Back to work:

Returning to work after stroke and aphasia

A collaborative project between Connect and CHANT

February 2010

FINAL REPORT

Contents

Executive summary

The *Back to Work* project was a collaboration between Connect – the communication disability network and CHANT (Communication Hub for Aphasia in North Tyneside), working in partnership with local authorities and social services, national and local third sector and government agencies and people living with stroke and aphasia.

Through scoping research, interviews and focus groups, we explored the barriers and facilitators influencing return to work and retention of work after stroke and aphasia. We heard about significant challenges for both people living with stroke and aphasia and service providers, besides some encouraging experiences.

We modified Connect's original *Communication Access Toolkit* in order to create an effective and practical training tool for:

- Employment and benefits advisers, to enable them to make their service documents, interactions and environments fully accessible;
- Colleagues, managers and employees of people living with stroke and aphasia, to facilitate smooth and successful return to work for teams which include a member of staff with a communication disability;
- Rehabilitation staff and third sector organisations, to ensure the specific needs of clients with communication disabilities who wish to return to work are met.

The modified training tool was piloted with 11 local authority employees in North Tyneside and received encouraging feedback. This report makes recommendations including further development of the training resource.

The Back to Work project engaged with the following groups:

People living with stroke and aphasia	5 in depth interviews 4 at focus group 6 'expert' advisors from original toolkit 2 participants in new DVD clips 3 participants in original DVD clips (Approx) 30 at CHANT launch **TOTAL: 50**
Relatives/carers	2 in depth interviews (Approx) 15 at CHANT launch **TOTAL: 17**
Local authority staff	5 at focus group 11 at pilot training (including 4 from focus group) (Approx) 6 at CHANT launch **TOTAL: 18**
Voluntary sector organisations	6 in depth interviews (Approx) 10 at CHANT launch **TOTAL: 16**

About Connect

Connect is a national charity working collaboratively with people with aphasia to provide practical, creative and lasting solutions. Connect promotes effective services, new opportunities and a better quality of life for people living with aphasia, to enable them to:

- Reconnect with life
- Have a voice in the wider community
- Have access to a wide range of services and support.

Through a range of innovation projects Connect pilots and implements effective long-term support services and develops practical publications and resources for people living with aphasia. We also develop publications and resources to enable providers to transform their services, undertaking practical research to underpin our work. Whenever possible we seize the opportunity to work with policy-makers to give people with aphasia a stronger voice.

Connect provides training and consultancy to share our knowledge, experience and expertise. In particular we work with decision-makers and front-line providers in health and social care, leisure, education, arts, public services and the voluntary sector. The work and benefits focus of our collaboration with CHANT reflects our commitment to extending the reach of our consultancy and training work to an even wider audience base.

Project background: the original *Communication Access Toolkit*

Connect developed the *Communication Access Toolkit* to address the fact that numerous, often invisible, barriers can prevent people with communication disabilities from engaging on equal terms with health, social care and other public service providers. Barriers to communication access arise from service providers' lack of knowledge about how to interact, how to make written information easy to understand, and how to create a service environment that supports rather than impedes vulnerable communication. Yet often the access requirements of people who have communication disabilities are poorly understood (Parr, Byng and Gilpin, 1997; Parr 2007; Pound et al 2008).

An advisory group of people with aphasia pooled their experiences of accessing health and social care services and identified core training issues. Following a trial, the training resource was modified and developed. The final version (Parr, Wimborne, Hewitt and Pound, 2008) is an attractive and user-friendly cascade training resource that enables the principles and practicalities of communication access to be quickly and effectively disseminated to an entire team. The *Communication Access Toolkit* has been welcomed by front-line service providers, healthcare regulators and professional bodies, and now plays a central role in Connect's training programme.

The original *Toolkit* training is composed of eight modules which trainers deliver to their trainees:

- Thinking about access
- What is communication disability?
- What is communication access?
- Making interactions accessible
- Making documents accessible
- Making environments accessible
- Communication access stories
- Action plan

Each module uses a range of materials to explore key learning points, including PowerPoint slides, DVD clips, group discussion and team activities. The original training also includes six workshops and advice sessions to enable delegates to work through the practicalities and challenges of cascade training:

- Making a business case for communication access training
- Difficult scenarios in training
- Engaging people with communication disabilities in making services accessible
- Toolkit resources
- Some practicalities
- Action plan and next steps

These were beyond the remit of the current project and were not included in the new resource, but there is potential to incorporate them at a later point if required by CHANT.

Back to Work project remit

The *Back to Work* project was a collaboration between Connect – the communication disability network and CHANT (Communication Hub for Aphasia in North Tyneside), working in partnership with local authorities and social services, national and local third sector and government agencies and people living with stroke and aphasia.

Back to Work drew on Connect's previous experience of developing and delivering resources and publications to support service improvement, in particular the *Communication Access Toolkit*. We felt there was considerable potential to modify the existing resource, in order to create an effective and practical training tool for:

- Employment and benefits advisers, to enable them to make the documents, interactions and environments in their services fully accessible;
- Colleagues, managers and employees of people with stroke and aphasia, to facilitate smooth and successful return to work for teams which include a member of staff with a communication disability;
- Rehabilitation staff and third sector organisations, to ensure the specific needs of clients with communication disabilities are met.

Our **aims** were:

- To pilot a set of resources to support:
    - People with stroke and aphasia
    - Employment advisers
    - Community and Third Sector organisations
- To maximise the possibility of successful return to work (paid or voluntary activity) for people living with stroke and aphasia.

The **outputs** we agreed to deliver were:

- A work-related training package for providers, adapted from Connect's *Communication Access Toolkit*
- A team of local champions trained and motivated to support access to work after stroke and aphasia
- A report outlining key barriers and facilitators affecting return to work
- Numbers of service providers and people living with stroke and aphasia engaged in the project
- Recommendations for development of additional resources to support return to work on a local and national scale.

The key project **activities** undertaken were:

- Scoping of key issues, barriers and facilitators through
    - Desk research relating to policy and good practice
    - 5 interviews with people with stroke and aphasia (including 2 in North Tyneside)

  - 1 focus group with people with stroke and aphasia
  - 1 focus group with local authority service providers in North Tyneside
  - 5 Interviews (including 4 in North East England) with Third Sector and government agencies supporting return to work
- CHANT team attending Communication Access Training at Connect
- Preparation of new training and resources by Connect
- Pilot delivery of one day communication access training by Connect using the new training resource
- Launch event for people living with stroke and aphasia, third sector and government agencies in North Tyneside run and facilitated jointly by CHANT and Connect
- Dissemination of learning and findings, including this final project report to CHANT from Connect
- Advise on methodology for monitoring anticipated longer term outcomes beyond the lifespan and scope of the project.

Longer term **outcomes** anticipated by Connect included:

- Identified individuals and organisations offering employment advice in North Tyneside will have increased confidence and skills in supporting people with stroke and aphasia to return to work
- Third sector organisations will have increased awareness of the needs of people with aphasia and improved confidence and skills in making their services communicatively accessible to people with stroke and aphasia

- People living with stroke and aphasia will have increased opportunities to access work and voluntary activities in North Tyneside
- People living with stroke and aphasia in North Tyneside will have increased confidence, quality of life and emotional well being resulting from engagement with meaningful life after stroke activities.

Scoping research

Before adapting the *Communication Access Toolkit*, Connect undertook scoping research to establish current practice, explore the needs and concerns of all parties (people with aphasia, work and benefits professionals, local authority and third sector agencies), and gauge the key issues which a new training resource should address. For transcripts and notes from all interviews and focus groups please see separate appendices document.

1. People with aphasia

We spoke to nine people with aphasia and two carers:

- Three had continued working for the same employers (although not in precisely the same roles)
- One had found new work since her brain injury (unfortunately she has since been made redundant due to organisation-wide cutbacks)
- One was currently on a voluntary placement
- Four were not working. One of these four had not been in any form of work since their stroke, one had an occasional voluntary role, one had done some voluntary placements but was currently unable to find more, and one had returned to her original role for several years but she and her employers had mutually agreed it was unsustainable.

Working for the same employer/in new work

- RC was a policeman who received an 'excellent salary' but needed to fulfil 30 years of service to qualify for a full pension. At the time of his stroke he had worked for 20 years. He now works in the police lost property department alongside two colleagues with acquired disabilities, cataloguing goods ranging from lost umbrellas to major drugs hauls. The work is boring but he feels grateful to have a reason to go out each day and sustain a routine. RC did not want to take early retirement when he had his stroke as he worried about stagnating and wanted to wait until his peers would also be free in the day time. Financially he would also have struggled as he had a child still at school and had not finished paying his mortgage. He sorely misses dealing with the public and the challenge and adrenaline of being on the beat in Metropolitan London, but his supervisors have said this would be impossible. RC is to retire on a full pension in three months time when he reaches his 60th birthday.
- AB has a specialised job in a major UK bank. She feels she is coping, but her confidence has declined due to lack of feedback from her supervisors. She has decided to keep detailed records of her work and how she perceives her performance, in case she needs to justify herself. She has asked for clear targets and impartial reviews of her progress, but has not received them. AB's return to work was gradual but she feels she went back too soon because she was anxious she might otherwise lose her job. She says her company makes proper

allowance for people with physical disabilities but does not have enough experience of communication disabilities. AB feels her colleagues do not understand the nature of her impairment: 'They don't see [not being able to be spontaneous with numbers any longer] as being a problem with your speech or your communication. What I've found is I went from being disabled, and most people could come to terms with the fact that I'm disabled, they can put a box around it, and then as I recovered I moved out of that definition, so people don't see you as disabled BUT you're not actually back to where you need to be to do your job, and what I've found, the bit that lies in between in terms of most people is called being stupid.' She feels protected by her special status on a return to work program at the moment but is worried that when this ends she will be in a vulnerable position. AB is 42.

- DK is a building surveyor working in the voluntary sector for the Anglican Church. He thinks his company's attitude has allowed him to keep his job; it is much more accommodating than the firm of architects he worked for until six months before his stroke. He finds his job tiring as he has to do a lot of talking. He works full time but his workload has been reduced. DK knows he will be under performance review for a year, but is he is not party to the content of these reviews. He finds it stressful dealing with clients face to face as he can tell they are surprised by his hesitant speech, although nobody has commented. He has adapted to using more written communication such as email at work when possible, which he believes supports his competence and allows him breathing space to calmly compose what he wants to say. DK is 37.

- DHC had a traumatic brain injury aged 21 and had very limited work experience prior to this. After rehabilitation she took basic skills classes at an adult education centre, then voluntary placements which led to permanent paid employment for a London borough council. She did not receive a diagnosis of aphasia until 12 years after her head injury and assumed she had 'acquired dyslexia.' She has developed many adaptive strategies including creating standard letters which she can modify, being willing to ask for more time on an ad hoc basis when required, and telephoning her sister for spelling advice before circulating written work. DHC says her colleagues are reasonable about mistakes, but she doesn't think they fully grasp the variable nature of communication disability. She is helped by the council's policy of writing all documents in an easy to read format and style. DHC also has a resilient sense of self, and a belief that her employers have no choice but to accommodate her communication disabilities in order to ensure her workload is completed effectively. She aims to approach stressful situations such as telephone calls positively, feeling this will improve the chance of a successful outcome. Unfortunately DHC was recently made redundant along with several colleagues. DHC is now in her early forties.

Voluntary placement

- BI was an administrator for a pharmaceutical company until her stroke four years ago. She is technically still employed by them and receives a blank payslip each month but says she would not go back as the hours were long and the commute stressful. BI misses the camaraderie of an office environment. She is 37 years old and bored at home. Her partner is self-employed and has greatly reduced his hours; their plans for early retirement have gone on hold. BI is about to begin a work placement and is feeling apprehensive but keen. She will be doing administrative work two mornings a week at Disability North, a role found for her by Momentum. BI and her partner said the biggest challenge they have faced is negotiating the benefits system and ensuring they receive everything they are entitled to. They have found the system baffling and at times hostile, and have a sense that service users need to know what to ask for, and how to ask for it, in order to receive it. BI's partner said: 'Ideally, once somebody has a stroke you would meet somebody once you went back home, and they would say '*This is what you're entitled to, these are the forms that you need to fill in, give us a shout we'll help you fill them in and send them away*.' Sorted, end of story.'

Not currently working

- GC was a freelance television producer for the BBC. His work involved a great deal of computer work which he cannot do now. He received a very generous retirement package and feels he was well treated, but he is frustrated and disappointed as he really loved his job. He is 51. He has had an occasional volunteering role. GC has severe aphasia.

- SA is also 51 and has severe aphasia. He used to work in library services. He has been advised by medical staff not to try to go back to work because it might permanently jeopardise his benefits. SA is financially comfortable but lives alone and feels bored and isolated.
- GJ was a freelance political consultant before her stroke. She maintained the job part-time for about 7 years, during which time she moved away from London. Eventually she and her employers decided together to terminate her contract. GJ sits on the board of trustees at Connect. She contacted a Disability Employment Adviser at JobCentrePlus on the telephone and asked for a face to face meeting but this request was refused. The DEA she spoke to on the phone dismissed the notion of GJ finding paid work. GJ found the process of seeking information tiring and frustrating. She has lost confidence and doesn't feel able to pursue things further. She is 56.
- SK was an electrician before his stroke. He did an interview skills course and CV preparation with Momentum, and several voluntary placements, the most recent of which was on a factory production line assembling cardboard boxes. SK has moderate to severe aphasia, but rates his physical disabilities as more limiting since he used to work with his hands. He feels he is continuing to make improvements although his stroke was nine years ago, but is not optimistic about

finding work in the current economic climate. He is financially comfortable but lives alone and says boredom is a problem. SK is 47.

2. *Voluntary sector*

We interviewed five voluntary sector organisations, four of which have headquarters or a base in the North East of England:

- **Shaw Trust** – 'a national charity which supports disabled and disadvantaged people to prepare for work, find jobs and live more independently'
    - Significant proportion of work done on government contracts such as New Deal for Disabled People, Work Step, Work Prep, Pathways to Work
    - Most clients are 'long-term unemployed' with health conditions such as back injuries, depression or stress
    - Nexus, YourHomes Newcastle and the Crown Prosecution Service are their most successful work placement partnerships
    - When asked about communication disabilities, Shaw Trust focused on visual and sensory impairment, but they pointed out mentors were available for job interviews to ensure adequate time and accessible information were given.

- **Remploy** – 'Government-funded providers of employment services and employment to people with disabilities and complex barriers to work'
  - Largest portion of client group is people with learning disabilities, next largest is people with mental health issues; when asked about communication disabilities focus was on visual and sensory impairment
  - Block funded, income not dependent on successful outcomes.

- **Momentum** (formerly Rehab UK) – 'a registered not-for-profit organisation which provides assessment, training and development programs that enable people with disabilities to break into the workforce or to sustain employment'
  - Open referral system
  - New intake every twelve weeks, of approximately 15 people maximum
  - Program is timetabled for 12 weeks; clients can choose which days they come in but are advised 2-3 days a week in order to get the best from the program
  - Program divided into elements A and B. Element A is 12 weeks long and teaches people the necessary skills and adjustment to brain injury (12 weeks) including cognitive memory sessions, IT and essential skills; Element B is an open ended work placement – clients can stay on Element B until they have an outcome (training, education, voluntary or paid employment)

  - Disability North is a regular source of voluntary work placements for clients with communication disabilities
  - Clients on Element B are assigned a key-worker, a tutor and a job coach
  - Momentum also offers a job retention service and brain injury awareness training for employers.

- **Bridge Project** - 'a registered charity providing education, support and guidance for over 3500 women in the North East of England'
  - Offers flexible education and training to women who may not have formal qualifications, or may have caring roles (for children or elderly), or lack confidence or specific skills
  - Some groups have members affected by stroke: Mature Friends, Chat and Craft.

- **SHARE Community** – 'the Self Help Association for Rehabilitation and Employment for people with disabilities'
  - Demographic is approximately 33% learning disabilities, 33% mental health and 33% sensory impairment, including some clients with more than one condition
  - Primarily offers training, with signposting to further education college, and voluntary organisations
  - Increasingly clients are funded by local authority on individual budget basis

- No clients where communication disability is primary disability, but documents are accessible owing to high proportion of clients with learning disabilities.

3. *Local authority*

CHANT convened a focus group of five local authority staff in North Tyneside with the following job roles:

- Local Partnership Manager, JobCentrePlus - works with external partners to support projects and initiatives which help people find work;
- Disability Employment Advisor, JobCentrePlus - assists people with any type of disabilities to obtain and retain suitable employment;
- Adults with learning disabilities programme coordinator, Adult Learning Alliance - main role is to oversee courses for all service users with learning difficulties and other disabilities;
- Senior Welfare Benefits Officer, North Tyneside Council - manages welfare benefits team, working to maximise benefits for users of adult social care, and support benefits claims for people moving back into the workplace;
- Serving Communities Delivery Team Manager (Libraries), North Tyneside Council - the Serving Communities Delivery team includes libraries, community centres, customer service centres and tourist information centres.

The group told us the main challenges for them were:

- Clients with brain injury were sometimes very emotional
- Clients often expressed frustration at not being able to access certain benefits immediately

- Ensuring they allowed sufficient time to explore peoples' concerns
- Managing families and carers taking over and ensuring they heard the voices of clients with aphasia first-hand
- Clients lacking confidence to express their needs and concerns
- Ensuring referrals from other agencies explicitly indicated when clients have communication disabilities so adequate time for completing forms can be allocated
- Managing change within their own workplace: introduction of new and replacement benefits, changes within staff teams
- Increasing shift towards a telephone rather than face to face service (telephone voice recognition systems are particularly challenging)
- Ensuring referrals from other agencies explicitly indicated when clients need a face to face visit
- Managing clients' expectations and understanding of their own abilities
- Probing for what clients don't reveal
- Simply delivering a normal service with job cuts and increased demand is a challenge – training would be a luxury
- Enormous variety of people through the door - how to manage all of their varying needs

  Perception that stroke is seen as resulting primarily in physical disabilities, which have consequently been prioritised at expense of communication disabilities
- Clients not wanting to acknowledge their improvement for fear of knock-on effect on benefits.

The group also told us:

- They felt fortunate to be able to capitalise on previous in-depth assessments undertaken by organisations such as Rehab UK who have specific expertise
- They acknowledged training could save time in long run and enable other members of the team could handle queries
- Several short training sessions would be preferable to one long session
- Recent changes in staff team structures meant now is a good time to target individuals with less experience of dealing with communication disabilities.

4. Wider research data

We reviewed recent research literature to provide additional background and context to the project. Wolfenden and Grace's 2009 review cited fatigue, emotional lability, higher levels of anxiety, depression and frustration, loss of identity, reduced self-esteem and lowered social confidence as some of the disabling barriers to re-entering the job market after stroke. They note 'the medical profession and the person who has a stroke seem to hold a different perception of the meaning or recovery', whereby the medical profession focuses on enabling functional independence, while working age people who have had a stroke feel frustrated by lack of participative programs that focus on individual needs beyond initial recovery. Wolfenden and Grace contend that of supreme importance is employers' willingness to listen to and be guided by the person who has had a stroke's own assessment of their abilities, since people may use different means to achieve an equivalent result.

Dalemans at al (2008) undertook an extensive literature review of 'participation': 'Participation is the performance of people in actual activities in social life domains through interaction with others in the context in which they live.' They found most aphasia literature focuses on linguistic aspects maximising progress and minimising impairment in early months after onset, with little public knowledge of participation of working age people with aphasia.

Lock et al's 2005 study used an inclusive focus group methodology to explore people who have had strokes own perspectives on what helps and hinders paid or voluntary work after stroke. It was conducted in partnership with Different Strokes (an organisation of younger people who have had a stroke) and emphasises the combined effect on their employment chances of having taken long-term sick leave and of returning to work as a disabled person. The individuals they spoke to perceived barriers arising from their initial rehabilitation, which they felt occurred too early and for too little time, stopping as soon minimal functioning was regained, and focusing simply on getting people back on their feet and out of acute hospital care. They also felt workplaces weren't equipped to deal with the unique nature of brain injury, where residual effects continue and recovery is not clear cut. People who returned to work said adaptations including equipment and modified hours and responsibilities had helped, but that sick leave arrangements needed to be made more flexible. They had positive experiences of voluntary work, which they reported helped restore their sense of purpose, but found the benefits system inaccessible.

In summary, returning to work is highlighted in the literature as a neglected area for younger people with stroke and aphasia, and there are currently many barriers to re-entering the job market. Since up to 25% of people who have a stroke are of working age (National Stroke Strategy 2007, 11), this is a significant concern. The National Stroke Strategy identifies return to work as a key quality marker, emphasising that work is good for physical and mental health and allows both economic benefits and valuable social relationships. It also points out that '*it may be important to offer support for employers and voluntary organisations in adapting working conditions, especially for people with physical, communication and cognitive difficulties. This may include offering guidance on how to educate co-workers about the condition and what it means in practice for the individual's role in an organisation*' (National Stroke Strategy 2007, 48).

The modified toolkit for Accessing Work training

Each of the eight training modules was meticulously adapted to meet the needs of their new target audience.

PowerPoint slides:

- New examples of interactions, documents and environments were selected and inserted
- Wording in all the slides was changed to address the new target audience
- Additional notes for trainers (in powerpoint documents) were comprehensively amended to ensure trainers were fully supported to deliver the training.

Trainees' workbook:

- The introductory section of the workbook was re-written to include project background and learning outcomes
- Key concepts and summary points of the training were comprehensively reviewed for the new audience
- The seven activity worksheets were amended where appropriate
- Three new communication access stories were written to allow delegates to explore the impact of their interactions, documents and environments on service users
- The workbook forms the basis for small group activities during the

training, and new materials were gathered for these where appropriate for the pilot training. As with the original *Communication Access Toolkit*, we recommend trainers find their own examples of accessible and inaccessible documents wherever possible.

DVD clips:

- Four new DVD clips were developed using people with aphasia and actors
- Two clips are 'talking heads', in which people with aphasia comment on concerns frequently raised by their peers and speak of their own experiences: *Beejal on returning to work* and *Basia on going to the JobCentre*
- Two clips are filmed dialogues between a person with aphasia and an actor playing the role of Disability Employment Adviser, illustrating how using communication access techniques can drastically alter the progress of an initial interview. These were based on the interview and focus group data from people with aphasia gathered during the scoping phase of the project
- The modified toolkit retains three further more generic DVD clips illustrating good and poor communication from the original training.

Template documents for trainers:

The toolkit contains ten additional word documents to help trainers run the course in their own setting. Some were adjusted slightly e.g. attendance register, while others such as the course outline and 'making a case for communication access training' were completely overhauled.

Feedback from events

Event 1: Advisors with aphasia group meeting, November 2009

Connect invited the original *Communication Access Toolkit* advisory group of 'expert' people with aphasia to attend a meeting in November 2009, and six of the eight members were able to participate. We asked them to give us feedback on:

- The three new communication access stories

The advisory group were broadly happy with the stories, which were closely based on interview data from BI and partner (appendix document pages 50 to 61), GJ (appendix document pages 75 to 80) and AB, a member of the focus group of people with aphasia (appendix document pages 81 to 87). One member of the group felt the stories sounded 'twee' on paper, but were more powerful when read aloud. Peripheral information and description has been added to all of the stories to allow an audience to relate to them, as in the original *Toolkit*. The group agreed they were comfortable with this. Connect has written consent from all participants whose data was used to create the stories.

- The four new DVD clips

The advisory team were particularly moved by the two clips in which an actor plays a Disability Employment Adviser. They found them provocative and related strongly to them. They expressed concern that trainees might deny examples of poor practice like this take place, or feel defensive. Nevertheless, the group felt it was important the clips were used in the pilot training to gauge reaction from delegates. They also approved the use of the 'talking heads' clips.

Event 2: Pilot training, December 2009

CHANT convened 11 delegates to attend a pilot training session in North Tyneside, including representatives from Welfare and Benefits, NEXUS (the Tyne and Wear transport executive), JobCentrePlus, the Adult Learning Alliance, VODA (Voluntary Organisations Development Agency), North Tyneside Council Serving Communities team – libraries and North Tyneside Council housing services. Owing to delegates' constraints on availability and time we agreed the pilot training should run from 11.30am until 4.30pm on this occasion. The trainees were a lively and engaged group, keen to debate and discuss. They provided a good deal of useful feedback:

Structure and organisation

- The training would have benefited from a slower pace. Running a full day session should ameliorate this and offer more time for group work and discussion. Trainees also suggested reducing the length of the two DVD clips of Jane and the Employment Adviser, as they 'got it' early on. Connect recommends retaining the full length clips in order to avoid jumpy editing and allow maximum flexibility, but to show parts or all of them selectively depending on audience composition and time pressures;
- Owing to its introductory tone, the DVD clip of Alan should be moved to

one of the initial modules – we have actioned this;

- Of the three modified communication access triangle modules, Interactions is longest by far and includes most of the DVD clips. Delegates felt we should preserve the number of clips but adjust time slots for each session – we have actioned this;
- More time for action planning was required. This should be remedied by a slightly longer training session – in the meantime we have adjusted the time slots slightly.

Training content

- CHANT staff were encouraged to find that senior and experienced delegates felt the training offered fresh ideas for them, and was pitched at an appropriate level for their needs;
- A disability employment adviser among the trainees said he was certain incidents such as those shown in the DVD clip were commonplace and sometimes even more severe in nature. He approved of the clip; this positive response was fed back to the advisory group of people with aphasia.

Cascading training

The delegate representing VODA expressed an interest in running the new training toolkit for her organisation. VODA convenes an annual training event each summer, focusing on a different aspect of equality and access each year for a day long session, and is keen to showcase the toolkit at their

Summer 2010 session. We agreed to stay in touch with her and discuss how best to facilitate this.

Feedback form ratings

Content - 6 very good, 4 good, 1 average;

Delivery and presentation - 5 very good, 5 good,1 average.

Event 3: CHANT Launch event, January 2010

This was a multi-faceted event designed to enable:

- People with aphasia and their relatives and carers to find out more about CHANT's work
- Local service providers to meet potential service users and hear more

about their needs and concerns

- Connect to briefly summarise the findings of the Back to Work project. We showed the audience the DVD clip *Jane and the Employment Adviser: poor communication* and one person with aphasia told us: 'It was so real I had to leave the room because it made me so angry. It was just like how I was treated when I went for my interview.'

Total attendance on the day was 70 people, and 37 returned feedback forms to the CHANT team at the end of the event; CHANT will report the feedback to their steering committee.

Key barriers & facilitators affecting return to work and retention of work

Barriers

- Insufficient feedback/targets/reviews from employers
- Colleagues lack of awareness of impact of communication disabilities, and the variability inherent in aphasia
- Returning to work before ready owing to fear of losing job
- Company policy attends to physical but not communication disabilities
- Age – the people with aphasia we interviewed who were approaching retirement age doubted the point of seeking work for their relatively short remaining working life due to risk of jeopardising benefits, or felt they would not be taken seriously by prospective agencies or employers
- Specialised skills used in previous job which are no longer possible e.g. social interaction in high stress situations (policing on the beat), fine motor skills (electrician), computer editing (television producer)
- Fear of permanently losing benefits if working is ultimately unsuccessful
- Current economic climate – even non-disabled jobseekers are struggling
- Voluntary sector organisations who enable people with disabilities (with the striking exception of Momentum) do not have in-depth understanding of the specific needs of people with communication disabilities
- Inaccessible initial attempts at finding information and consequent loss of confidence deterring further attempts.

Facilitators

- Accommodating/flexible attitude of employers, for example being willing to negotiate reduced workload, adjusting responsibilities
- Person with communication disabilities being proactive in developing own strategies and adaptations (though this is likely to be limited to people with mild impairments and accommodating work environments, so should not be seen as a substitute for formal measures being put in place by employers)
- Initial referral from voluntary sector to another organisation for placement where both parties have a good understanding of communication disabilities and share a willingness to be open about progress and challenges with the employee
- Informal meeting with manager before returning for an update on workplace developments
- A gradual increase in hours of work
- 'Treat me as me'- as far as possible, it helps if colleagues are relaxed and natural.

Recommendations

- Target pilot training delegates who expressed an interest in cascading the modified training resource through their organisation; CHANT and Connect to discuss the most appropriate means of delivering this
- Develop supplementary training modules to fully enable the cascade model
- Tweak the modified training to actively involve people with aphasia in delivery e.g. role-play, providing feedback
- CHANT to aim where possible to target people with aphasia of working age, and enable them to access appropriate information and support to facilitate return to work
- Disseminate the findings of this pilot project more widely; CHANT and Connect to discuss appropriate academic journals, conferences or other publicity and awareness-raising avenues
- Nurture links with Momentum North East – Ben Marram (occupational psychologist) has expressed a desire to continue information and knowledge sharing
- Nurture links with local authorities to capitalise on their future training needs.

Bibliography

Dalemans R et al **A description of social participation in working-age persons with aphasia: a review of the literature** *Aphasiology* 2008, 22: 10, 1071-1091

Department of Health (2007) National Stroke Strategy

Lock S, Jordan L, Bryan K & Maxim J **Work after stroke: focusing on barriers and enablers** *Disability and Society* 2005, 20: 1, 33-47

Parr, S, Hewitt, A, Wimborne,N and Pound,C (2008) *The Communication Access Toolkit.* London: Connect Press

Parr,S. (2007) **Living with severe aphasia: tracking social exclusion** *Aphasiology*, 21, 1, 98-123

Parr,S, Byng, S and Gilpin, S (1997) **Talking about Aphasia** Buckingham: Open University Press.

Pound, C. Duchan, J, Penman, T., Hewitt, A. & Parr, S. (2007) **Communication Access to Organisations: Inclusionary Practices for People with Aphasia**. *Aphasiology* , 21, 1, 23-38

Waddell,G and Burton, KA (2006) **Is work good for your health and wellbeing?** London: The Stationery Office

Wolfenden B & Grace M **Returning to work after stroke: a review** *International Journal of Rehabilitation Research* 2009 , 32, 93-97