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An asset-based approach for stroke survivors with aphasia and their families: promoting and sustaining wellbeing in the long-term

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Executive Summary

Background

- 150,000 people have a stroke for the first time in the UK each year; around one third of these people will have communication impairments, including aphasia.
- Aphasia is a language impairment affecting one or more language modalities: speaking, understanding, reading or writing. Aphasia affects a person's ability to communicate, their ability to participate in everyday activities and social life, and impacts on their quality of life and wellbeing.
- People with aphasia and their family members have a higher incidence of depression, anxiety and an overall poorer quality of life, than those post-stroke without aphasia, resulting in increased contacts with health services and poorer prospects of recovery and adjustment to life after stroke.
- The undeniable improvements in acute stroke care over recent years have not been matched by more effective post-hospital support for stroke survivors generally or for those living with aphasia.
- An asset-based approach, based on the theory of salutogenesis, focusing on what makes and keeps you well, has the potential to provide coherent strategies for people with aphasia and their families to live well and successfully with aphasia.

Exploration and findings

- An asset-based approach has been successfully applied across disciplines, including community development, education, business, social care and more recently health, but the approach has not yet been applied in the area of stroke or aphasia.
- We consulted a diverse range of stakeholders, including: people with aphasia; family members; clinical commissioners; speech and language therapists; and third sector organisations, who felt that this was an approach that had potential to help achieve and sustain well-being for people with aphasia and their family members. While a number of questions and reservations remain there was agreement across all stakeholder groups that this approach should be further investigated, and incorporated at all points on the stroke care pathway.
- Further information is needed on how this approach can be operationalised and optimised at all points along the stroke care pathway.

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Background

Stroke and aphasia

About 150,000 people have a stroke for the first time in the UK each year (1). The increased incidence of non-fatal strokes means that people live longer with stroke related disabilities, further increasing the disease burden (2).

Stroke is the most common cause of aphasia, a communication disorder due to a specific language impairment. Aphasia affects a person's ability to communicate, quality of life and ability to participate in activities, across contexts (3).

The personal experience, impact and resultant disability of aphasia is highly individual, resulting in an extremely heterogeneous population of stroke survivors living with aphasia.

People with aphasia report an overall poorer quality of life (4), with a higher incidence of depression and anxiety than those post-stroke without aphasia (5). People with post-stroke depression have increased contacts with health services (6), reduced motivation and engagement in rehabilitation (7) and poorer recovery (8).

Aphasia and NHS care pathways

Despite a recent research focus on how people live successfully with aphasia (9,10) and improvements in acute care, there is little evidence of improved long-term post-hospital support and outcomes for people with aphasia (11).

In addition, psychological needs have been identified as a neglected area in UK services for both people with stroke and caregivers following discharge from hospital (1,12). Recent stroke guidelines (12) also indicate the need for psychological care across acute and community services, and attention to psychological needs of all people affected by stroke. Evidence for psychological interventions for the person with stroke is promising (13,14) albeit only in the early stages post-stroke and with mixed findings (15). There are limitations in both resources and evidence for meeting psychological needs specifically for people with aphasia and their families.

Asset-based approaches to health

An asset-based approach, underpinned by the theory of salutogenesis (16), focuses on what makes and keeps a person well, rather than on the pathology or the problem. The underlying principles include creating, maintaining and sustaining health, through focusing on the person's own abilities and capacity, capitalising on the resources within themselves and those in their communities (17). Taking an asset-based approach necessitates four key steps (18):

1. Reframing thinking, goals and outcomes;
2. Mapping and describing the individual, organisational, associational, economic, cultural and physical resources available to communities;
3. Mobilising assets for a purpose; and
4. Co-producing outcomes.

An asset-based approach: a scoping review of the literature

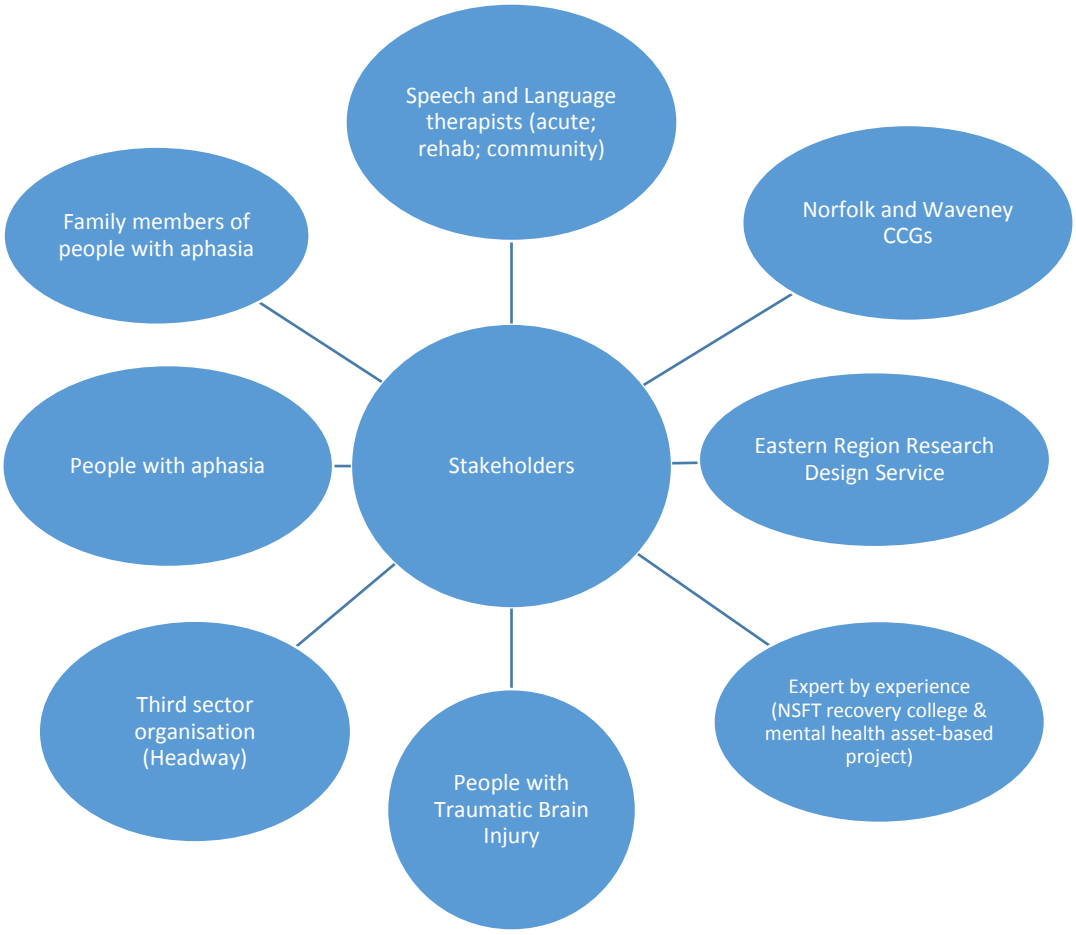
We conducted a cross-disciplinary scoping review which revealed that an asset-based approach has been applied across subject areas, including: community development; poverty alleviation; education; business; social welfare; and health, with positive outcomes. There is no evidence of an asset-based approach being applied in the area of stroke or aphasia rehabilitation.

Stakeholder and collaborator consultations

Our previous research has established it is feasible to use an asset-based approach by working with people with aphasia and their family members (19).

To investigate how an asset-based approach could be incorporated and operationalised across the stroke pathway, the research team met with a range of stakeholders (January – April 2017) (Figure 1)

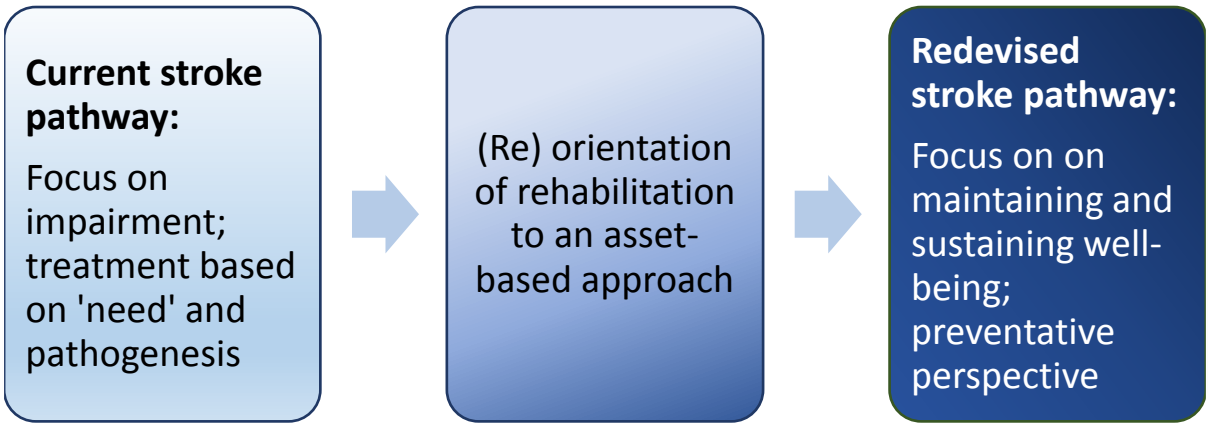
Figure 1. Stakeholder consultations



Findings:

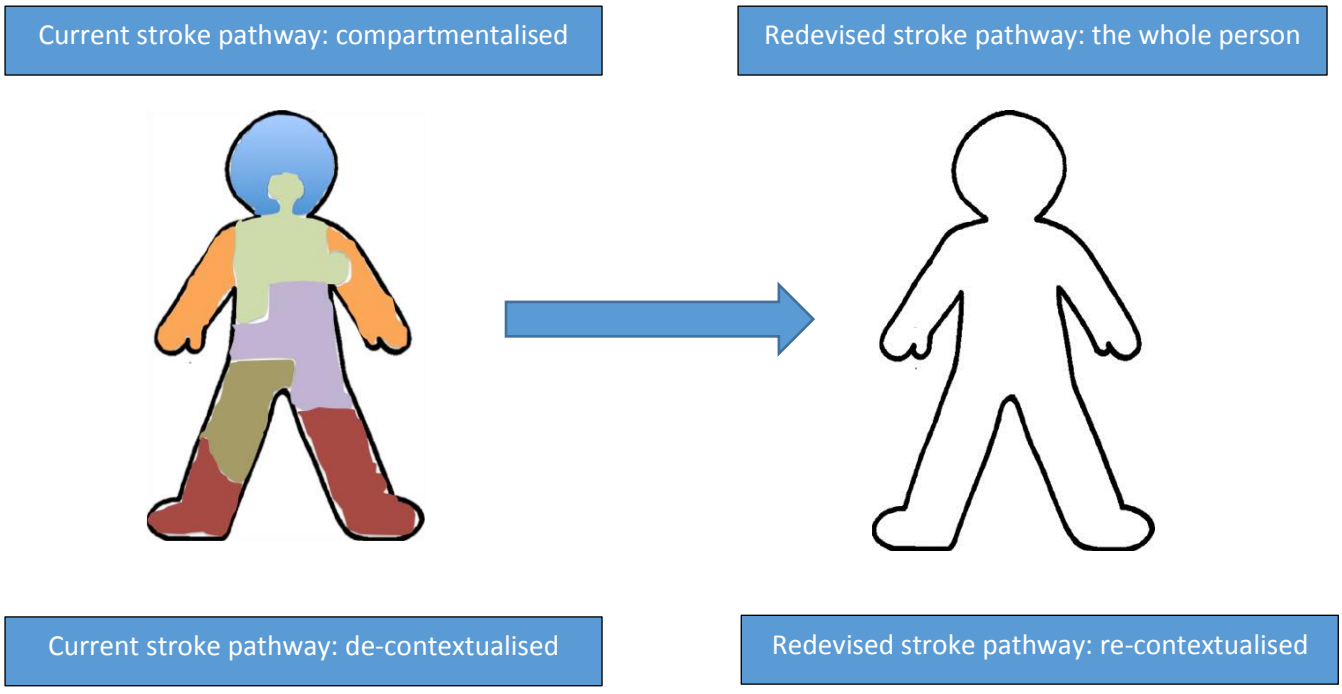
The following themes emerged from meetings across stakeholder groups.

The need for change



An holistic approach

- People with aphasia and their families wanted a greater focus on the whole person, their mental health and well-being, rather than the individual problems and components e.g. knee, arm, speech etc. They wanted rehabilitation that was more all-encompassing, and included friends and family. People with aphasia also wanted to be seen and understood within their place in the world (re-contextualised), rather than being removed from their place in the world (de-contextualised).



Acknowledging the long-term nature of aphasia

Speech and language therapists	People with aphasia and their families
It was important to be honest about the person's difficulties and the long-term nature of these, while still maintaining hope.	This approach could enhance their hope, as it portrays a more positive message to them – that you can live a successful life with aphasia.

Timing: an asset-based approach along the whole stroke care pathway and beyond

- The timing of an asset-based approach was very important. It was imperative that it was introduced early on in the acute setting to orientate people with aphasia and their family members to an asset-based mind-set and to develop an expectation of asset-based approaches throughout the stroke pathway. Early introduction of this approach may prevent people from being disabled in their rehabilitation – 'people need to be enabled, rather than additionally disabled' e.g. through using the 'language of loss'.

- This approach needs to be taken throughout the stroke pathway, with connections between services. There is a need for greater collaboration and communication across the stroke services to make the journey easier for people with aphasia and their families. In addition, the patient-caregiver relationship needs to be transformed into a collaborative partnership in order to promote health and well-being for people with aphasia and their families.

- An asset-based approach could help to guide a person's trajectory and vision of the future by: increasing the person with aphasia's motivation in rehabilitation; reducing reliance on healthcare professionals; empowering people with aphasia to take control of their own stroke journey; providing coherent strategies for people with aphasia and their families to live well and successfully with aphasia.

Barriers to implementation

- Introducing the concept, scope and exploring the potential of an asset-based approach was initially challenging;
- Some stakeholders found the terminology difficult or could not orient to asset-based practices;
- Unclear whether their current practices were already asset-based;
- Resistance to change.

Overcoming barriers

- Reframing was a vital initial step to this process;
- The process, terminology, resources (training and implementation) and outcome measures used need to be co-produced with a wide variety of stakeholders;
- Training, particularly in asset-based values would be essential. Implementation may depend on the training, experience of the therapists and how comfortable they feel communicating with people with aphasia.

Summary: key findings

- An asset-based approach has the potential to benefit people with aphasia and family members at all points along the stroke pathway.

- Stakeholders expressed difficulties with current rehabilitation stroke pathways, for example rehabilitation focused on learning what you cannot do rather than enhancing what you can. An asset-based approach could be incorporated at all points along the stroke pathway and may provide opportunities to enhance and optimise some aspects of current rehabilitation approaches.

- A wide range of stakeholders discussed how an asset-based approach should be incorporated early in the stroke pathway, with buy-in from all key stakeholders, including NHS managers and clinical commissioners. Early implementation has the potential to engender and sustain well-being in people with aphasia and family members and to forge and strengthen the connections between the NHS, third sector and community organisations.

- To ensure sustainability of an asset-based approach it should align with current service user and carer strategies, such as co-production, and links should be established with existing initiatives e.g. Recovery Colleges. It is important that links are made to community initiatives beyond health e.g. Men's Sheds, in order to broaden the scope of opportunity for people with aphasia.

- Reframing is an essential component of the process and for asset-based conversations to happen in a meaningful way.

Next steps:

- Investigate how this approach has been operationalised in the area of health and what outcome measures have been used to evaluate this.
- Explore how an asset-based approach could be incorporated into the current NHS stroke pathway, to maintain and sustain well-being of people with aphasia and their family members.
- A research bid will be submitted to conduct further research.

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