Catherine Cookson Foundation

Investigating the impact of social participation programmes for people with aphasia: The NETA Support Centre: Final report

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If you would like to know more about NETA, please visit the website at: www.neta.org.uk. NETA can also be contacted by telephone on: 0191 208 8550 or by email: aphasia@ncl.ac.uk
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Introduction
This is a report which details the independent evaluative research undertaken by staff at the Research Centre for Learning and Teaching (CfLaT) into the views of participants (and their families) of the NETA support Centre. The research has been funded by the Catherine Cookson Foundation and commissioned by NETA staff.

Context
In recent years there has been increasing recognition of the value of longer term support in enabling people with aphasia to participate fully in everyday life and society. Aphasia is an acquired communication problem, often following stroke, and means the person may have problems speaking, understanding, reading and/or writing. People frequently report loss of confidence alongside the communication difficulties. These difficulties can have profound effects on their lives, impacting upon employment, social and leisure opportunities.

The NETA Support Centre, based within premises in Newcastle University, is an innovative centre, which aims to work with people with aphasia, providing social opportunities and provision of peer support, in order to build confidence and develop participation. The Centre has an onward and outward looking focus, providing opportunities and staged challenges for people. These can range from attending a special project group (e.g. photography, art) through to volunteering roles or to becoming leaders of groups themselves. The Support Centre is funded via the charity NETA (North East Trust for Aphasia) which prides itself on having people with aphasia as trustees; the Chair of NETA, Janet Speight has aphasia. People with aphasia help to develop and lead the programme of activities the Centre runs, and many individuals continue, using the supporting and nurturing environment, to develop and become leaders in their own right. See http://www.neta.org.uk

It is always important to be able to demonstrate what value a service offers, but this is challenging in this context. The benefits can be varied and subtle: increased confidence may mean that the person becomes confident to use public transport on their own or is prepared to order for themselves at a café or restaurant. It may mean that they simply feel more confident and accepting of their own communication or they may develop skills to volunteer or lead. They may rekindle a previous interest or develop new ones. Attendance may also result in the person having the confidence and skills to access non-specialist provision or courses. The benefits are multifaceted and often not predictable. Traditional measures, for example of quality of life, are unlikely to detect all these subtle individual changes as questions may simply not target the appropriate area.
The Research Brief

The study aimed to investigate the benefits of attendance at the NETA Support Centre. This was done via focus groups of people with aphasia, facilitated by CfLaT staff, who are expert focus group facilitators, alongside the use of Visual Methods to facilitate participation (see, for example, Clark et al 2013). Techniques from the Visual Methods approach are highly appropriate with this group; the pictorial support enabled discussion and stimulation of discussion, supporting both comprehension and expression of ideas.

The following questions for participants with aphasia were designed in partnership with NETA staff and the research team:

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<tr>
<td>1.</td>
<td>What does NETA mean to you?</td>
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<td>2.</td>
<td>Thinking back to when you first came to NETA what's changed for you? How have your roles changed both within NETA and in the wider world?</td>
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<td>3.</td>
<td>What are the benefits of NETA Support Centre?</td>
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<td>4.</td>
<td>How do you influence NETA Support Centre? How far do you feel included in planning and delivering the service?</td>
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Other key factors we explored (as identified in the wider literature) included:

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<td>1.</td>
<td>Ownership – choice, user control. Being able to shape how the Support Centre operates. Accountability to users.</td>
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<td>2.</td>
<td>Journey -the transition through different roles and self-perception from “patient” to “member” to trustee or as far along that journey as suits the individual</td>
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<td>3.</td>
<td>Benefits – more concrete outcomes including impact on life outside NETA</td>
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Other themes and ideas we explored were taken from anecdotal findings and feedback sheets that had been collected previously by NETA staff, where people with aphasia had reported benefits such as:

- Communication practice/improvement
- Social life – meet old friends/make new friends
- Helping others
- Peer group from attendance at intensive therapy clinic (TAC)
- Confidence/independence/self esteem
- Rising to new challenges
- Learning new skills
- Return to old skills
- Rediscovering self and expressing identity
- Something of my own away from the family
- Fun
- A reason to leave the house
- Safety and support
- Information.
The Research Process

We were aware that we would have to be sensitive to the needs of the groups we were researching with and that we would need to be flexible in our methods. Our priority was to seek the views of people with aphasia (and their families) in a way that facilitated expression and conversation. As many researchers have reported, the use of visual images and activities tends to relax participants and encourage the involvement of those who find reading and writing uninviting (O’Brien et al, 2012) or who would prefer not to talk to a researcher about sensitive issues. We tried, therefore, to use images and photographs to stimulate discussion or provide a focus during the focus group discussions. We also provided paper and pens for those clients who wanted to write anything down, and clients were also able to use any technology devices, such as IPads, to write on or use them to ‘speak’ words on their behalf.

We conducted focus groups with a total of 21 NETA clients, across 3 separate groups. Group 1 included 9 clients (6 male and 3 female); Group 2: 8 clients (4 male and 4 female); Group 3: 4 clients (2 male and 2 female). We also conducted a focus group discussion with one group of family members/carers (13 in total) who were related to some of the NETA clients in our groups. The themes and ideas generated by Group 1 were then built into the discussion with Group 2 and then Group 3. The themes/contributions were cumulative and it was an iterative process (see figure 1 below). The focus groups took place between February and April 2015, followed by some brief analysis and then a feedback session to 8 of the NETA clients at the end of April.

In order to help facilitate discussions with the NETA clients, we used visual prompts including flashcards and laminated photographs to represent various activities. We were also very mindful of the pace of the discussion and allowed time and space for everyone to respond either verbally, through written contributions, electronic (via I-pads) or through gestures.
Focus group attendees with aphasia largely knew each other and were comfortable in supporting each other’s communication.
Key Findings

Among the clients we spoke with, their time of involvement with NETA varied, with some having contact for over 15 years and some only a few months. Regardless of the level of contact, their views of the NETA support centre were overwhelmingly positive.

Benefits

There was a consensus that attendance at the support centre was a very positive experience, and all clients reported that they had taken part in several (occasionally all!) of the programme of activities on offer. There was a view expressed that whatever the activity on offer, they would take it up.

“I’d be here to do anything, as long as I can do something”

Almost everyone spoke of the support centre providing a ‘safe’ environment where they could spend time with people “who are all in the same boat as me” where they could relax and “be yourself” – something which some said was not always easy to do at home or with their family. Time away from the family whilst at NETA was seen as a bonus. This was also regarded by the clients as equally beneficial for their family members/carers. Clients who said they had no family described the NETA support centre as their family.

Improving communication skills was widely talked about as a positive feature of NETA – both formally through the programme activities (e.g. conversation groups) but also by just meeting up and talking with other clients informally.

“They are not speech and language therapists!”

“It’s easier to do at NETA because it gives me confidence, it’s more relaxed and I’m more likely to practice”.

Other activities, such as the music group and art group, also were regarded positively. For some this has meant they have been able to ‘re-discover’ old skills, such as painting, which they had not done for decades.
For others it has opened up opportunities for trying something they had never tried before. Several clients who particularly struggled with their speech discovered they were able to sing within the choir. One client had wanted to join the music group (as he did play an instrument) but this was cancelled due to a lack of interest. He was encouraged to join the art group instead, something that was completely new to him, he told us:

“you can be as crap as you want to be, nobody will judge you”

He discovered he was good at pencil drawing.

**The NETA journey**

Everyone described themselves as being on a ‘journey’ and there was general agreement that whilst they had gone through similar experiences, everyone was at a different point on their journey with specific needs that were manifested in very different ways. Some clients described themselves as verbally articulate but “I can’t do numbers” whilst another described their symptoms as “not a memory problem, but a concentration problem”. Others described how they used to be avid readers and writers but had lost that ability after their illness.

However what was very positive was the shared experiences of those who were further on in their recovery journey with those who had a much more recent experience of aphasia. One client told us:

“It’s good coming here because nobody knows who I used to be. People here only know me and I can say what I mean”.

Other clients were aware that they had been through a progressive recovery and could serve as examples to other clients:

“10 years ago I had no speech, 3 years ago my speech returned. Time is a healer, it’s a process”
Others told us:

“I’m here as proof that you can get better and a new person coming in can see me having a good life”.

“I come here to show I’ve got better, to show people and really prove that they can get better”.

Most of the clients we spoke to told us that they were involved in other activities outside of NETA, such as the Stroke Association. However, they reported that NETA was the only place where Aphasia was the focus.

Their NETA experience also supported their lives outside of the support centre – several clients spoke of joining choirs or singing groups outside of the NETA choir, something that they said they “would not have done that without NETA”.

There was agreement that there were several ‘new challenges’ that attendance at the NETA support centre had helped them with. Activities that were commonplace previously, such as going to the shops, or answering the telephone, became very difficult or “scary”. Attendance at NETA and the opportunities for practice and in turn the building up of confidence was described positively. There was a general consensus that “your skills get better the longer you come to NETA” and one said that the skill they got from NETA was “the ability to be accepting”.

Ownership

The concepts of choice and control and the opportunities to exercise these within the NETA support centre were discussed with clients.

All the clients we spoke with said they felt they had sufficient opportunities to input or shape the way the Support Centre operates:

“you can change anything, we have choices”.

There was an awareness by some clients that the support centre and the activities were designed to encourage clients to do more for themselves, “shouldn’t we be doing more for ourselves?”.
Various clients described their levels of engagement with the existing structures and activities available, including the newsletters, booklet, Facebook page, website and committee or trustee roles. However, it was clear that those newer to the NETA support Centre were less aware and therefore less engaged with these activities.

Clients were aware that fundraising was always an issue but that it was not the sole purpose of NETA, as one told us “there are other ways to make a difference”. Awareness raising of aphasia generally was considered to be an important issue by all the clients. There was a consensus that nationally there was very high awareness of strokes (and the symptoms of a stroke), and possible physical/motor difficulties as a result of a stroke. However, there was the view that there was very low awareness and knowledge of aphasia and that they hoped something could be done about that, perhaps a large national campaign. This was a view also reflected by their relatives.

Student involvement in the NETA support centre was seen as a real benefit to both the clients and the centre – it was very much regarded as a reciprocal arrangement - “we learn and they learn”. The idea that the clients themselves were ‘useful’ to students and for NETA generally was seen as positive.

The views of relatives

In addition to gaining the views of those with aphasia, we wanted to explore the perspectives of their relatives, who in many cases, had become primary carers. We conducted a focus group with 13 relatives, comprising of spouses, partners and siblings. The focus group discussion concentrated on similar questions to those asked of those with aphasia, including the benefits that both those with aphasia, and their relatives, got from NETA. Those with aphasia had described to us the ‘journey’ of aphasia, from first diagnosis to the road to recovery and managing the condition. We decided to use this notion of a journey to prompt the discussion by the relatives and asked them to think about the changes over time that they had perceived whilst being involved with the NETA centre (see figure 2).
The role of NETA in supporting families along the journey

Relatives described ‘a new life’ of aphasia, not just for those with aphasia, but for themselves too.

“It’s a new life for both of us really, which is no better or worse than the one we had before, it’s different”

“It’s a new life for both of us really, which is no better or worse than the one we had before, it’s different”

“Your life as you knew it is gone”
They described their lives before aphasia, when their family members had responsible jobs, varied interests and activities and a defined role in the family and in society. They described comfortable and independent lifestyles that overnight had changed into lowered incomes and caring responsibilities. For one family, the onset of aphasia meant the closure of the family business, and for some, activities they had once took for granted, such as walking, or going out with friends became impossible due to the extra costs involved and the time needed for caring. Relatives told us that they find it very difficult to talk about their family members, especially talking about the past and ‘the way things used to be’. NETA had given them a forum to be able to talk to others in the same, or similar, situations who understood their lives and the challenges that having a family member with aphasia could bring.

“The most valuable thing for us is that the experience is extremely isolating and this place deals with that because everyone is in the same boat to some degree, the sociability, the mutual support, the fact that you are with people, even if it’s unspoken, who have an understanding of the situation you are in. That doesn’t happen anywhere else.”

“When you have a stroke, everything falls apart, your whole life, your work, everything just becomes more difficult, and to just have something to build up on – lots of things are pushed away, things that you are used to don’t happen anymore, your life is different at home, probably work has stopped, you don’t get out to see friends like you used to, and all that stops and its horrendous, and then you come here and you meet other people who are in the same boat or as near as you can get in the same boat, and friendships are built up and people care about each other, and care about what’s happening in their lives.”

The lack of understanding about aphasia by the wider community was something that the relatives felt needed to be addressed. While awareness of stroke symptoms was seen to have grown rapidly in recent years, relatives reported that even GPs often had little understanding of aphasia and how to support it, and the general public had rarely heard of it. This could be very isolating, and being involved with NETA was seen as extremely valuable in overcoming that sense of isolation and being able to see how others had progressed.
The lack of information and advice available to people with aphasia and their families was highlighted. Often, families had found out about things almost by accident, such as discounts for carers, but through NETA, were able to share this information informally. They were able to share ideas and coping strategies as well as ideas for how to adjust in order to take part in activities. Relatives thought that collating information about these things would be a valuable exercise and a leaflet could be made available in GP surgeries.

Relatives referred to themselves as ‘the lucky ones’ as they had been able to attend NETA and access this kind of support. Other benefits that they saw for themselves included being able to have a few hours respite from caring responsibilities, as NETA was seen as a place that they could trust and they felt that their family members with aphasia were ‘in capable hands’. The worry that relatives felt ‘it’s a 24/7 worry’ meant that they often felt unable to leave their family members with others who may not have the depth of understanding of aphasia.

There was a realisation by relatives that their family members with aphasia needed to make changes in order to develop a meaningful, but different, lifestyle. One husband commented that in the past, he and his wife had been too busy for hobbies and outside interests, but that coming to NETA had enabled his wife to have the confidence to try new things (such as flower arranging and crafting), and had stimulated her to try doing them at a more advanced level elsewhere:

“the activities she’s done here has given her outside interests as well, which has been a big benefit because it has given her more to do.”
There was general agreement that attending NETA had been vital in giving people with aphasia the confidence to try new things, and with that, to take on new roles in their lives. One husband described how his wife now ‘mentors’ others with aphasia. Another relative described how seeing someone with aphasia drive a car to the group had given his family member the inspiration to learn how to drive again and ‘that was such a massive thing for him’.

“What they [NETA] are doing, and what they have done, has stimulated the people that come here to at least have a go at something that they maybe haven’t thought about before and if they are good at it, take it on independently themselves.”

Relatives agreed that any kind of therapy available from the NHS tends to finish very quickly. Other charitable and voluntary groups exist, such as the Stroke Association and Different Strokes NE, but it was felt that these groups tended to concentrate on the physical aspects of recovery rather than the social and emotional side, involving communication. Attending NETA enabled family members to make friends who had not known them before their aphasia, and who could accept them for who they were now, and support them in improving their communication skills. This also enables people with aphasia to ‘give something back’ when supporting others, which in turn gives them more confidence and meaning in their lives.

“places like NETA enable them to become as normal as they can.”

Moving forward

“What we need is to cope with what we’ve got, and make it better, because it [aphasia] isn’t going to go away completely.”

Some activities were more popular than others and clients reported that they had been on waiting lists for particular groups, and that several were over-subscribed. The Café Out activity elicited mixed responses. Some clients said it was not for them, they struggled with the background noise or did not feel it was a ‘safe’ environment, whilst others regarded it as just a chance to meet the same people again.

Relatives appreciated being kept up to date, for example with the newsletter, but felt that they could sometimes have more information. A suggestion was made that they could know what had been discussed in the discussion groups, so that they could carry on those
conversations at home. Their family members often had poor recall or memory problems that made knowing what was going on at NETA difficult, particularly if new classes were offered, or there was a cancellation.

There was a general view expressed by clients that they felt like “we are the lucky ones” in that they had access to the NETA support Centre and that hundreds of others did not. Discussion around the size and possible scaling up of the centre prompted mixed views. There were those who thought that it could be made open to larger numbers of clients across the region, but this provoked objections that the real value of NETA and the ‘safe’ space it provides would get lost. Other suggestions included having similar sized support centres in different geographical areas, whilst acknowledging that there are genuine cost and resourcing implications.

NETA was valued highly by relatives, both for the benefits for themselves and for their family members. Relatives valued the expertise of the staff, and the positive, optimistic and easy going atmosphere. They described it as ‘a special environment’ and one that all those with aphasia should have the opportunity to be part of. Nevertheless, they realised that part of NETA’s success lay in it being local and small and responsive to users’ needs. They cautioned against NETA becoming bigger, as it may lose the ability to develop from the grassroots, but felt that groups like NETA should be available to more people in their local areas.

“it has to grow from within rather than try and be everything to all, and that’s the beauty of NETA – it has always taken account the people that come here, not just gone down a blind alley.”

NETA, and the staff who work there, was highly regarded by both people with aphasia and their relatives. The benefits were multiple and for many, it was seen as a ‘lifeline’, whichever stage in the journey they were at.
References


