THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by

LOUISE CATO
(Senior Speech Pathologist, State Head Injury Unit)
Chairperson RECONNECT WA
louise.cato@health.wa.gov.au

2010 Churchill Fellow

Purpose of study: To explore
COMMUNITY SUPPORT AND ADVOCACY FOR THOSE LIVING WITH
COMMUNICATION IMPAIRMENT FOLLOWING ACQUIRED BRAIN INJURY
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- In London, UK Connect and Speakability.
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- In Amsterdam, the Afasiecentrum.
- In New Jersey, the Adler Aphasia Centre.
- In Toronto, The Aphasia Institute of Toronto.
- In Vancouver, the Stroke Recovery Association, Jennifer Sweeney and the acquired brain injury team at GF Strong Rehabilitation Centre.
- In Oakland California, the Aphasia Centre of California.

To the Committee and members of Reconnect WA, I extend a big thank you for your support and assistance. I hope the information I have gathered from visiting these centres of excellence, will assist our organisation to grow and develop into a sustainable entity that will provide those living with long-term communication impairment the support and services they deserve.
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EXECUTIVE SUMMARY
Louise Cato
Chairperson Reconnect WA
Senior Speech Pathologist, State Head Injury Unit
Sir Charles Gairdner Hospital
Hospital Ave Nedlands WA 6009
Ph: +61 (8) 9346 4488 Fax: +61 (8) 9346 4489 Mob: 0400 258 381

Study Purpose: To explore communication support and advocacy for those living with communication impairment following acquired brain injury.

Communication impairment (CI) following an acquired brain injury (ABI), such as stroke or trauma, results in long-term social isolation and potential for the development of anxiety and depressive illness. Reconnect WA was formed in 2006 to provide post public health services and advocacy for those living with CI, in particular aphasia. It is an organisation still very much in its infancy hoping to develop the most appropriate service model for its members.

Although Reconnect WA is affiliated with similar Australian based self-help groups it is acknowledged that the most highly regarded and well established exist in the northern hemisphere. There are many self-help groups and centres of excellence providing support to people living with aphasia and other CIs. My aim was to visit 6 aphasia support centres as well as some associated services, in order to learn as much as possible about establishing and developing Reconnect WA. By identifying the successes and failures of these organisations I felt I would be able to develop a model appropriate to our needs. These organisations generously gave of their time, knowledge and professional expertise to assist me in that process.

All centres visited hold a similar ethos, and function from a similar platform. The belief that people living with long-term CI need regular, supported social contact to maintain and develop their communication skills and avoid social isolation, is central to the framework of all aphasia centres. Even if “treatment programs” as such are offered only by a few centres, skill maintenance and development is essential to the mission.

Conclusions and Recommendations
In general Australian health services provide longer-term outpatient therapy support for people with CI. These services do eventually cease, however, and the person living with long-term CI often faces a future of isolation and lower than normal rates of community participation. It is therefore, up to the not-for-profit organisations such as Reconnect WA to provide continued support, alleviate social isolation and maintain communication gains made in therapy. The key components in progressing Reconnect WA are:
• Establishing core values and a clear strategic plan while remaining small and sustainable
• Being able to offer a communication friendly environment such as a regular meeting place that is identified also as a centre for information and education for the wider community.
• Having well trained volunteers to provide supported communication strategies, both within a centre and home environment.
• Having a reliable, recurrent funding source to ensure service continuation, and to be able to employ at least one staff member in the initial stage.
• Establishing strong linkages with rehabilitation services and universities to ensure the continuation of best practice and support research.
LIST OF COMMONLY USED ABBREVIATIONS

ABI = acquired brain injury

TBI = traumatic brain injury

CI = communication impairment

PWA = person/people with aphasia

SP = speech pathologist. Although this is the accepted term to describe an Australian professional working with the communicatively impaired, speech therapist, speech-language therapist and speech-language pathologist are terms used elsewhere and are all interchangeable. To simplify matters I have chosen to only use “speech pathologist” in the context of this report.

SCA = Supported Communication for Aphasia

EXPLANATION OF TERMS

Acquired brain injury - any injury or neurological illness occurring post birth or early childhood. Usually used in the context of adult disorders and may be the result of traumatic brain injury, stroke, tumour or infectious process. The term does not generally refer to degenerative illnesses such as Multiple Sclerosis or Parkinson’s Disease.

Traumatic brain injury - ABI resulting from physical trauma such as blow to head resulting from an assault, a fall, or commonly a motor vehicle accident.

Aphasia - a disorder of language processing usually resulting from ABI. It has an impact on speaking, understanding, reading and writing. It has no direct impact on intellectual function.
INTRODUCTION AND BACKGROUND TO PROJECT

The impact of long-term communication impairment (CI) results in consequences well beyond the initial post injury phase. Common issues reported by those living with CI following stroke or other acquired brain injury (ABI) are social isolation, loss of role (whether work or other meaningful pursuit), helplessness and anxiety related to the inability to communicate effectively, and sometimes major depressive illness. Kauhanen et al (2000), found that 70% of aphasic patients fulfilled the DSM-III-R criteria for depression 3 months after stroke, and 62% 12 months after. The prevalence of major depression increased from 11% to 33% during the 12 month follow up period. Clearly there is the potential in this population for depression to become a chronic and entrenched condition.

A snapshot of stroke and aphasia prevalence in Australia and WA provides the following statistics (The National Stroke Foundation; Australian Aphasia Association).
- In Australia there are 8,600 new cases of aphasia each year.
- 80,000 Australians have aphasia as a result of stroke
- Of these people 60% still have aphasia after a year.
- Stroke is the most common cause of aphasia.
- Approximately 3,300 people annually are admitted to WA hospitals to manage stroke.
- An estimated 30-40% of these will experience aphasia and up to another 15% will experience motor speech disorders.
- Close to 20% of strokes occur to people under 55 years.
- Only 40% of stroke survivors with aphasia will have a full recovery within one year following their stroke (the time when outpatient services is usually suspended). This means that 60% continue to live with the impact of their deficit.

The prevalence of traumatic brain injury (TBI) in WA is 29,200 (Brain Injury Australia website). 30-40% of those experiencing TBI will have some form of discrete CI. Almost all adults sustaining severe brain injury, however, demonstrate deficits in cognition, personality and/or behaviour. These deficits have a direct impact on communication efficacy, particularly in the area of pragmatics - the rules that govern appropriate social communication. Without these rules people experience social ostracism and isolation.

Aphasia, a disorder of language (not intellect) affecting speaking, understanding, reading and writing, is the most common CI following stroke or ABI, and possibly the most difficult to manage and compensate for. People with aphasia frequently experience significant word-finding difficulties and report constant frustration at being considered unintelligent because they are unable to express themselves easily or, because they require more time to process information. Aphasia is a little known disorder in terms of public awareness.

Public Health services in Western Australia, for the most part, provide adequate inpatient rehabilitation for the communicatively impaired person post ABI. Depending upon the health catchment area you live in (whether metropolitan or rural) you may receive reasonable short to medium term speech pathology outpatient services. There is always a point where services must cease, however, and for the person living with long-term CI this is a sometimes desolate moment. Aphasia, like many chronic conditions is not a static entity, and PWA need the opportunity to have their skills maintained and even improved. Having worked in aphasia therapy for over 30 years and in community support services for 10 years, it is evident to me that people do not stop improving simply because you stop treating them. They do, however, benefit from having that improvement facilitated. PWA may go through many “relapsing and remitting” phases rather like a person with a
degenerative illness. Depending on life circumstances, general health and well-being and emotional issues, their communication ability may fluctuate, as does their ability to respond to treatment. I have seen significant changes occur in people several years after their ABI due to some shift in their “readiness” to respond to therapy. In addition to this people who for some reason – geography, severity of illness perhaps - miss out on therapy can often benefit several years down the track if greater therapeutic intensity is then applied. Once out of the system, however, it is difficult to get back in, hence the value of a continuum of care that feeds these people into support groups where they can be monitored.

In many areas of health provision it is necessary for non-government organisations to fill the gap for those requiring ongoing support, services and advocacy beyond the public health system. Stroke, diabetes, heart conditions and degenerative diseases are managed long-term by successful, not-for-profit organisations which often receive considerable financial support from health authorities and other government instrumentalities. ConnectGroups, a collaboration of support group networks in WA, reports that the average budget for a self-help groups in WA is a tiny $1,000, demonstrating that much can be achieved from little. In addition to that they engage over 1500 people per year at an average cost of $0.70. Self-help groups are indeed a cost effective means of providing support. The power of the group is well recognised in terms of support, shared experiences, empathy and lobbying effort. In addition to these benefits PWA and CI need the opportunity to practice their language skills and reduce their social isolation.

Deborah Hersh (2007) established the South Australian aphasia support group ‘Talkback’ in 1995 because she identified a lack of follow up services for her clients once active therapy had ceased. She found in her research (2003) that PWA needed and wanted more help and that speech pathologists felt conflicted about the need to discharge when a perceived plateau had been reached, and the need to ensure that their clients were well supported. Many services cease due to the pressure of turnover – there will always be more patients/clients requiring care and space must be made on the caseload for them.

In addition to service issues, community attitudes are often extremely negative regarding people with CI of any sort, resulting in discrimination and reduced community participation. Reconnect WA members report surprisingly frequent prejudices and being met with impatience when attempting to interact with their community.

“.....negative attitudes come through a lack of knowledge and skills. Faced with the unknown, people can react with fear and rejection. Lack of confidence in how to respond can lead people to avoid or ignore people with communication impairments”. (Royal College of Speech & Language Therapists, 2005)

Reconnect WA was formed in response to the need and desire for continuing support and advocacy for people living with aphasia and other CI. In the 5 years since its incorporation we have identified that people living with CI:

- Require opportunities to maintain their speech and language skills through regular contact with peers and others, well beyond the provision of hospital outpatient services.
- Would like the opportunity to enjoy activities that others enjoy, but feel unable to due to their CI. Even participating in an art or craft class can be daunting when verbal communication or comprehension is limited.
- Would like to receive support in dealing with complex communication interaction, such as speaking to a doctor, bank officer or a lawyer (or even a shop assistant).
• Would like the general public to be more aware of communication impairment, specifically aphasia, in order that prejudices around those living with aphasia and other CI can be reduced.

With these aims in mind Reconnect WA has made a start in supporting some basic conversation groups (Subiaco, Fremantle and Nedlands); publishing a book of first person accounts of recovery from ABI and CI (‘Celebrate!’); and has received a small grant to develop a community awareness education tool.

It became clear, however, that the direction of the group was somewhat stalled and we required both information and impetus to move forward. Many models of successful aphasia centres exist and it was difficult to determine which model was most appropriate to the needs of our specific environment (Perth and WA), our members, and our budget - at present very limited!. With, as yet, no ongoing funding source, we had the opportunity to learn how best to develop the organisation and its resources so it would be sustainable in the longer term.

*Reconnect WA & State Head Injury unit Women’ Group at launch of “Celebrate!” A book of stories of recovery from acquired brain injury and communication impairment.*
PARTNERS OF VISITS
It has long been recognised that people with communication deficits require an appropriate
social setting in which to develop and practices functional skills (Holland, 1982). Communication groups for PWA exist to promote the concept of Supported
Communication as pioneered by Aura Kagan (1998) and her colleagues from the Aphasia
Institute in Toronto (SCA ™). The model is based on the idea that the skill of a
conversation partner is crucial to eliciting the best communication effort from the person
with aphasia. By learning appropriate strategies to prompt, facilitate and support the
person with aphasia, the communication partner will assist them to produce optimal
communication. This is largely the approach taught to volunteers who work alongside
PWA either within more structured centre based programs or as part of home visiting
schemes.

Communication or aphasia groups may also provide training and education to
carers/families, health professionals and the wider community. Many produce resources
such as information booklets about aphasia, stroke and ABI; or specific publications to
assist the PWA to communicate with others (eg Speakability’s Medical Passport). Some
groups are agents for system wide change while others may focus on personal advocacy
for people with long-term CI and aphasia.

Ellen Bernstein-Ellis and Roberta Elman (2007) from the Aphasia Centre of California
identified the following core values as guiding principles for their organisation:

- Choice
- Shared leadership
- Age appropriate service
- Community building

It was with these principles in mind that I approached each of my visits to the identified
centres of excellence in order to observe how effectively each of them achieved their
mission and what barriers existed to impede their goals.

The following areas were focussed upon during the centre visits and during discussions
with service providers and researchers.

- Organisational structure
- Funding sources
- Programs and services, including non-verbal activities or activities not specifically
  focussing on communication.
- Advocacy – for personal or broader representation
- Volunteer training
- Professional staffing
- Membership
- Accessibility and environment
PROGRAM OF CENTRE VISITS AND MEETINGS 2011

London
• Speakability - 4th May. Lindsey Coleman, Melanie Derbyshire, Diana Moir
• UK Connect - 5th, 6th May. Helen Mann, Sally McVickers, Nicky Wimbourne, Emma Burley, Alan Hewitt

Edinburgh
• Headway - 16th May. Bill and Jean Bryden, Kim Taylor.
• Communication Forum Scotland - 16th May. Amanda Bennett

Amsterdam
• Afasiecentrum - 19th May. Marita Gerarts, Tjitske Klazinga-de Boer

New Jersey
• Adler Aphasia Centre - 9th June. Karen Tucker, Gretchen Szabo.

Toronto
• Aphasia Institute - 14th June. Rochelle Cohen-Schneider, Marisca Baldwin, Shannon Hill, Aura Kagan.

Vancouver
• Stroke Recovery Association British Columbia - 17th June. Tim Readman.
• Meeting with Jennifer Sweeney - 20th June
• *GF Strong Rehabilitation Unit - 21st June. Sacha Arsenault, Sue Barlow, Kelly Sharp, Bradley Hallam.

Oakland California
• Aphasia Centre of California - 30th June. Sue Ewing, Roberta Elman.

* As a government funded provider of general rehabilitation services I have not included a report on this organisation in this document. I attended a meeting with the ABI outreach team out of specific interest related to my employment with the State Head Injury Unit.
SUMMARY OF VISITS AND MEETINGS
My program of visits was devised to incorporate a wide range of centres of excellence across the northern hemisphere. As a consequence I was fortunate enough to select an eclectic group - small and large, newly formed and well established, big budget and small. Some were highly developed in terms of organisational structure and complexity of service delivery; others had a simpler approach. Some had been very successful and others less so. All were inspiring examples of the desire to provide ongoing support to people with CI.

The vast majority of centres visited were not-for-profits relying on funds from a variety of sources - trusts and other philanthropic organisations, bequests and donations, fundraising and grants from health authorities, universities and community services. In the wake of the global financial crisis all aphasia centres, and ABI services (apart from Afasiecentrum which is a wholly government funded service), were suffering from the fall out. The ever increasing competition for the “charity dollar” was having an impact and several centres could foresee the necessity to align themselves with larger organisations.

I have reported on each visit with some consistency but as each group was distinct in its approach I have made some individual variations. I have reported in some detail on programs that I found particularly interesting, and appeared popular and successful amongst participants, in an attempt to capture the atmosphere and structural specifics. The larger organizations which provide more expansive services are generally described at greater length.

SPEAKABILITY LONDON 4th MAY

History, Building and Offices
One of the most well established of self-help organisations in Britain, (currently celebrating its 30th year) Speakability started life as ADA - Action for Dysphasic Adults. Initially set up by a person living with aphasia, it now has 80 groups run by volunteers & students all over Britain. The central administrative office and one of the meeting rooms for the London branch are housed at 1 Royal Street Lambeth in a building owned by St Thomas’s Hospital. The organization pays a small rent here. There are 9 London branches in all.

Staffing
Despite the reach of the organization it retains only a small paid staff. There is a CEO, Melanie Derbyshire, who has many years experience in managing disability charities. Lindsey Coleman, the aphasia services coordinator is employed full-time. Apart from these 2 people there is a part-time clerical/reception person. An accountant does a yearly audit and a book-keeper comes in weekly. It is interesting to note that none of the employed staff at Speakability have a background in speech pathology.
Funding
Like most charities in UK Speakability is managed by a trust which oversees its administration & finances. The yearly budget is not fixed so the amount to be raised to cover costs must be annually reviewed. Funds are raised by events, donations, legacies (not often) and sales from information publications. There is also occasional access to Department of Health funds.

Programs and Initiatives
Apart from being the central HQ, Lambeth offers a fortnightly group (2.30-4.30) run by 2 x volunteers - Diana Moir a retired SP who is also on the board of trustees; and a student studying speech pathology. Although mostly aimed at PWA others with a variety of communication impairments are welcome to attend. Attendance is usually between 4-8 people. The group today included 3 men a one woman with an age range from 40’s to 70’s. Activities are very informal - discussion of news items, individual news of the past fortnight, and games which facilitate word retrieval. Today we played a game similar to “Pictionary” but required modelling in playdough instead. Although seemingly rather childish it provoked a lot of interest, fun, and discussion about varying degrees of skill.

Initiatives of Speakability in recent years have been:
• Medical Passport to assist PWA to discuss health issues with their doctors.
• IT project in Edinburgh which accessed assistance from IT professionals from the University of Stirling to create an aphasia friendly training program for accessing the internet and computer technology. This 3 year project trained 35-40 PWA to a level of computer competence.

Observations and Impressions
• Speakability remains a small grass roots organisation, despite having 80 branches throughout Britain. It has retained a small administrative core with only a few salaried staff and relies heavily on a team of well trained volunteers.
• Emphasis is on retaining control of its development by keeping small. The philosophy is still one of self-help and volunteering. In this way they are able to spend all donated monies to provide the services desired by members. A larger organisation, in contrast requires a sizeable management structure, many more salaried professional staff and a significant business plan.
• In the worse case scenario where funds are withdrawn or become difficult to can be run by well organised volunteers.
• Support for the regional branches is provided from London in the form of funding and education and training.
• The website has enhanced the function of the organisation providing access to publications for sale and allowing online forum/discussion which appeal particularly to the younger members.
• Publications are simple and inexpensive.

Conversation group Speakability
UK CONNECT LONDON 5th & 6th MAY

**History**
Established approximately 10 years ago by speech pathologists Sally Byng and Carol Pound with funding from trusts, including the Tavistock Trust for Aphasia, the only British trust dedicated specifically to supporting aphasia research and services. Funding continues to be provided by trusts (including the Dunhill Medical Trust), donations, fundraising events and the sale of materials and training programs.

**Building and offices**
Connect occupies 2 floors in a building owned by the Dunhill Medical Trust, for which they pay a small rent. The ground floor is orange to distinguish from 2nd floor which is lime green (colour association being a helpful to PWA who may have difficulty reading signs). The staff work in open plan offices and there are some larger group rooms and several smaller rooms. There is elevator access for wheelchairs and those with mobility issues. The ground floor has the reception area and “cafe” like area with tables and a kitchen where visitors are encouraged to make a cup of tea and relax. There are also some quieter corner areas with comfortable lounge chairs as well as a lap-top set up if people need to access it.

**Programs and Services**
Connect offers a range of services to PWA and those who work with them:
- Daily groups including peer led conversation groups.
- Befriending scheme.
- Community awareness education and initiatives.
- Training for volunteers and professionals working with PWA.
- Development of materials and resources.
- Training care staff in residential facilities.
- Research.
- Development of “Hubs” in other parts of UK. Pilot program in Cornwall has been very successful so Connect hopes to continue developing more branches.
Groups Observed
Drop-In
Drop-In, with its fantastically welcoming atmosphere, is run by volunteers (with or without aphasia), students and a speech pathologist. Up to 30 PWA may drop in over the space of 2 ½ hours on any Thursday morning. It is deliberately informal and has no specific purpose other than a social catch up. There is a pre-meeting of volunteers and any others who arrive early, in which an agenda is discussed (a large A3 size sheet is used with different bright colours breaking up segments, clear large font and some pictures). On today’s agenda I was mentioned as a speech pathologist visiting from Australia, as were some people attending for the first time. They also review the last Drop-In as a reminder of what occurred. There were around 20 people dropping in today with an age range of 20ish to 80ish and a mix of genders.

In the “cafe” style area there are about 5 tables and a quieter lounge corner with easy chairs and a coffee table. There is also a lap-top for people to access if they need to look things up during a discussion. It is important to reiterate that there is no structure to this meeting. It is not a “conversation group” per se. People talk to whomever they wish. They can ask for help with things from the volunteers, however.

What was most interesting about Drop-In was that it totally refuted the belief that PWA need quiet environments with limited distractions in order to function well. There was constant noise and chatter going on, people coming and going, the receptionist answering the phone, staff moving in and out of the nearby offices etc. It was a scene of high energy, laughter and discussion. It was of course possible for people wanting a quiet chat to step around the corner into the kitchen, sit at a table in a corner or sit in the easy chair corner. It was, however, impossible to escape the noise completely and yet everyone appeared to coping very well and enjoying themselves. I would imagine, however, that this scene would definitely not suit everyone, and if you were shy or lacked confidence, or simply weren’t keen on big groups, you might choose not to come to an environment such as this.

Music Group
Music group occurs weekly on a Friday morning. There are 1-2 volunteers without aphasia who co-facilitate with several PWA. Today there was only one volunteer, Carol, a retired school teacher whose brother has aphasia. The volunteer meets with all those attending and the co-facilitators in the cafe area on ground floor. One or 2 songs are chosen from each of the CDs brought in by members - around 8-10 songs. The purpose of this is to then have participants vote by a show of hands which songs they like - they may vote for
as many songs as they choose. From this score the top 4 songs and the bottom one are played. The chosen songs are written on post-it notes and stuck to each CD. Once this part is completed attendees go up to the group room where there is a CD player and large butcher’s paper pads. Today there were 3 x tables of about 4-5 people. Each table had one co-facilitator (a PWA) who was responsible for writing down the scores and recording each participant’s opinion of a song. On each table were aphasia friendly prompting materials - an A3 easy-read analog scale from 0-10 with pictorial prompt (sad face/happy face), A3 size sheets with lists of words which could describe the music or emotions evoked by the music. These were broken into alike categories eg. love related words such as, romantic, passionate, frisky, sexy, idyllic, sensual, tender, dreamy etc. There was also a sheet with 15-20 facial expressions defining these emotions for those with little reading ability. Another sheet acted to prompt discussion with points such as: memories, composer, musician, culture. Another had pictures of instruments.

Each song is listened to and each person gives their score on the scale and chooses some words to describe how they responded to it. Scores are written down and averaged out by the co-facilitator. These averaged scores are then written on the butchers paper for all to see how each table responded. The words that each table choose is also written and this provokes much discussion. Once all songs have been listened to the most popular song is identified.

During the “listening” participants are encouraged to look through piles of post cards to look for cultural links eg. a post card of Capri was found while Pavarotti sang. There were also books from the “scrapbooks” series (focus on different eras) in which an artist from, for example, the 60s might be found to match a song.

A new member with a rehab support worker was in attendance and looked a bit overwhelmed by the activity. He contributed to the scoring, but clearly had very limited speech. There were varying degrees of interest and participation but overall people seemed to enjoy the activity and I got the impression that all had a real interest in music. Once again attendance on any given day is variable. Although there were about 10 today there may sometimes be as many as 20. Age ranged from 40 - 80ish but interestingly today’s group were all men except for Jane a long-standing member and music-lover.

**Other Groups** run by Connect include a photography club, an art group, a gardening group (members go to local allotment/community garden) and a women’s group.

**Training and Education**

UK Connect trains both volunteers and health professionals and attached to each training program is a kit. Examples of training programs:

- **Communication Access training** - 2 day training program for anyone who may have contact with PWA - eg doctors, allied health, professional carers. It is hoped that this knowledge is then spread further (train the trainer concept). Part of this program includes a discussion with a PWA who provides feedback to the participant re their ability to be a supportive communication partner.
- **Running a Conversation Partner Scheme** - for professionals wanting to establish schemes for volunteers.
- **Making Communication Access a Reality** - raising awareness in organisations about communication access issues.
- **Develop your Communication Skills and Make a Difference** - one day workshop for anyone working with PWA offering practical ideas for facilitating communication.
• UK Connect also trains PWA to go out into community as ambassadors and communication partners. This often appeals to people who prefer not to go to groups but want to contribute.
• How to Run Peer-led conversation groups.
• Befriending workshop - for PWA.

Projects, Programs and Initiatives
Connect has had a series of community initiatives funded. For example they have produced a variety of documents including ‘Access to the Arts’, ‘Including PWA in Research’, ‘Volunteering and Aphasia’. I was told the first has not been particularly successful as arts providers find it too difficult to accommodate PWA fully within their budgets. For example adapting forms or labelling art items in exhibitions differently requires extra work, time and money. The Tate Modern is one exception and Connect has collaborated with them on one or 2 projects.

Staffing
There are approximately 24 paid FTE staff. This appears to be a very large infrastructure for small organisation. Staffing is split between services and consultation and training. Sally McVickers, a SP and researcher is Director of Services. There is also a CEO who oversees the entire organisation and its day-to-day operation. Only some staff have SP backgrounds and others have quite varied professional experience, often in commercial or marketing fields, which is particularly useful.

Funding
Initial funding was provided by a lotteries fund and various trusts continue to provide funding - Dunhill Medical Trust (in which Connect’s offices sit) is the largest current contributor. Applying for grants, writing letters requesting support, and developing fundraising ideas is a full-time job.

Martyn Holland is the fundraising manager whose job it is to court potential trust donors. Large trusts in UK may be set up with a specific purpose but will then offer grants to smaller charities. Although Connect’s budget is 1 million pounds annually, it needs to keep a sharp eye on keeping the funds flowing through not only old sources but also new ones. The global financial crisis has had a huge impact on the charitable sector in Britain as well as government health instrumentalities. Connect also receives Department of Health funding for specific projects. Some services are “commissioned” (paid for by government funds or specific grant), others rely on charitable efforts and fundraising. For example Cornwall, Wandsworth and Gloucester are commissioned services but London is not.

Connect to date has not charged subscription fees for membership, the philosophy being that all services should be free to anyone in need. They have a data base member list of 8,000 SPs and about 2000 PWA, so they are now considering charging a membership fee.

Volunteers
All volunteers who come to Connect do a compulsory day of training. Most volunteers (who are not PWA) are SP students, retired teachers or health professionals. It is not hard to attract volunteers due to the economic climate and the fact that there are far more graduate SPs than there are jobs at present. Connect takes about 10 calls per day requesting volunteer opportunities. Following the training day volunteers may go on to do other training which addresses such issues as befriending, how to facilitate conversation with a PWA, or how to run a group for PWA.
**Befriending Scheme**
This service aims to provide short-term support for PWA as they leave hospital and settle back into home and life. Volunteers with aphasia are provided with training and supervision in order to provide one-to-one support to others with stroke and aphasia in hospital and at home.

**Referrals and Membership**
As mentioned there are no subs so membership is free. Referrals can come from any source and SPs are the main referrers. Information is made freely available to clinics in both public and private health systems.

**Research and Evaluation**
All members who participate in any of Connect’s programs are administered a communication survey. This provides a baseline for future reassessment or research.

**Observations and Impressions**
Although a very impressive organisation (especially given only 10 years since establishment), this is probably not a viable model for Reconnect to consider initially. With a million pound annual budget it has a huge job to maintain the income and the services. The open and friendly atmosphere created by Drop-In was extremely positive and welcoming. People of all ages mixed freely and there was an energy that was quite palpable in the groups I observed. There was a very strong sense that this was ‘their place’ and with that came a confidence that even those with greatly impaired communication demonstrated.

**HEADWAY EDINBURGH 16th MAY**

Although not a dedicated aphasia centre, Headway employs SPs and supports programs assisting PWA and other CI. It is a very well established organisation which has sustained and developed services over many years.

**History, Buildings and Offices**
Edinburgh is the head office of Headway Scotland which is affiliated with Headway UK. The organisation was established by Bill and Jean Bryden nearly 30 years ago following their son’s ABI. It developed from a monthly meeting of families and interested professionals to the significant not-for-profit organisation it is today. The Bryden’s were supported by a leading neurosurgeon, Professor Douglas Miller. Headway is located on site of Astley-Ainslie Hospital, one of the main rehab hospitals in Scotland which houses an ABI unit. Headway managed to secure rent free accommodation in what was the dining room of the hospital. They initially had one room (now the offices) but over time they were able to access adjoining rooms including a very large group room, a facilities room (for art group etc) and a well equipped and roomy gym.
Staff
Approximately 6 paid staff and many volunteers. I was shown around by a member who had an ABI (MVA) in 1983, and now spends each day volunteering at Headway. There is a full-time coordinator for the Befriending Program who trains volunteers. The services manager plans, timetables and runs various groups. Bill represents the organisation on various national government and other boards advocating for changes to the system and services for people with ABI.

Funding
Part funded by government grants as well as privately raised funds, Headway runs as a charitable organisation. One significant event is a concert which raises tens of thousands of pounds on a single evening. Another is a series of marathons run by a man whose mother died of a brain tumour. Members do not pay any subs but if they attend a group they pay a pound per day for tea, coffee and biscuits.

Groups and services
Groups run from Monday to Thursday and offer a range of activities. I witnessed a “Reminiscence” group running involving a range of people with varying degrees of ABI severity and issues, including CI. This was held in the large group room. Participants sat around a large table, but there were also a couple of comfortable easy chair nooks for smaller conversations to take place.

Befriending Scheme
The Befriending Scheme aims to provide people with newly acquired brain injuries with a companion who will assist them with socialisation skills to build confidence. This is funded by the Edinburgh City Council, and although it must be re-funded annually it has been running for about 15 years. The volunteers are recruited via a central recruitment bureau (similar to Volunteering WA), and they are rarely short of them. Volunteers are offered 12 hours of training 3 hours weekly. This allows the volunteer to test out their time commitment - if they cannot find 3 hours weekly to attend the course they are unlikely to be able to offer an adequate amount of time to support the ABI person.

Following the course the coordinator/trainer follows the path of each volunteer as they provide support to the person with ABI. The aim of the program is not to provide permanent or long-term support for the person with an ABI, but to act as an active training period to improve socialisation, community access and independence. Once this is achieved the volunteer will pull out. It may be necessary, however, for the person with an ABI to have further permanent support by a professional carer. Some volunteers will develop friendships with the person they are supporting and then introduce them to other friends and family. This is not discouraged but during the training phase it is made clear that volunteers should not involve family and friends in their “work”.

Observations and Impressions
A well run small organisation with considerable commitment demonstrated by both volunteers and paid staff. It has evolved slowly but very successfully over the past 30 years due to the astuteness and dedication of key supporters. Representation on government boards to press their case has clearly been successful. This is not, however, a large or powerful organisation, but one in which personal service is highly regarded. This is a model that Reconnect WA would do well to emulate.
Although not a centre based service provider like Speakability, UK Connect or Headway, CFS attracted my attention due its system wide approach to changing community attitudes and ensuring service provision for people living with CI. An important part of Reconnect WA’s mission is to educate the community about CI and the access issues people face when living with a CI.

CFS is more an alliance of organisations representing people of all ages with CI, rather than a single entity. Under the assumption that ALL communities include people experiencing CI, its aims are:

- To promote awareness of CI and the diversity of need.
- To support and encourage participation of people with CI in all community enterprises.

The organisations which formed this alliance included Speakability Scotland, College of Speech Language Therapists, Different Strokes and the Chest Heart and Stroke Scotland.

Amanda Bennett is the coordinator of the Civic Participation Network, which was funded in 2007 by the Scottish Government’s Equality Unit. Its purpose was to remove barriers to community participation for those with CI. Specific aims reflect those of aphasia centres and services world wide:

1. To increase the involvement of people with CI in consultation, decision making and service development.
2. To promote inclusion within service provider organisations.
3. To train communities to understand CI in order to increase awareness and understanding, as well as improve service provision.
4. To share and disseminate ideas and practices.

To this end the Talk for Scotland Toolkit was devised and made available to any interested community service or organisation. The tool arose from a project to raise awareness in 3 different organisations whose role it was to remove discriminatory barriers within specific sectors - Engender (women’s issues), Momentum (disability support) and Age Concern Scotland (aged care). It was Amanda’s role, for example to work with Engender to train 5 aphasic women in issues relating to empowerment and raising awareness of communication barriers.
CFS is closely linked with the Independent Living Movement in Scotland which addresses access and inclusion issues. This is a Scottish Government initiative to which CFS contributes and advises regarding communication access issues.

Observations and Impressions
As a time-limited government funded initiative CFS runs the risk of losing support if a change of government occurs. Funding is not recurrent as yet, so it must be fought for and justified annually. I was extremely impressed with the purpose and mission of CFS as a mechanism for creating system wide change. I would be very keen to see Reconnect WA and its national affiliates work towards a similar end.

AFASIECENTRUM AMSTERDAM 19th MAY
Structure, Staffing and Funding
One of 2 groups based in Amsterdam but part of a larger organisation covering The Netherlands. Head office is based in Arnhem and that particular centre provides support to the others. This is a totally government supported organisation which provides both outpatient style services as well as social conversation groups offering longer-term support. In the 2 Amsterdam centres there are 10 SP employed. The group I visited is based in central Amsterdam near the Fredericksplein. The reason for a specific “aphasia centre” (although they do also provide support for other communication and swallowing problems) is due to the fact that ongoing longer-term therapy can only be accessed from rehabilitation centres if 2 x therapies are required eg. physiotherapy and speech pathology. Once other issues resolve or are deemed to be no longer remediable, PWA or other communication problems will not be able to continue attending. As PWA continue to improve over a long period of time and may in fact not be initially amenable to therapy, the role of the Afasiecentrum is very significant.
Convocation and skills groups Afasiecentrum

Groups and services
Afasiecentrum appears to operate in a similar manner to a community support service (such as WA’s State Head injury Unit or Rehab in the Home) offering therapy (group and individual), home visits, and review services. Conversation groups are run at this centre on Tuesdays and Thursdays. Computer groups and one-to-one computer support are also offered. A group providing support and practice for proficient English speakers is offered 1 x weekly (usually people who require good English ability for work etc). Up to 35 people attend groups weekly and the larger groups are usually broken into 2 - those requiring more or less communication support. Volunteers are used to assist with groups only and are not used for home visiting support.

I attended a group with 4 PWA – some spoke English and were interested in engaging in conversation about Australia. Others relied on the volunteers and therapists for translation. They were very interested in how similar groups ran, attitudes to and of PWA in Australia, as well as hospital and rehab services. A woman of 38 years asked about the attitudes of younger people with stroke/aphasia, as she had encountered varying attitudes herself. She was clearly a very positive pro-active person who sought services and wished to keep perfecting her skills. She spoke about a friend who had aphasia whose attitude was the complete opposite. This she found upsetting and challenging. I related the experience of a young woman in Perth who had attempted but failed to successfully establish a young stroke survivor’s group in Perth, which resonated with her experience.

The group was delighted to be offered the “Celebrate” book. They were establishing a library of personal accounts so this was well received.

Observations and Impressions
This is a good model for Reconnect WA despite being a purely government funded service. It is small and offers both centre based and in home support for PWA. Although it employs only SPs, it is feasible that volunteers trained and supervised by SPs could offer the same service.
Buildings and Access
On entering the town of Maywood you are met with a banner stretched across the one of the main proclaiming that “Aphasia - loss of speech NOT the intellect”. Turning the corner and before arriving at the Adler Centre you encounter yet another banner! It is, indeed, very impressive that such a little known condition be promoted in this way. The banners are not a permanent fixture, however. June is aphasia awareness month in USA and the local council supports the campaign.

Set in a large one level building in Maywood NJ donated by its founders Mike & Elaine Adler, the centre offers services to about 100 PWA per week (40-50 per day). It is mostly open plan and has a large dining room (where people first gather when they arrive at 10-10.30am). This then leads into a very large room (equivalent space to ~ 12 rooms) which has an area set to one side for open plan offices (for staff), a meeting room that is also semi-open (partitioned with glass only but allows for some privacy), a jewellery making area (a recent enterprise), a computer area for members to work on their own or with volunteers, and a few other tables where members may play cards or engage in other activities.

More rooms spill off this entry room, including another very large room which is used for training purposes and groups including Adler’s Court. Beyond this there are smaller rooms where the research staff are housed and there is a testing room.

The Centre provides services to the immediate area of New Jersey but also allows people from other areas to attend if they are able to get there. There are a number of local supported transport organisations and it is up to the member, with some assistance from centre, to organise this. One man travels 30 miles to and from the centre several times per week. The longer the distance, however, the less likely the member is to sustain the program over time.
**Model and Philosophy**
The Adler’s model is a social enablement and independence one. Most programs are designed to enhance member’s lives, allow them opportunities to improve their communication and increase their confidence in their communication efforts. Many of the programs are non-verbal, which allows members to focus on other aspects of their lives and other skill development - eg. art, jewellery making, exercise class. These activities can involve communication development of course.

**Staffing**
There is approximately 5 full and 10 part-time staff at the Adler Centre, including SLPs, 2 x program coordinators and 2 x researchers and a volunteer training person. Karen Tucker is the CEO with a background in gerontology and medical administration. Audrey Holland is the Director of Research, but is based at the University of Arizona in Tucson.

**Membership, Orientation and Induction**
Before a member commences a program they must undergo an Aphasia Education Week comprising of approximately 4 sessions. This involves family and covers such issues as what is aphasia, facilitation techniques, what to expect of the program etc. These occur at 3 separate intake points through the year. Members may undergo the pre-program assessment during that week or it may occur in the following 6 weeks. Often a cohort of members who enter the program together will make connections and remain friends.

**Programs**
Members choose their own programs based on interest. Some may select programs aimed mostly at developing verbal skills, such as conversation, current affairs discussion, or Adler’s Court. Others may choose more non-verbal pursuits such as art and others may select a mixed program. Programs run from Monday to Thursday from 10.30am to 2.15pm. They offer a broad range of different activities on different days – cooking, cards, newspaper discussion and current affairs, art, book club, computer skills and language programs, jewellery making and Adler’s Court, a mock trial exercise. In addition to this the members put on a concert each summer and a great deal effort is put into painting scenery and rehearsing a musical that has been modified. Groups have come and gone over the years and some programs have not been so successful; a gardening group for example failed. Members may choose to come only one day or as many as they are interested in or can afford. Cost is from $4-25 per day and assistance may be provided if someone is unable to pay.
The jewellery making enterprise started because a member was interested in developing it and had the skill. This has now grown into an income producing strand of Adler which created $20,000 last year. The organisation has now gone online with the sales.

Adler’s Court is quite a challenging exercise for both PWA and the SPs who have to put in a significant effort to adapt the scenarios. These are taken from real life court cases and the story lines simplified. A script-like crib sheet is provided to each person who is given a role in the trial. They have a week to prepare and can do their own research as well if they are able. Obviously there are roles that require more verbal skill than others. The prosecuting attorney and the defense attorney must be able to argue well, whereas the jury members may simply have to listen, ask occasional questions, and then vote. In this way most people can take part. In discussion with a woman who had taken the part of a druggist who had supplied a drug (legally) to the plaintiff, she revealed that most of the info she had provided when being questioned she had done “off the cuff”; although she had studied the info well during the week. She also had minimal aphasic symptoms.
During the proceedings of the court the 2 SPs assisted and shaped any “inappropriate” behaviour. The prosecuting attorney, for example was very involved with her role and argued vehemently but not always fairly. During the defence attorney’s summing up and the judge’s comments to the jury she interjected regularly and had to be “contained” by the facilitators. Simple notes were written on a butcher’s paper easel, and pictograms were added to assist understanding. At the end this was referred to if people requested a review of material.

In discussion with the 2 SPs it became clear that the mock trials were very time consuming to prepare. The idea grew out of having limited staff and too many members, and was a solution to deal with the staff to member ratio. It is clearly a very successful program, but does require a huge staff commitment. The event was hugely entertaining and also inspirational to observe such high level discussions being undertaken by people with language impairment.

Computer Classes
These focus on both normal access to a computer, such as emailing and internet use; as well as training in specific speech and language programs such as Parrot and Bungalow. An iPad training program is under consideration.

Research and Therapy
All members are assessed with a battery of tests before entering the programs - these are generally more qualitative assessments such as Communication Activities of Daily Living (CADL) and Assessment for Living with Aphasia (ALA). In the past 3 years this has been streamlined and members are screened within 6 weeks of commencement on the Western Aphasia Battery (WAB), CADL, Rehabilitation Institute of Chicago’s (RIC) Confidence Scale and the ALA. Assessments are usually done in 2 x one hour sessions, but more time may be allowed if required.

Recently the Adler Centre has begun to offer individual therapy to members at a reduced cost of $50 per 50 minute session. This is due to both member demand (not everyone receives an adequate amount of hospital based outpatient treatment I the USA), and to facilitate the Centre’s research. Members are required to do regular daily home practice. There is about 60% compliance with this. As a pool of PWA (100 members) the Centre has also developed strong affiliations with other research organisations, such as the RIC.
Volunteer Program
The centre has approximately 60 volunteers who are all centre based. They undergo a 3 module training program. They recruit through volunteer organisations and word of mouth. They assist with a variety of programs and often work independently (e.g., card group, computer programs).

Education and Training
The Adler provides training of both an informal (lunch-and-learn style talks) and a formal nature (on-site training programs at the centre). Supported communication skills are taught to families, allied health professionals and volunteers in various community contexts. Current training programs include an introduction to aphasia for residents and interns at 2 local hospitals.

Funding
Mike and Elaine Adler set up the organisation after Mike suffered a stroke about a decade ago. Realising how little is known about aphasia and the limited ongoing services available to those experiencing it, they sought to redress this by developing a centre that was both aphasia-friendly and capable of offering support to PWA and their families. The couple donated a significant seeding amount to set up the foundation and engaged Audrey Holland to establish the ethos by which it would run. Today the organisation operates on some government funding, specific grants, donations and fundraising.

Observations and Impressions
A large well run organisation with close involvement of a significant benefactor which allows it to continue flourishing in quite difficult times for charitable groups. The centre itself is welcoming and champions the concept of a need for a “place”, a base or a centre where people can feel comfortable coming along. I think this is very important to consider along with location and whether one centre suffices or several smaller ones are preferred. Particularly impressive were Adler’s Court and the jewellery making enterprise, which provides not only meaningful craft activity but an income for the centre.

APHASIA INSTITUTE OF TORONTO 14TH JUNE

This centre, established by Pat Arato in 1979 was the first independent, community-based Aphasia Centre. It was set up in response to a perceived paucity of ongoing services for Arato’s husband whose stroke had left him with aphasia at quite a young age. Starting off as a small volunteer led group, the Aphasia Institute now serves as a local, provincial, national, and international resource. It is managed by a board. As the forerunner for all such centres it was on the top of my list of service models.

Buildings and Access
The Aphasia Institute (AI) rents the ground floor of a building in a suburban area about 30 minutes drive from the centre of Toronto. It is the only centre of its kind in Toronto, but
York-Durham Aphasia Centre is a rural counterpart. It has good access for those in wheel chairs and its interior is open and spacious with a generous waiting area. Again, an open plan design is employed with program participants sitting around tables of 4 or 5. There are some individual rooms including a large meeting room which accommodates training and music therapy sessions. Staff offices are mostly open plan. The AI website describes the centre as “communicatively accessible”.

**Model and Philosophy**
Similar to UK connect and Adler, the AI has a social enablement and enhancement philosophy. There is a strong emphasis on both, maintaining and developing holistic communication skills as well as offering non-verbal activities. It promotes the Life Participation Approach, emphasising re-engagement in society. The centre itself has a friendly, positive life-affirming atmosphere where members are encouraged to participate in a range of activities. To this end it is currently involved in a Canada wide project, Getting on with the Rest of your Life after Stroke, funded by the Canadian Stroke Network. Research is a significant component of the AI’s work under the directorship of Aura Kagan. Members’ communicative abilities are assessed prior to commencement of programs.

**Services**
There are currently around 150 active members receiving services. The centre offers 3 distinct services:
- Direct member services at the centre
- Outreach programs - Home Visit Program and a Partnership Agency Training Program.
- Training and Resources - for members, family/carers and professionals working in the field.
**Centre Based Services**
Services to members are delivered through the Pat Arato Centre in blocks of 2 semesters - January to June and July to December. There is a registration process and all services incur fees. There is, however, a bursary system for those unable to afford this. A compulsory 12 week introductory program for members and families provides important psycho-social orientation to living with aphasia. This is run by a speech pathologist and a social worker. Following completion of this program, members can pay a semester fee of $294 to participate in any of the programs which are offered 5 days per week. Thursday is a, however, a closed program for the introductory course.

Members attending the centre could hope to attend any of the following:
- Conversation groups
- Music therapy
- Book groups
- Creative writing
- Art classes – painting, creative expressions
- Exercise & wellness classes
- Toastmasters International Aphasia Gavel Club

New members are welcomed and supported via the Peer Helper Program, similar to the British Befriending Schemes. People with aphasia work in partnership with staff and volunteers to provide support to people new to living with the condition.

I participated in a drumming session run by a music therapist. There were 12 participants using drums of various sorts and a range of other percussion instruments, many one handed. Each person takes a turn at leading the group. The group was very cohesive and clearly enjoyed the opportunity to express themselves without words. Those who were more verbally able were, however, quite chatty between songs making jokes and discussing the rhythms. Under the leadership of the music therapist (who works one day per week at the centre) the group has explored and researched different drumming cultures to enhance their experience of the music. Several of the members had been participating in the drumming workshops for many years, and saw it as a highlight of their centre attendance.

**Outreach Services**
The Home Visit Program offers a 10 week program for those unable to attend the centre. Trained volunteers visit the home to help with adjustment and to promote greater
communicative confidence. Family members and carers are encouraged to observe strategies and techniques utilised by the volunteers to maximise effective communication.

The AI also works in partnership with Adult Day Programs and long term care homes in the Greater Toronto Area to provide training and consultation to staff working with individuals with aphasia.

**Skill development vs supported conversation**
Although the model for service delivery has always been a social conversational one with less focus on specific “treatment”, the AI has run skill development groups. With increasing pressure to offer “therapy” due to diminishing outpatient services, AI is now considering an intensive skill development program.

**Training and Resources**
The AI has a strong training focus offering workshops and courses to professionals such as speech pathologists and other allied health workers, families and volunteers. Supported Communication for Aphasia (SCA) is a key component of all training. The centre developed the Assessment for Living with Aphasia and markets this along with other resources. They are also currently involved in a project to train 2nd year medical students about aphasia in the hope that the information will be disseminated via presentations to their respective classmates.

**Funding**
Although initially established via fundraising and grants the majority of funds are provided by the Ministry of Health and local health authorities. The weekend before my visit members, families and staff had taken part in the annual “Walk for Talk” raising over $60,000. This is organised by the City of Toronto and many different charities take part. Each organisation is responsible for seeking their own sponsors but overheads for the individual charities are kept low in this way. Research grants are regularly sought for specific projects which allow for service development. A certain amount of income is gained via services fees, as well as fees for training and resources.

**Staffing**
Speech Pathologist Aura Kagan, a pioneer in the field of SCA and associated with the centre for over 26 years, is CEO and Director of Research. It is through her determination and commitment that the centre has been so successful. There are approximately 15 paid staff including a Director of Clinical and Educational Services, Director of Operations and Development (daily operations and fundraising), Education and Learning Coordinator, Volunteer Coordinator, speech pathologists and administration staff. Specialist consultants such as music and art therapists are contracted to provide classes.

**Volunteering**
Training volunteers in the principles of SCA was pioneered by AI. They now have around 100 volunteers working in the centre and in their outreach programs. Volunteers are recruited through a local volunteer agency, or word of mouth. They are rarely forced to actively recruit. “Linking Boomers”, an organisation aimed at harnessing the increasing numbers of well-skilled retired Baby Boomers has been a resource for volunteers.

Volunteers are asked to observe the conversation groups at the centre to determine whether they feel the role will suit them. Those who choose to take part in the program must participate in the core training program in SCA (approximately 10 hours). They observe videos of people with aphasia and practice skills in role play situations. They must
agree to commit a year to the role and they must volunteer for a period at the centre before being considered for outreach work. 2 x volunteers will work together at a conversation table. Both a speech pathologist and a social worker are involved in the training to tackle issues like dealing with difficult emotional conversations. An online refresher course is offered to volunteers of long-standing who wish to update their skills.

Volunteers are trained to provide support in the home via the 10 week Home Visit Program. They educate the PWA and family members about aphasia and how to make the most of their communication skills. They are required to send in weekly reports to the speech pathologist who is monitoring the member/volunteer interaction.

Posters displayed around centre describe ethos, mission and roles

Observations and Impressions
This is a well established organisation of 30 years standing that has grown slowly with the use of good evidence and significant dedication by several of its staff - 3 senior staff have been at the centre for over 25 years. Its research base is the key to its continuing funding success and its impressive volunteer training scheme allows for a far-reaching service delivery. The diversity of programming was also impressive and something I would hope to emulate with Reconnect WA, especially the music and art therapy. I was also impressed by the fact that through Aura Kagan’s effort aphasia and stroke have become very closely linked in the eyes of the wider community.
As mentioned in my reporting on Headway in Edinburgh, I was keen to meet with organisations that were not aphasia specific but were providing services to people with CI. The Stroke Recovery Association (SRA) is one such organisation. It has been established for over 30 years and grew out of the self-help movement of 1970s. Small local groups began to appear and in 1980 a provincial coordinator was appointed via a government grant. From that came the recommendation that a provincial body be formed unifying all the smaller groups. 37 branches now exist throughout British Columbia.

I met with Tim Readman the current CEO who explained that the group had a strong history and ethos of empowerment and inclusion. Like all disability based groups, however, the contribution of the membership is often inhibited by the nature of the disability. Consequently professional assistance and support by family and others is required.

The SRA is managed by a board which was once unwieldy in its size (47 members) but has recently been pared down to 11 members.

Funding and Staffing
Funding comes from 3 sources - the regional and provincial health authority, proceeds of gaming (provincial wide), and the Heart and Stroke Foundation (HSF) which is the research focussed organisation involved in health promotion/illness prevention and resource development - the equivalent to our National Stroke Foundation. The SRA office is housed in the Heart and Stroke building and funds provided by HSF pay the staff salaries. The staff is small - CEO, office manager and 0.8 FTE accountant. The SRA pays the salary of a part-time coordinator who works 4 hours per week in each of the branches. It is their role to organise activities and outings for the membership. The SRA also employs SPs to provide services, train volunteers and set up models of supported conversation.

Branches
Each branch has its own bank account and the larger groups may have significant funds due to bequests. Membership numbers vary enormously from approximately 10 in the smallest branch to 180 in the largest. This presents problems in inequity between groups and results in challenges for the central administration. It also results in groups in more disadvantaged areas not having the capacity to grow in the same way as the more socially privileged areas. Branches may be led by stroke survivors, family members or volunteers. Most branches meet weekly for approximately 3 hours.

I found the discussion with Tim regarding establishing a board particularly helpful. He candidly identified the following key components of a successful board:
• Philanthropists
• People with connections
• People with health management experience
• People with integrity
• People who turn up!
The organisation has recently developed a 5 point strategic plan which it hopes will create significant improvements in its services.

Observations and Impressions
Reconnect WA is affiliated with the WA branch of the National Stroke Foundation and consideration could be given to having a stronger alliance or integration within the Stroke Support Groups.

MEETING WITH JENNIFER SWEENEY FORMER COORDINATOR OF THE BC APHASIA CENTRE VANCOUVER 20th JUNE
Despite the closure of this aphasia centre I felt it would be extremely beneficial to meet with Jennifer who started the BC Aphasia Centre in 2001. She established the organisation in rent free rooms in downtown Vancouver, offering a weekly social conversation group for about 8 people. Slowly she built the group as a not-for-profit and set up a board. To establish connections and develop the board she approached a local MLA who assisted her in holding informal dinners to inform interested influential people about aphasia and the need to support the organisation.

Problems and issues resulting in closure
The group closed in 2006 as Jennifer found it difficult to sustain the momentum required to lead and develop such an organisation on her own. An enormous commitment is demanded of any person giving time to a not-for-profit endeavour. Individual forces within any environment vary. Jennifer found that she did not receive a lot of support from the speech pathology community and most referrals were in fact coming from GPs, the Stroke Recovery Association and word of mouth. There are questions around whether rehabilitation services in Vancouver found her group in direct competition to their services, but this seems unlikely given the need for longer-term services in the Canadian health system.

APHASIA CENTRE OF CALIFORNIA OAKLAND 30th JUNE
Roberta Elman established the ACC 15 years ago in response to a lack of continuing speech pathology services in the Bay Area of California. It was the first independent aphasia centre in the USA and was established via Elman’s efficacy study (1999) similar to that conducted by the Aphasia Institute in Toronto. She is still the driving force behind the centre and the development of services for members. Research is a significant component of the centre’s mission. 160 people with aphasia receive 4000 service episodes per year.

Building and Access
The centre is housed in rent-free rooms in a seniors centre. It is old but functional and has good access, despite the 2nd floor location. The accommodation is simple but meets the group’s needs. Communication groups are held in a classroom sized room, while the exercise group is held in a larger room in the same building.
Model and Philosophy
Based upon the SCA model of the Aphasia Institute of Toronto, groups are more about improving communication skills via social interaction rather than individual skill development. The ethos of the organisation is “keep it small and manageable”. Roberta remains the linch-pin of the ACC and is involved at all levels. It is a not-for-profit group that is overseen by a board.

Unlike most other centres visited, the ACC does not assess its members on entry to its programs. The philosophy of the centre is that services and programs should be totally member focussed so assessment, which is essentially a tool for the practitioner, is not relevant to service provision.

Services
The centre started small but now offers
• Eight weekly communication treatment groups (2 x daily for 4 days Monday to Thursday).
• A weekly Book Connection (reading and writing) or News Forum group.
• Individual speech-language pathology sessions.
• A quarterly educational series on stroke.
• A caregiver’s group.
• A "Sit and Be Fit" exercise class as well as "Club Aphasia" for social interaction during card games and dominoes.

The groups I observed were run by a SP, a SP student and a volunteer. They employed a social conversation model using SCA and visual aids such as writing, pictures, maps alphabet boards etc. They were not overly structured allowing for a more natural conversational flow. The lower level group (more severe impairment) obviously required greater facilitation by the SP. Members were encouraged to ask specific questions of others in the group and those answering utilised their communication books, iPads and other tools.

Although individual advocacy is not the specific role of the AAC, the SP, in the process of managing the groups, may identify member’s needs which require attention or referral to another agency. For example, when a member was returning to driving, the SP accompanied the member to the motor authority to assist them with their application.
**Funding**
Funds come from several sources – government grants, donations, service and training fees and specific events, such as a recent sponsored walk raising approximately $60,000. Service fees are kept low ($190 per 10 sessions), and a bursary system applies to those requiring financial assistance.

Roberta manages all fundraising and is of the belief that funding sources must be diverse in order to spread risk. This is particularly relevant in terms of the squeeze on the charity dollar and competition for funds.

**Observations and Impressions**
The ACC was a very friendly, relaxed environment to visit. It was clearly member focussed and both PWA and their families were quite at home in the centre. Roberta's philosophy resonated strongly with my own views on retaining a small and slowly developing service to avoid the rapid growth and burn out phenomena that can afflict not-for-profit organisations.
ISSUES FOR CONSIDERATION AND DISCUSSION

In the course of my program of study many questions arose regarding not only the model of service Reconnect WA should adopt but also the manner in which it would implement its services. The points below will need to be discussed at length by our membership in order to create a clear conceptual framework for the organisation.

1. To assess or not to assess? As discussed in the body of this report there are many good reasons for assessing participants before they enter a program. The most compelling is support for funding. If a program can demonstrate efficacy it is more likely to attract dollars. Evidence based practice is encouraged in all areas of health provision so why not in a not-for-profit? If assessment is to be integral to service provision screening tools must be selected with care and discretion. There are a number of appropriate qualitative tests measuring improvements in mood, confidence, social ability and communicative success. They can be administered in a sensitive manner ensuring no negative impact on the test recipient.

But is this what we people living with CI want from an organisation? I doubt whether it enters their heads. If a service is actually offering treatment, rather than social opportunities and conversation practice, then baseline and progression assessments may be appropriate. As Barbara Shadden (2007) of the Stroke Support Group of North-West Arkansas points out, assessment suggests that the aphasia group is an extension of the medical model and objectifies the participant. It is not the goal of Reconnect WA to provide therapy and the model it supports is social conversation. In addition the assessment process can be very time consuming. Not-for-profit organisations rely heavily on volunteer time and are nearly always overburdened by the number of tasks required to be shared.

2. Age group concerns. It was pleasing to see that in most centres, although the majority of members were of an older age group, there were a number of people in their 20s, 30s and 40s. Due to the correlation between stroke and ageing, many day centres designed for people with disabilities can have the appearance of a senior’s citizens group. This is always a concern for aphasia centres wishing to provide a service to people of all ages. It would be preferable to encourage a broad range of age groups to be involved in Reconnect WA.

3. Single vs multi centre model. At present Reconnect WA has 3 conversation groups running on a weekly or fortnightly basis. There is, however, no “headquarters” as such where a dedicated office space could be established. I think a central HQ is essential to establishing identity and a sense of place. The organisation will have to make decisions around how they wish to operate.

4. Services and programs - what to develop first? Decisions about program development will have to be carefully considered. Should this be a tiered development starting with one program at a time or should it be a multifaceted structure with offshoots in many directions? Should all programs be of a communicative nature or should we also attempt to offer alternative activities such as music, yoga/exercise, craft activities? I am personally very keen to explore these options as I feel the person with long-term CI is constantly faced with the fact of their linguistic failing. Non-verbal activities offer a complete change of focus and utilise other parts of the brain. Observing the interest and excitement of the participants in the music group at UK Connect and the drumming workshop at the Aphasia Institute was enough to convince me that these programs should have equal importance.
5. Funding sources - where to begin? There are a number of options for funding, but starting with small grants to establish the organisation via Community Services, Department of Health or Lottery West would be the wisest choice. Philanthropy is also an important source, but will take longer to establish due to the amount of time required to foster relations. Fundraising activities can be large or small but take an enormous amount of time and personal effort. Reconnect WA has commenced the process of forging corporate partnership schemes and hope to develop them further.

6. Large or small? Independent or affiliated? Although many of the groups I visited were established as independent organizations for PWA, there appeared to be considerable Support for affiliation with larger associations. Some organisations, even the larger ones, were finding the charity dollar hard to compete for in these more conservative post global financial crisis years. One group has worked hard to align aphasia with stroke, so that stroke is not spoken of without consideration for the possible presence of aphasia. In a similar manner CFS links all communication impairment in order to effect broad system wide change. I think it would be in the best interests of Reconnect WA to continue to develop its links with the WA branch of the National Stroke Foundation given the commonality of the cause and the shared mission.

CONCLUSIONS AND RECOMMENDATIONS
The Churchill Fellowship has allowed me to explore aphasia centres and ABI services in many parts of the world. It has given me an opportunity to observe “the best of the best” and learn from the successes and failures of these organisations. I feel enlightened, enriched and enthused about the potential to take this information and invest it in my own not-for-profit organisation Reconnect WA.

An important part of my journey has been to distill from all the observations I have made and the vast amount of information I have absorbed, the essence of an appropriate model of service for Reconnect WA. With this in mind I feel I can create a conceptual framework for Reconnect which will fit the environment, the population (and its needs), and the aspirations of its membership.

- Start small and remain sustainable. The most successful and sustainable organisations I observed had developed slowly achieving clearly defined goals over many years. Whether large or small the key was remaining sustainable, not relying on any one source of funding, keeping paid staff to a minimum and responding to need rather than wants.

- Being able to offer a communication friendly environment such as a regular meeting place is paramount. Although difficult to establish centrally located premises in geographically spread out Perth, it is extremely important to have an identifiable “headquarters” where an office, meeting place and storage space can exist. This does not rule out the existence of other meeting places that serve a particular region. Reconnect’s Fremantle conversation group has been established for many years and is very successful. Finding rent free or low rent premises will be one of the first tasks once funding sources have been explored.

- Having well trained volunteers to provide supported communication strategies, both within a centre and home environment. The most successful and far-reaching services seem to have excellent volunteer forces. Recruiting and training volunteers to provide
human services is a very time consuming and exacting task, as is maintaining and refreshing the supply. In order to do this effectively a paid project coordinator would be desirable.

• Having a reliable, recurrent funding source to ensure service continuation, and to be able to employ at least one staff member in the initial stage. Reconnect WA has received small grants in the past but in order to develop programs that will serve our membership in the long-term we will need to seek larger more sustainable funding sources. Grants from Community Services, Lotterywest and the Department of Health will be a first option with philanthropy and fundraising developed as time and resources allow.

• Linkages with rehabilitation services and universities to ensure the continuation of best practice and support research. Fortunately, Reconnect WA has close links with Edith Cowan University School of Speech Pathology and Curtin University. We are affiliated with the Australian Aphasia Association and will be focussing future efforts to establish strong links with the University of Queensland and Professor Linda Worrall who was instrumental in establishing the AAA. I have also become an affiliate member of the Clinical Centre for Research Excellence in Aphasia Rehabilitation, which exists to further the understanding of aphasia and how to provide services for those living with it.

• Developing a tight and focussed strategic plan with clearly defined goals and directions. This will be an essential but not easy task which may require outside facilitation to achieve a clear direction.

• Developing close linkages with the community and corporate sector to continue raising awareness of the existence of CI and aphasia and the challenges of living with this condition.

Banner in Maywood New Jersey promoting Aphasia Awareness Week
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Afasiecentrum website www.afasiecentrum.nl/

Aphasia Institute Toronto Canada website www.aphasia.ca/

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Communication Forum Scotland website www.communicationforumscotland.org.uk/

ConnectGroups website www.connectgroups.org.au/


Headway Edinburgh www.edinburghheadway.org.uk/


Speakability website speakability@speakability.org.uk

Stroke Recovery Association of British Columbia website www.strokerecoverybc.ca/

UK Connect website www.ukconnect.org/