁹ https://www.iaith.cymru/uploads/general-uploads/welsh_speakers_experiences_of_health_and_social_care.pdf

¹⁰ <https://www.gov.wales/sites/default/files/publications/2022-07/more-than-just-words-action-plan-2022-2027.pdf>



individuals in identified priority groups such as older people, children, mental health, speech therapy, learning difficulties, and stroke services”¹¹.

The Stroke Association Wales produced a Welsh language policy in 2021 in which the organisation affirms its commitment to adhering to National Policies concerning Welsh, including providing an

equivalent service to Welsh speakers as to English ones. Care provision in choice language is recognised as “more than a matter of choice, but a matter of need” within this document and strategies to implement an ‘Active Offer’ from the Stroke Association are documented in the policy.

¹¹ <https://www.rcslt.org/news/rcslt-responds-to-welsh-language-health-and-social-care-plan/>

The challenge

There is limited research available on the experiences and needs of people who speak Welsh in health and care contexts. The research that does exist is characterised by studies of small numbers in groups of people with specific conditions. The “Welsh speaker’s experiences of health and social care” report⁸ identified that, for many respondents, the use of the preferred language is powerful for creating affinity and forming closer professional relationships between providers and recipients of health and care services. Irvine and colleagues (Irvine et al., 2006) found that healthcare professionals perceived that providing language choice, and thence care in the language of choice, enhanced care by facilitating holistic care processes, supporting communication, and establishing relationships. A study exploring the experience of English-speaking therapists providing stroke rehabilitation to non-English-speaking individuals suggested that ‘subtle communication’, which it was thought to be an important therapeutic tool, was at risk of being lost across a language barrier (Taylor and Jones, 2014). A recent study into the experience of people in care homes with dementia reported that the incongruity between people with dementia who spoke Welsh and their non-Welsh-speaking carers resulted in inappropriate care and increased risk in social isolation (Martin, Woods and Williams, 2019). These research sources point to a disruption of the therapeutic alliance that is key to successful health and care interventions.

Literature concerning speech and language therapy, bilingualism, and aphasia is characterised by single case-studies; the combination of languages is vast and the profile of individuals’ journey to acquiring two or more languages is different and thus impacting the ability to compare outcomes from therapy across cohorts. There is very limited

evidence on the success of cross-linguistic transfer, that is the likelihood of therapy in one language influencing linguistic performance in additional languages (Ansaldi et al., 2008; Kambanaros, Grohmann and Theodorou, 2010). A unifying principle for addressing the needs of bilingual people with aphasia is provided by Grosjean: the bilingual

client is not two monolingual persons in one body (Grosjean, 1989). A bilingual person's use of languages may vary. For example, a Welsh-English speaker may prefer to read and write in one language but speak the other. The "Welsh speaker's experiences of health and social care" report⁸ identified that context might inform choice, for example a Welsh speaker may feel more comfortable speaking Welsh when needing to express their feelings and thoughts, another person may prefer to do this in English. A patient may prefer a consultation in Welsh but find completing forms easier in English. Others will prefer all services in Welsh. Clinical guidelines for speech and language therapists working with bilingual clients advise that assessment and intervention must always be carried out in both (or every) languages (Pert and Bradley, 2018). In essence, research and clinical practice guidelines indicate that if someone uses Welsh and wants to see improvement in this language, they must receive assessment and therapy in Welsh, overseen by a competent clinician. Excluding a therapy offer in one language may isolate the patient by them not being able to access activities, family interactions, and aspects of their sense of identity (Kohnert & Patterson, 2012).

Much of the way people communicate and express themselves is connected to identity and how the social world perceives and interacts with individuals. For these reasons, aphasia has been

considered a condition of identity theft (Shadden, 2005). The role of speech and language therapy for people with aphasia has explored how therapeutic activity can help to reconnect people with their sense of identity (Simmons-Mackie and Elman, 2011). The Welsh language has to some extent been preserved because people connect their Welsh identity, and sense of Welshness, to their use of the Welsh language (Madoc-Jones and Buchanan, 2003) even more so than to where they are from (Jones, 2019). There is also an acknowledgement that bilingual people frequently use their native language for expressions of emotionality (Caldwell-Harris, 2014), which may be significant during a health event such as stroke. There is currently little information available, either from the research literature or health and care data, that illuminates the level of need for access to speech and language therapy in Welsh following stroke. Anecdotal evidence suggests that access to speech and language therapy in Welsh is limited¹², yet people who have aphasia following stroke may require support in their choice of language to be able to connect with family and friends, express their sense of identity, or access appropriate emotional support.

The aim of the current project was to explore the lived experience of people who need speech and language therapy for aphasia following stroke to inform further research and service development.

¹² <https://www.wales247.co.uk/welsh-language-support-essential-for-stroke-survivors>



The research project



**The project
had 3 key
objectives:**

- a. To understand experiences of aphasia after stroke in individuals who use Welsh as their language of choice for everyday interactions.
- b. To understand experiences of speech and language therapy (SLT) provision and intervention following stroke in individuals who require provision and intervention in Welsh. This may include individuals that received SLT input from NHS Wales and/or independent SLT services.
- c. To identify barriers and facilitators to receiving speech and language therapy for aphasia in Welsh following stroke from the reported experience of individuals and their families/carers/communication partner.

Method

The overarching aim of this project was to understand more about experience, so a qualitative research study was designed based on a phenomenological methodology. Qualitative research is concerned with the gathering of personal accounts to provide deeper insights into real-world problems (Denzin and Lincoln, 2018). "Phenomenology is a philosophical approach to the study of experience" (Smith, Flowers and Larkin, 2009; p11) - which is considered to have a significant interpretative element; that is, that people's experience is filtered through the interpretation and reporting of the person who is receiving and retelling their narrative.

Two speech and language therapists led this project; both have clinical experience of working with people who have aphasia, one is also a bilingual English/Welsh speaker (CW), and the other (KB) is a trained and experienced qualitative researcher. CW and KB brought complimentary skills and experiences to the project and reflected, through journaling and peer-mentorship, how their professional backgrounds guided their engagement with the project process, the data collection and analysis.

Public involvement

Public involvement is the process by which people with lived experience inform the development of research design and execution. Public involvement (PI), also known as patient and public involvement (PPI) or patient and public involvement and engagement (PPIE), is defined as research that is “‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or for ‘them’” (INVOLVE, 2012). This project was inspired by a Welsh-speaking person with aphasia who shared their concern about the current state of provision and support for people who have aphasia following a stroke and whose choice language was Welsh with the Wales branch of the Stroke Association. The question and research objectives were based upon this person’s experience and so the research team strived to continue to have public involvement inform the research development process.

The research team contacted the chair of a stroke group local to the Cardiff area to discuss the project further and gather some insights from the group members to inform the ethical approval application to Cardiff Metropolitan University (CMU). Two members of the group, a married couple Adam and Eirian (pseudonyms), - one of whom was a Welsh-speaking stroke survivor who did not have experience of aphasia - were invited to CMU for a conversation about their experience of stroke and stroke rehabilitation. Their feedback was sought on the accessibility of the recruitment materials that had been developed for the project. We also discussed with them the type of questions that should be asked during data collection interviews to gain insights into the experience of

Welsh-speaking stroke survivors. The research team were able to improve the recruitment materials following feedback from Adam and Eirian. The conversation also provided insight into the experience of stroke rehabilitation from a Welsh-speaker’s perspective. Eirian reported that there were very few occasions when she would have wanted to receive rehabilitation in Welsh as many of the medical terms she would only know in English. However, she spoke in Welsh daily to her sisters on the telephone and felt that she was always able to speak Welsh when she needed to during her rehabilitation journey. When she was asked what her Welsh language meant to her, Eirian reported “*I am Welsh*”, indicating the strength of the language link to her sense of identity.

Ethical approval

A research ethics application was made to the Cardiff Metropolitan University (CMU) research ethics committee reference number Sta-7240. The project was granted ethical approval on 28th February 2023 with subsequent amendments approved on 5th April and 28th July 2023.

Participants and recruitment

Participants were recruited, with or without communication partners (people who support individuals who have communication disability) using the following inclusion criteria: a) people who had experienced stroke within the past 36 months, b) people who had received a diagnosis of aphasia, and c) people who spoke Welsh regularly prior to their stroke. Bilingual project flyers were designed containing information about the project and contact details for the research team. Flyers were distributed via the Stroke Association's team in Wales, the Welsh Stroke Hub and local stroke groups, through the All-Wales Stroke Specialist group for SLT, and on various social media channels associated with these organisations, CMU, and the research leads (KB/CW). All recruitment materials were produced in accessible, bilingual versions. One project lead (CW) appeared on BBC Radio Cymru and Newyddion BBC to advertise the project. Three people who were Welsh- speakers and who had aphasia following stroke were recruited to the project.

As recruiting individual participants proved to be very difficult, an extension to the ethics application was made to include data collection via a focus group with an existing group of Welsh-speaking stroke survivors. The lead facilitator for this group contacted the researchers and invited them to attend the online group

for Welsh-speaking stroke survivors that meets monthly. Participant information was sent to the group members via the facilitator, and she recorded consent from the group members for a researcher to attend one of their online meetings. A table of participants' details is provided below (Table 1).

Data collection type	Identifier	Gender	Age	Year of most recent stroke
Focus group	G1	M	60+	2020
	G2	M	60+	2019
	G3	M	60+	2008
1:1 interview	P1	M	60+	2022
	P2	F	<50	2021
	P3	M	<50	2021

Table 1: Participant details

Data collection

The three people who expressed an interest in being involved in the project contacted the lead researchers by email. Further information was provided by the researchers about the project on request, following which in-person interviews were arranged at a time and location that was convenient for the participants. All individual data-collection interviews were carried out by CW and KB together. Interviews were offered in Welsh or English.

During interview appointments, consent forms were completed, a bilingual language case- history was taken, and the semi-structured interview schedule was followed. For one participant, who had significant aphasia, communication strategies including drawing, writing single words, and the use of objects of reference were all used to support the interview process. Where communication partners were present and involved in the interviews, their consent for us to use their contributions was also recorded. All interviews were audio and video recorded. Both researchers wrote field notes after the interviews where they recorded salient information about the context for the interview as well as their own personal reflections on the process and content of the interviews.

The focus group was carried out in Welsh by CW online using Microsoft Teams®. All group members received written information about the group and provided written consent to participate in the conversation and for their contributions to be recorded and used as data in the

project. Conversation within the group was guided by the interview topic guide used for the 1:1 interviews. The focus group meeting was recorded in Teams® and CW made reflective field notes after the group meeting had taken place.

Data analysis

Data analysis was guided by the Interpretative Phenomenological Analysis (IPA) method (Smith, Flowers and Larkin, 2009). IPA is informed by three key pillars: phenomenology, hermeneutics, and idiography. Phenomenology, as previously described, is the study or investigation of experience. Hermeneutics is the theory of interpretation, and specific to IPA is the notion of the 'double hermeneutic' whereby the researcher is making sense of the participant, who is interpreting the phenomena under investigation. This was of particular significance in the current study as there were two researchers with different experiences leading the study, which informed how the hermeneutic element of the analysis was approached. Idiography is concerned with the particular – allowing for deep and detailed analysis individual experience rather than seeking to identify specific themes or generalisations. This makes IPA a useful method for studies with small numbers of participants who provide rich insights.

IPA has been described as an iterative and inductive cycle: data is considered, interpretations are generated, and then data is revisited to test and challenge the interpretations and to seek conceptual insight. The following summarises the main phases of analysis:

1

Transcribing the data: all 1:1 interviews were transcribed in the language in which the interview took place. Transcriptions were then translated by CW into English where required. Field notes were also made by both researchers in their choice language and translated when necessary. Video recordings were used to note any significant non-verbal communication that informed the interview narrative.

2

Initial noting – the researchers examined the content of the transcripts separately highlighting salient or noteworthy aspects of the data that responded to the aims and objectives of the project. During this process, both researchers became familiar with the data and of how each participant engaged with the issues being discussed.

3

Descriptive comments – the researchers made notes, surmised initial interpretations, and generated comments on the data individually.

4

Linguistic comments – explicit meaning was attributed to the descriptive comments by researchers individually.

5

Conceptual comments – researchers came together at this stage to discuss their individual notes and comments, identify areas of synergy and dissonance, and discuss where their commentaries represented conceptual interpretations of the data.

6

Emergent themes – researchers looked across the individual participant transcripts and comments, their reflective fieldnotes, and the notes from the focus group and agreed on initial emergent themes within the data set.

Stages 3 and 4 of the analytic process were used to generate a descriptive narrative that responded to aim 3 of the project: what are the barriers and facilitators to receiving speech and language therapy in Welsh? During stage 5 of the analytic process, KB and CW compared their individual interpretations during an in-person discursive workshop wherein the data, individual noting, and linguistic and descriptive comments made separately were compared, contrasted, and connected to the

research aims through in-depth discussion and abductive reasoning. Through an iterative process of reflecting on the interviews, reviewing the transcripts and field notes, and critiquing individual commentary a conceptual picture of the emerging mutual understanding of the experience of the Welsh-speaking aphasic participants was devised. KB and CW then identified sub-themes (stage 6 of the analytic process) within and across the individual experiences reflected in the data.

Researcher background

Research background is important in qualitative research because it enables researchers to address explicitly the history and experience that may inform how they approach the data analysis.

KB had clinical experience of working with people who have aphasia and of carrying out qualitative research with people who have communication disability. Her research has focused on the experiences of communication disability, theories, and concepts of communication and how they inform speech and language therapy in practice, and person-centredness in healthcare. She has no heritage connection to Wales or Welsh. She was able to reflect on the specific needs of the participants from speech and language therapy in general and was then able to use this foundation to critique where choice-language therapy may have enhanced their rehabilitation experiences.

CW's clinical specialism is stroke and acquired neurological communication disorders. She has extensive experience of working with people who have aphasia. CW is a Welsh speaker and considers Welsh to be her first language. Her case load whilst working within the NHS had several Welsh speaking clients. Her upbringing was in a Welsh speaking family and her education was predominantly through Welsh. She was able to provide insight into the cultural and political background of the Welsh language during the analysis process. CW also contributes to clinical lectures on bilingualism on an undergraduate degree and training course in Speech and Language Therapy.

Results

The results of this study suggest that there are significant challenges to accessing speech and language therapy following stroke, presented as a theme labelled 'service'. The experiences of being a Welsh speaker with aphasia are represented by two overarching conceptual themes: 'identity' and 'emotionality'.

Three subthemes: family, community, and political, were generated to represent deeper insights into the similarities and contrasts of individual participant experience. A diagram (Figure 1) presents the analytic process, results, and how they connect to the aims of the project. The following narrative provides greater detail about the results, with examples from the data to evidence how emergent themes were generated.

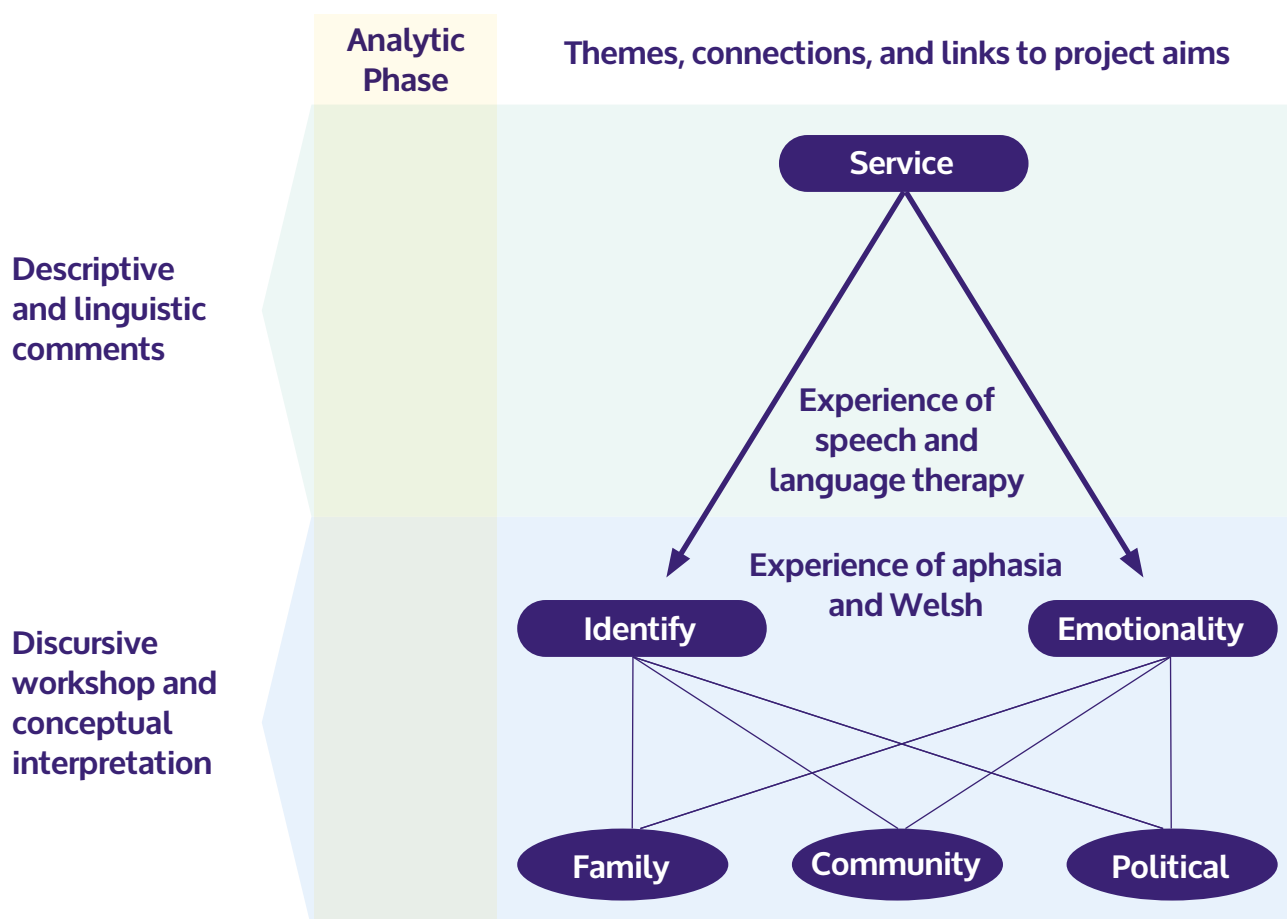


Figure 1: A diagrammatic representation of the results of the data analysis

Access to speech and language therapy

Theme 1: Service

All the participants in this project reported that they had very limited access to any speech and language therapy following their stroke. None of the participants recall being offered speech and language therapy in Welsh. Those that did receive speech and language therapy in Welsh (P2, P3 and one focus group participant) had to explicitly request this. P1 and members of the focus group all accessed some form of support group (P1 – in English, focus group – in Welsh) but there was little evidence that these provided targeted therapeutic benefit to their communication.

The focus group enjoyed the opportunity to socialise and did not consider the group to be for therapeutic gain; they were all able to communicate effectively but liked “being able to talk to other people that understand everything after stroke” (G1).

During discussion in their data analysis workshop the researchers noticed, in the absence of detail about stroke rehabilitation that participants were able to provide, a lack of awareness about the stroke services that are available from either voluntary or statutory services. P1 was unclear about the roles of the professionals that he encountered “I don’t know was it a speech therapist? She worked on this (wiggles his fingers) worked on my fingers all night”.

There was also evidence of significant gaps in the stroke pathway between statutory and voluntary services. P1 was connected to a local stroke group by his stroke consultant’s secretary. P2 reported only a brief period of rehabilitation following discharge from hospital and this was not provided in Welsh. When asked about the support available from local voluntary and community sector organisations, P3 frowned and shook his head, “gesturing to suggest that it’s a service for older people and he got quite upset at this” (field notes, KB).

The dearth of speech and language therapy or local support services, and the gaps between moments of access to support, left people with aphasia frustrated that they were unable to express themselves clearly or make any improvement to their communication.



"We have a chat to start with [...] Then we split up into a small group for about an hour. Doing memory tests and that sort of thing. Which I think, it wasn't very useful this morning..." (P1)

The experience of being a Welsh speaker with aphasia

Access to aphasia therapy or support in Welsh was a primary concern for P2 and P3, who spoke Welsh in their daily life, whereas P1 considered therapy in Welsh to be “a huge bonus”. The way that aphasia affected them as Welsh-speakers was distinct. P1 spoke Welsh to his sibling, to his children, and to some of his grandchildren. The impact of aphasia on his Welsh language was most significant in relation to his ability to interact with family (subtheme – family). P2 was part of a Welsh-speaking community in which speaking Welsh was her “natural” mode of communication (subtheme 2 – community). Whereas for P3, his connection to the Welsh language was political (subtheme 3); he answered the door wearing a t-shirt with ‘Cofiwch Epynt’ on it – a protest to remember the community on Mount Epynt. He acquired proficiency in Welsh as an adult and felt passionately about the purity of the language and its association to nationhood. These subthemes represent some of the distinct features of the experience of Welsh speakers and can be represented within two distinct themes: identity and emotionality. These themes are manifest in the differences and similarities between each of the participants and what being a Welsh- speaker meant to them.

Theme 2: Identity

P1 grew up in a Welsh-speaking community “the whole family spoke Welsh”. He had his early education in Welsh at “Ysgol Cymraeg” (Welsh school). At the “Ysgol Gramadeg” (Grammar School) “the language there was English [...], but the language in the yard was totally Welsh”; growing up he always spoke “Welsh with friends”. Welsh was the language of his home life and his social life until he left home and went to university. P1 also chose to speak Welsh to his children, although his wife does not speak Welsh. He commented that he still speaks Welsh to his children even though “they all speak English to one another”. He also speaks Welsh with his Welsh-speaking grandchildren, supporting one grandchild in a Welsh-speaking extra-curricular activity for 12 years. His commitment to the Welsh language suggests that he wants the Welsh language to continue to be part of his life “I wouldn’t want it to disappear”, and that it connects him to his roots and his sense of heritage. When asked what the Welsh language means to him, P1 reports “It’s where I come from”.

P3 had an entirely different experience of the Welsh language. A supported conversation, using maps, gestures, and some timelines, uncovered that he had learned the Welsh language as an adolescent and young man, developing his language proficiency through higher education and work. His partner, for whom neither Welsh nor English was a first language, reported that “P3 and me don’t speak Welsh. P3 wants to...”. P3 also chose to bring his family up as Welsh speaking and “he worries that he can’t speak Welsh with them [his children]”.

For P1, the Welsh language connects him to place – where he comes from – through family. He spoke in Welsh to CW and about Welsh in connection to his upbringing, schooling, children, and grandchildren. It is through speaking Welsh to his family both locally and in his hometown, that he connects to this element of his heritage and identity. For P3, although he wants to speak Welsh to his family, his sense of identity and how it connects to the Welsh language is not linked to his personal history and familial connections in the same way.

P2 also grew up in a Welsh-speaking community, one that was a small part of an English- language dominated town, and continues to live and be part of that community. She had all her education through Welsh, and then worked in a Welsh school. Although she used Welsh and English with friends and colleagues, Welsh is “Mwy naturiol... mae'r ymennydd yn dweud” (more natural... what the brain says). KB commented in the fieldnotes: “I felt that she was still coming to terms with the changes to her person and life that the stroke precipitated”. Welsh is the language of her whole community “It's my natural thing..dyna dwi'n gyfarwydd hefo” (it's my natural thing... that's what I'm familiar with), and so not being able to communicate in Welsh isolated her from that community. Members of the focus group also alluded to the notion of community, and of feeling isolated following stroke: “... oni'n stryglan. Dwi byw ar ben fy hunan. Oedd neb yn y tŷ, neb i siarad gyda, neb i gael sgwrs a dyna beth oni ishe” (I was struggling. I live on my own. There was no one in the house, no one to talk to, no one to have a chat with and that's what I needed).

P2 reported that Welsh means “popeth” (everything) to her. When she says “mae'n unigryw ini” (it's unique to us) she gives the sense that she is a proud member of a distinct community and that she connects a sense of her identity with being a member of this unique community. P2 goes to the Eisteddfod, “mae mynd fanne yn peth eitha mawr i fi.... so mae'n rhywbeth dwi wedi 'neud ers oni fach” (going there is a big thing for me... it's something I've done since I was little) whereas P1 stated “I'm not in National Eisteddfod. I'm not one of those people”. This difference in P1 and P2s connection to Eisteddfod indicates that P1 recognises the sense of ‘otherness’ that the Welsh-speaking community have. He also said “it must be difficult if you're not a Welshman. My wife found it difficult”.

P1 is positioned across communities – being a Welsh-speaker but acknowledging that he can get by with English in his day-to-day life. Interestingly, P1 acknowledged that “if I were living in [home town], I'd be fighting nooth and tooth and nail [sic]... for something else”, that “something else” being therapy in Welsh. He recognises the importance of being able to communicate in the language of your community, and for P2 that language is Welsh.

P3's t-shirt, noticed by CW when we arrived who then explained the significance to KB, suggested that nationalism and the political implications of Welsh were an important element of his identity. This was reinforced in moments throughout the conversation. He was an active member of Plaid Cymru, a member of the town council, and has bookshelves full of political books.

Welsh was a part of P3's family, and community life but his identity was tied up in occupation, action, and his ongoing commitment to and respect of the Welsh language. He had been unable to recruit a Welsh-speaking personal assistant to support him at home. He had found it distressing when Welsh-language materials used in therapy were outdated and culturally unacceptable: “it is important for resources to be grammatically correct and culturally sensitive” (P3's wife).

CW: So, gwleidyddiaeth.. Rili pwysig (so politics, it's really important)

P3: rili pwysig (really important)

[P3 becomes upset and clicks his fingers – to indicate ‘just gone’]

P1 and P2 were both native Welsh-speakers but didn't directly address the political realm of the Welsh language in their interviews. They both alluded to their commitment to the endurance of the Welsh language, which is an active political pursuit in Wales⁹. P1 spoke of



During the interview, P3 reached out for a picture of a Welsh flag and held it up. In her field notes KB, who couldn't follow the interview interaction as it was all carried out in Welsh, noted:

"it was clear from his language, gesture, and the pictures and images around his home that he was a very proud Welsh-speaker and that his communication disability was disrupting his sense of self and identity"

the "revival" of Welsh in the 1960s, and despite not speaking Welsh his wife worked in the ysgol meithrin (preschool) "because there was no money to keep it going" suggesting that they wanted to invest in maintaining access to Welsh-language opportunities for children. P2 had an ambition to teach adult Welsh-learners prior to her stroke "trio cael pobl i siarad mwy o Cymraeg" (try to get people to speak more Welsh), which

suggests recognition of the importance of speaking Welsh to the sustainability of the language. The focus group also noted that "mae'n bwysig siarad Cymraeg" (it's important to speak Welsh), which CW connected to a "sense of duty" in her field notes. For P3, the Welsh language connected him to a sense of his identity though politics, nationalism, and pride. The political aspect of the Welsh language, though less explicit in interviews with P1 and P2, manifest in all narratives through the participant's sense of duty to the continuation of language learning and use.

Theme 3: Emotionality

Participants expressed their emotional connection to Welsh in different ways during the interviews and focus groups. P1 was initially reticent about how important the Welsh language was to him. He was offered an interview in English or Welsh, and he stated: "it doesn't make any difference to me". He explained that his higher education and career had been through English, that his wife didn't speak Welsh, and that he tended to use English in most of his social situations. He then went to say "I speak to my children in Welsh. I wouldn't like that to disappear..." and so concluded: "yes, it's important to me then". CW asked him, in Welsh, how it would have felt if someone had spoken Welsh to him in hospital, and his response was "yn hyfryd" (wonderful). These more emotional questions referring to his children, as well as to moments of vulnerability when in hospital, enabled P1 to notice and express the strength of importance that the Welsh language plays in aspects of his life that hold significant emotional value; his family.

P2 described a sense of relief when she was able to access therapy in Welsh: "Oedd yn neis bod nhw'n ymateb iddo fe achos dyna beth ym..... dyna y peth naturiol i gael y Gymraeg" (It was nice that they were responding to it, because that's... that's what is natural, to have Welsh). KB observed that "the interviewer and interviewee were very focused on one another during the dialogue: there was clearly a strong connection". Their shared language provided a mutuality and the basis for a relationship that enabled the interview process to proceed fluidly. This was evidenced in the narrative once it was translated into English: "I feel it's something natural to me, speaking Welsh with someone"

(P2). She described the prospect of attending a Welsh-speaking aphasia group as "cartrefol" (homely), reiterating the emotional connection that being able to speak Welsh in rehabilitation groups meant to her. The focus group echoed this sentiment: "cyfle i siarad Cymraeg, gallu siarad â pobl eraill sy'n deall holl beth ar ôl strôc" (opportunity to speak Welsh, being able to talk to other people that understands everything after stroke), "mae'n neis siarad Cymraeg" (it's nice speaking Welsh"). The sense of community that speaking Welsh offers people can provide comfort, solace, and is conducive to positive relationships during rehabilitation.

P3 pointed to a sad face when asked how he felt at the rehabilitation hospital “they were nice but no one spoke Welsh” (P3’s wife). He pointed to CW’s lanyard to suggest that he knew which staff were Welsh-speaking from the lanyard they wore, and that this was very important to him. He was a long way from home during his time in the rehabilitation hospital and felt even more isolated by the lack of Welsh-speakers and Welsh-speaking services. He expressed significant distress when trying to describe how difficult he found the jubilee celebrations on the rehabilitation ward, and when asked what Welsh means to you, CW used the word “angerddol” (passionate), to which P3 nodded:

P3 currently has no access to SLT, because there is no suitable Welsh-speaking therapist available but does pay for private music therapy because it is available in Welsh. This indicates the strength of his emotional connection to the Welsh language – that he would rather pay to have music therapy in Welsh than access NHS-funded speech and language therapy in English. He also indicated that he would not be interested in attending groups that were not in Welsh. P3 wore his emotionality and expressed his commitment to Welsh throughout the interview through his gestures, facial expressions, and key words in Welsh. His strength of feeling about the Welsh-language was the driving force behind his life choices including his stroke rehabilitation, and this was a significant barrier to him being able to access appropriate services.



CW: “mae o fan hyn” (It’s here)
[CW points to her heart -
P3 follows and points to his heart]

Discussion

None of the individual participants or members of the focus group who were interviewed during this project were offered speech and language therapy in Welsh. Two of the 3 individual participants sought out speech and language therapy in Welsh, but access was hindered by the lack of availability of Welsh-speaking therapists. The participants' experiences of Welsh provide insights into the requirements of aphasia support for Welsh-speakers. The results of the analysis indicate that the provision of statutory and voluntary services in people's choice language could be mapped to people's individual needs at different points on their rehabilitation journey. Some participants wanted and needed speech and language support in Welsh immediately following their stroke, whereas others realised that they would benefit from support when they were back at home and re-engaging with their families and communities. This study provides indicative suggestions for the development of a) policy that can enhance the experiences and outcomes of this population, b) services for Welsh-speakers with aphasia from speech and language therapy, and c) support from voluntary and community services including the Stroke Association.

Welsh Government is committed to increasing the number of Welsh speakers in Wales¹² and More than Just Words⁹ is one of the policy mechanisms that they are using to achieve that goal – by ensuring that statutory services acknowledge Wales as a bilingual nation. The experiences gathered and reported in this study suggest that not only were people not made the Active Offer of services in Welsh, but there was also little evidence that there was any advocacy for Welsh language services. If Welsh language is to gain parity with English, greater awareness of the Active Offer is necessary across the health and social care workforce along with mechanisms to evaluate whether the policy is being implemented.

People who wanted to access speech and language support in Welsh had to ask for it or seek it out. Those who could have benefitted from speech and language support in Welsh were not encouraged to recognise that therapy in Welsh was important if improvement in Welsh was a desired outcome. The research evidence available about bilingualism indicates that there is no cross-linguistic transfer of therapy gain (Ansaldi et al., 2008). If people want to see an improvement in the linguistic performance in both or all the languages that they speak, then they will need to receive therapy in those languages (Kambanaros, Grohmann and Theodorou, 2010). Epidemiological data from across the UK suggests that there

could be around 4,000 people in Wales who have aphasia and who speak Welsh² (Berthier, 2005). The Welsh government have identified speech and language therapy as a priority area within their plan for providing health and social care services through the medium of Welsh⁹. However, to be able to evaluate whether therapy support is being targeted appropriately, further data is required about the number of Welsh speakers who have aphasia across the population as well as in each health board area. It is also necessary for health boards to understand whether the Active Offer is being made across the stroke pathway to be able to plan workforce and language access needs accordingly.



There is some research evidence to suggest that in bilingual nations, people defer to the majority language (Uriarte and Sperlich, 2021) which will ultimately result in the extinction of the minority language. This was at risk of occurring in Wales, until the “revival”, which P1 mentioned during his interview, in the 1990s and the subsequent governmental policy efforts to reverse this decline. Research also indicates that social commitments to minority language alone are not sufficient to ensure use or survival; individual decision-making and the raising of critical consciousness about the importance of minority

languages is crucial to their sustainability (Landry *et al.*, 2022). Participants to this study and the bilingual researcher all recognised, whether implicitly through their actions or explicitly, a sense of duty to the Welsh language to support the language to survive and thrive. The health and care workforce also need to play a significant part in realising the intentions of the current national policies through implementing actions, like the Active Offer, with targeted actions required across education, workforce and leadership to facilitate access to Welsh language services (Prys, Hodges and Roberts, 2021).

Speech and language therapy

Participants in this study had to seek out speech and language therapy services in Welsh. This is at odds with one of the core principles of Mwy Na Geiriau/ More than just Words⁹, the Active Offer / Cynnig Gweithredol, and of the professional clinical guidelines for working with bilingual clients (Pert and Bradley, 2018). This finding leads to further questions about the level of awareness about political and professional policy in speech and language therapy services in Wales, the availability of Welsh-language skills in the workforce, and of how speech and language therapy support is conceived within services.

Clinical guidelines for speech and language therapists provide structured advice about how the workforce should support bilingual clients. The guidelines provide specific recommendations concerning bilingual assessment and the use of interpretation services (Pert and Bradley, 2018). The guidelines also state that language assessments should not be translated into different languages for use with bilingual speakers. There is currently no simple way to access data that indicates how many people with aphasia need Welsh-speaking speech and language therapy support or the number of Welsh-speaking speech and language therapists that provide support to Welsh-speakers in line with national and professional guidelines.

In the present study, participants had different experiences of acquiring and using Welsh in their daily lives. This indicates that speech and language therapists, as well as making the Active Offer, should attend to how that offer is to be actioned to best meet the needs of individuals who speak Welsh. Two participants in the study spoke Welsh in their day-to-day lives, and lack of speech and language therapy in Welsh significantly hindered their ability to connect to their communities, which risks isolating people from participation in activity and in relationships with family and friends (Kohnert & Patterson, 2012). We identified specific socio-cultural needs of Welsh speaking people with aphasia in terms of how their communication

impairment in Welsh affects their sense of identity. Aphasia therapy can support people to re-establish their sense of identity (Shadden, 2005; Simmons-Mackie and Elman, 2011) so being able to offer therapy in an individual's choice language is an important aspect of this therapeutic intervention.

Language choice is also an important element of creating a relationship and therapeutic alliance between patients and healthcare providers (Caldwell-Harris, 2014; Taylor and Jones, 2014).

The results of this study support the notion that Welsh-speakers connect to a sense of emotionality – both to how they are feeling and to people or subjects that create strong emotional reactions – strengthening the call for healthcare professionals to acknowledge that language choice is an important component of rehabilitation and for them to consistently make the Active Offer as part of their therapeutic interactions.



Stroke Association

None of the individuals who were interviewed for this project were offered communication support in Welsh from voluntary or community sector services. There is evidence that long-term support for people with aphasia can improve quality of life (Mumby and Whitworth, 2012) and the Stroke Association aim to provide communication support to people following stroke⁵ which is particularly important following the cessation of statutory service input. The results of this study offer suggestions as to how the Stroke Association can bolster their support for Welsh-speaking people with aphasia and enhance the research that can inform service development in this area.

Members of the focus group reported how important the group was for them to connect with other people who had shared experience. Post-stroke support from voluntary sector organisations can be an essential component of improving relationships for stroke-survivors and reducing the risk of loneliness and isolation (Hilari et al., 2019). Providing language choice can facilitate service provision by creating affinities and establishing relationships (Irvine et al., 2006). Voluntary support in choice language can therefore be an essential component of the adjustment journey that people go on following stroke.

The barriers to accessing communication support in Welsh identified by our participants were 1) the availability of suitable groups in Welsh, b) the age appropriateness of services offered, and c) the therapeutic value of existing group offers. There is a space and opportunity for the Stroke Association to provide an essential service to people who have aphasia and who speak Welsh by providing targeted Welsh-language therapeutic group support with advice and design input from speech and language therapists with specialist knowledge of aphasia and bilingualism.

Limitations

The impact of this research study is constrained by the small number of participants that we were able to recruit. We adapted the method of analysis to add conceptual depth to our analysis of the data that we were able to collect. We also drew upon previous research and current political strategic drivers to ensure that the recommendations from this project were relevant and implementable.

Stroke Association support workers were invited to participate in the project via an email sent to the distribution list for this network by a Stroke Association staff member. We were not successful in our attempt to recruit Stroke Association employees as participants in this study. Their perspective could enhance our understanding of what services are and are not available to Welsh-speaking people who have aphasia following stroke. This data may have provided greater insight into the barriers and facilitators to accessing support in Welsh. Research is an important mechanism for understanding the strengths and gaps in support and therefore inform the improvement of services. Frontline staff provide valuable insights to research and so it is important that they are made aware of the value that their knowledge holds for organisations committed to quality improvement. Greater understanding of the barriers to workforce involvement in research could help increase recruitment to studies in future. There is a role for the

Stroke Association in raising awareness amongst their workforce of the needs of people who have aphasia and who speak Welsh. One of the mechanisms to do this may be to promote and encourage opportunities to engage with and participate in research.

There were challenges for the research team in working bilingually. The researchers carrying out the project, KB and CW, maintained an open and reflective dialogue throughout the project to ensure parity across English and Welsh was maintained in all aspects of the project: recruitment materials, communication with participants, and in our approach to data management. There is relatively little guidance on conducting qualitative research bilingually and so we chose to adapt existing qualitative methods to reflect the parity established between the research team to the collection, translation, and interpretation of the data. This has added to the integrity of the results and the strength of the recommendations.

Conclusion

This research has identified some core components of the experience of Welsh-speaking people with aphasia that require greater attention across the profession of speech and language therapy, services provided by the Stroke Association, and in policy concerned with equity across language access in Wales. The recommendations reflect developments and areas for further research that will enhance access to communication support for people who speak Welsh and acquire aphasia following stroke.

Recommendations

For policy (epidemiological data and policy adherence):

1

Data collection and access that provides insight into the prevalence of aphasia following stroke in Wales and the need for rehabilitation support in Welsh.

- ▶ What is the need for SLT in Welsh for people following stroke?
- ▶ What is the number of Welsh speakers with communication disability in each health board area?

2

Evaluation of the active offer in health and social care.

- ▶ How is the Active Offer provided across the pathway?
- ▶ What data is required to understand whether the Active Offer is being consistently made, and what services are there available to match need?

For Speech and Language Therapy (professional practice):

3

Clearer understanding across statutory and voluntary organisations about the pathways for SLT support for aphasia when Welsh is a person's choice language.

- ▶ How is SLT support for aphasia conceived and what are the implications for support offered in choice language?
- ▶ Development of Welsh language resources to support assessment and therapy.
- ▶ Greater consideration of how SLTs can meet the socio-cultural needs of Welsh-speaking people with aphasia to support quality of life outcomes.

4

Education and training about the nature of aphasia for bilingual people and how therapy needs to target choice or both languages rather than majority language.

- ▶ What is the existing therapy offer for people who are Welsh speakers and does this align with the existing evidence base?
- ▶ What is the level of awareness about evidence for bilingual therapy in the SLT workforce?
- ▶ How is this awareness informing practice?

For the Stroke Association
(research and outreach services in Wales):

5

Enhanced aphasia services that support the communication needs of mono- and bilingual people in Wales – building Welsh-language communication support offer to enhance existing aphasia services and provide community-based intervention (e.g. groups) in areas where there is a deficit.

- ▶ How can Welsh speakers with communication difficulties be better supported by the Stroke Association?
- ▶ What additional training may be beneficial for support staff and volunteers?

6

To foster a culture that supports greater engagement with research about stroke in Wales

- ▶ How can the organisation encourage its volunteers, staff and beneficiaries to consider research into the Welsh language; how research can improve practice in this area and how the use of Welsh, post-stroke, is an under-researched area.
- ▶ Research priorities within Wales should be co-produced with staff, volunteers, and members to ensure that research is answering pertinent questions, and that people are willing to get involved, with particular focus on the Welsh language.

References

- Ansaldi, A.I. *et al.* (2008) 'Language therapy and bilingual aphasia: Clinical implications of psycholinguistic and neuroimaging research', *Journal of Neurolinguistics*, 21(6), pp. 539–557. Available at: <https://doi.org/10.1016/j.jneuroling.2008.02.001>.
- Berthier, M.L. (2005) 'Poststroke aphasia : epidemiology, pathophysiology and treatment', *Drugs & Aging*, 22(2), pp. 163–182. Available at: <https://doi.org/10.2165/00002512-200522020-00006>.
- Brady, M.C. *et al.* (2012) 'Speech and language therapy for aphasia following stroke', *Cochrane Database of Systematic Reviews* [Preprint], (5). Available at: <https://doi.org/10.1002/14651858.CD000425.pub3>.
- Caldwell-Harris, C.L. (2014) 'Emotionality differences between a native and foreign language: theoretical implications', *Frontiers in Psychology*, 5. Available at: <https://www.frontiersin.org/articles/10.3389/fpsyg.2014.01055> (Accessed: 28 November 2023).
- Denzin, N.K. and Lincoln, Y.S. (eds) (2018) *The SAGE handbook of qualitative research*. Fifth edition. Los Angeles London New Delhi Singapore Washington DC Melbourne: SAGE.
- Grosjean, F. (1989) 'Neurolinguists, beware! The bilingual is not two monolinguals in one person', *Brain and Language*, 36(1), pp. 3–15. Available at: [https://doi.org/10.1016/0093-934X\(89\)90048-5](https://doi.org/10.1016/0093-934X(89)90048-5).
- Hilari, K. *et al.* (2019) 'Adjustment with aphasia after stroke: study protocol for a pilot feasibility randomised controlled trial for SUpporting wellbeing through PEer Befriending (SUPERB)', *Pilot and Feasibility Studies*, 5(1), p. 14. Available at: <https://doi.org/10.1186/s40814-019-0397-6>.
- INVOLVE (2012) *Briefing notes for researchers: public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE. Available at: https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf.
- Irvine, F.E. *et al.* (2006) 'Communicative sensitivity in the bilingual healthcare setting: a qualitative study of language awareness', *Journal of Advanced Nursing*, 53(4), pp. 422–434. Available at: <https://doi.org/10.1111/j.1365-2648.2006.03733.x>.
- Jones, R. (2019) 'Place and identity: Wales, "Welshness" and the Welsh language', *Geography*, 104(1), pp. 19–27. Available at: <https://doi.org/10.1080/00167487.2019.12094058>.
- Kampanaros, M., Grohmann, K. and Theodorou, E. (2010) 'Action and object naming in mono- and bilingual children with language impairment', in *Proceedings of the 3rd ISCA Workshop ExLing*. Athens, Greece: ISCA Archive, pp. 73–76.
- Kohnert, K. & Peterson, M. (2012) Generalization in Bilingual Aphasia Treatment, In: Gitterman, M.R., Goral, M. & Obler, L.K. (eds) *Aspects of Multilingual Aphasia*. Bristol et al: Multilingual Matters, pp. 89-105.

- Landry, R. et al. (2022) 'Minority Language Learning and Use: Can Self-Determination Counter Social Determinism?', *Journal of Language and Social Psychology*, 41(3), pp. 240–269.
Available at: <https://doi.org/10.1177/0261927X211041153>.
- Madoc-Jones, I. and Buchanan, J. (2003) 'Welsh Language, Identity and Probation Practice: The Context for Change', *Probation Journal*, 50(3), pp. 225–238. Available at: <https://doi.org/10.1177/0264550503503004>.
- Martin, C., Woods, B. and Williams, S. (2019) 'Language and Culture in the Caregiving of People with Dementia in Care Homes- What Are the Implications for Well-Being? A Scoping Review with a Welsh Perspective', *Journal of Cross-Cultural Gerontology*, 34(1), pp. 67–114. Available at: <https://doi.org/10.1007/s10823-018-9361-9>.
- Mumby, K. and Whitworth, A. (2012) 'Evaluating the effectiveness of intervention in long- term aphasia post-stroke: the experience from CHANT (Communication Hub for Aphasia in North Tyneside)', *International Journal of Language & Communication Disorders*, 47(4), pp. 398–412.
Available at: <https://doi.org/10.1111/j.1460-6984.2012.00153.x>.
- Pert, S. and Bradley, B. (2018) 'Clinical Guidelines for Speech and Language Therapists: Bilingualism: Working with bilingual clients/patients with speech, language and communication needs'. Available at: <https://research.manchester.ac.uk/en/publications/clinical-guidelines-for-speech-and-language-therapists-bilinguali> (Accessed: 28 November 2023).
- Prys, C., Hodges, R. and Roberts, G. (2021) 'Rhetoric and Reality: A Critical Review of Language Policy and Legislation Governing Official Minority Language Use in Health and Social Care in Wales', *Minorités linguistiques et société / Linguistic Minorities and Society*, (15–16), pp. 87–110. Available at: <https://doi.org/10.7202/1078478ar>.
- Shadden, B. (2005) 'Aphasia as identity theft: Theory and practice', *Aphasiology*, 19(3–5), pp. 211–223.
Available at: <https://doi.org/10.1080/02687930444000697>.
- Simmons-Mackie, N. and Elman, R. (2011) 'Negotiation of identity in group therapy for aphasia: the Aphasia Café', *International journal of language & communication disorders*, 46(3).
Available at: <https://doi.org/10.3109/13682822.2010.507616>.
- Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis: theory, method and research*. Los Angeles: SAGE.
- Taylor, E. and Jones, F. (2014) 'Lost in translation: exploring therapists' experiences of providing stroke rehabilitation across a language barrier', *Disability and Rehabilitation*, 36(25), pp. 2127–2135.
Available at: <https://doi.org/10.3109/09638288.2014.892636>.
- Uriarte, J.R. and Sperlich, S. (2021) 'A behavioural model of minority language shift: Theory and empirical evidence | PLOS ONE', *PLOS ONE*, 16(7), p. e0254625.

Acknowledgements

This project was commissioned and funded by the Stroke Association (Wales). The project plan was developed in collaboration with Professor Yvonne Wren, Dr Robert Mayr, and Dr Abdul Seckam (Cardiff Metropolitan University). The authors would like to acknowledge and thank Llinos Wyn Parry at the Stroke Association (Wales) for her support with the project. We would also like to thank our public involvement contributors and all the participants who provided their valuable insights to this research.

For more information please contact:

Angela Contestabile,
Policy and Influencing Lead for Wales,
Stroke Association:
Angela.Contestabile@stroke.org.uk

George Moore,
Public Affairs and Campaigns Officer for Wales,
Stroke Association:
George.Moore@stroke.org.uk

Rebuilding lives after stroke



Cardiff
Metropolitan
University

Prifysgol
Metropolitan
Caerdydd