

Self-help me if you can

Many voluntary agencies support a diverse network of self-help groups. *Avril Nicoll* asks what contribution this can make to how someone adapts to and manages their communication difficulty, and where speech and language therapy comes in.

A search of www.amazon.co.uk for 'self-help' books produced over 40,000 results. The first page included classics such as Susan Jeffers's 'Feel the fear and do it anyway' and Stephen Covey's '7 habits of highly effective people'. (Also 'The Goddess' by Gisele Scanlon with "life-enhancing content" including "what you should have in your make-up bag to tackle every problem", "plucking the neatest eyebrows" and "looking after cashmere"...). Whatever the perceived problem, it seems that someone has written about how you might help yourself handle it.

This proliferation is reflective of a sea-change in opinion on who holds the power to bring about change. In an essay on NHS transparency, Edwards (2006) quotes Rowe *et al.* (2002) as saying "The professional paternalism that traditionally characterized public experiences of the health service, with patients being passive recipients of technocratic and medical expertise, now appears outmoded." Initiatives such as the Expert Patient Programme and the drive for Patient and Public Involvement recognise that individuals have much to offer not only themselves, but also their peers and health professionals.

While books can open minds to different ways of coping, not all people with communication difficulties will find books accessible or applicable – and in any case books do not address our need for social support. As Klein (2000) recognises, "A community of kindred souls affirms for us that we are not alone. To find that community, you may need to shed your cynicism and scepticism. You may need to swallow your pride and admit that people do need people in order to be fully human." (Preface xiii)

Speech and language therapists are acutely aware of how isolating a communication disability can be. Many people with communication difficulties face a particular challenge in finding and participating in social activities including self-help initiatives. So do we do enough to facilitate and support such groups? Do we value this as an integral part of our role, committing time and acting as a resource?

Liverpool speech and language therapist **Anita Williams** has a history of following a social model of working with

*"When I was younger, so much younger than today
I never needed anybody's help in any way.
But now these days are gone, I'm not so self-assured,
Now I find I've changed my mind and opened up the doors."
Lennon & McCartney (1965)*

READ THIS IF YOU WANT TO GIVE CLIENTS OPPORTUNITIES TO

- USE THEIR COMMUNICATION SKILLS
- GROW IN CONFIDENCE AND SELF-ESTEEM
- RAISE AWARENESS OF THEIR NEEDS

people with long-term conditions. However her attempts to get self-help groups going had in the past started well but fizzled out and she was "left with the feeling that I had done something wrong". A course at Connect – the communication disability network – provided welcome inspiration, and Anita has worked with **John McCreadie** and other users of Alternative and Augmentative Communication (AAC) to start CALLUP.

A funded and statutory communication aids service means Anita has a number of able clients with sophisticated aids. With an IT student, she set up a Communication Aid Practice Group which meets fortnightly. Anita observes that users no longer feel so isolated and become competent very quickly – and they also get a lot out of meeting and supporting each other. The self-help group CALLUP was the next step. Its mission is for people who use communication aids to support each other. Those involved also meet other people – in a group or one-to-one – to help them reach a decision about whether or not to use a communication aid. In addition, CALLUP has a buddy group where an experienced user helps a new user to manage their aid.

CALLUP is also educating health staff and others on what it means to be communication disabled. John and

Anita deliver training to local staff together, John using his aid and Anita using speech. They hope to expand this to other NHS professionals.

CALLUP is consulted by statutory services and is active in attending awareness days and conferences. Fundraising has been essential to securing transport but the speech and language therapy and assistant time and premises are offered by the Primary Care Trust, with a shared desk and phone line planned.

CALLUP is keen to alert manufacturers, commissioners and potential users to AAC issues. John was shocked when they encountered difficulties opening a bank account. "A number of us were in wheelchairs and none of us could speak without an aid. The bank wasn't wheelchair accessible but they asked us to attend a meeting in the bank! Then they wouldn't accept that a bunch of such disabled people could run and control a bank account." A banker eventually came to a group meeting to take the request to open an account – and the group made their views very plain.

John feels that more speech and language therapists could do with setting up self-help groups "as being unable to speak knocks the confidence out of you and taking some responsibility upon yourself starts the process of regaining that". Friendship is vital to John's adaptation, both maintaining old relationships and forging new ones. He was delighted to be asked to give a Best Man speech on his Lightwriter, and talks fondly of support gained (in relation to his percutaneous endoscopic gastrostomy) and friendship from CALLUP members from a variety of backgrounds. John "lost the power of speech" comparatively recently and describes the act of forming the group as a form of therapy. He is keen to offer positive advice to anyone thinking of starting a similar group (e-mail J.McCreadie@yahoo.co.uk).

Anita points out that people with long-term conditions have lots of different experiences and skills; she finds the more we can draw on that the better our service becomes and the more empowered and fulfilled the users feel. Voluntary sector organisations which actively campaign on behalf of people with communication difficulties started out when the founders recognised this expertise – and the need to find a voice for it. Not surprisingly, ►

then, Afasic, Speakability and the British Stammering Association all have national networks of self-help groups which they actively support and promote.

Safety in Stumblers is a Glasgow self-help group for people who stammer, with a dedicated website and e-mail forum as well as a monthly meeting. The group is held in a private area of a city centre bar and generally 5-6 people attend. The initial idea was to provide a follow-up to intensive therapy groups, so people could practise techniques such as block modification and voluntary stammering in a safe, supportive environment. The original members planned a speech / social mix, with the occasional invited speaker talking about a particular approach to managing stammering.

When I visited the group, Chairperson **John Mann** observed that "Some people come for a long time, others for a time, others for one night only and others never come." He noted that people come with different expectations but he welcomes the fact that there is "no sign of embarrassment or ridicule on the faces of the people around you – and you realise it's not that bad after all."

Callum, who is training to be a speech and language therapist, described his first self-help meeting (in Ireland) as "a revelation". He explained, "I had never really talked about it. Suddenly it was very easy to talk about it – so open – I felt a weight lifted off my shoulders." **James** wasn't fearful about coming to this, his first meeting. "I was looking forward to it; for the first time, I wouldn't have to worry about whether I would stammer." **Dev** agreed. "I don't really hear stammering around me, so it's helpful. It shows I'm not stupid – they're fine, all functioning human beings, so I don't feel so bad about stammering." **Susie** had been before but tonight she "had second thoughts, because I would have to confront the stammer, and over the past 8 years I have avoided it. I want to feel able to be more open about it. My speech and language therapist said I have to be OK with my stammer. In the end, I'm happy that I came."

The group members discussed what they get from Safety in Stumblers:

- Humour
- Confidence
- Opportunity to practise (e.g. booking rooms, ordering drinks)
- Friendship
- Learning
- Ideas and options
- Inspiration
- Telling your story
- Chance to hear other people stammering

This fits with Klein's description (2000) of the three elements of successful groups: a place to be heard; a place of acceptance; a place where one can feel cared for.

It's clear that the group really appreciates the practical support of speech and language therapist **Carolyn Allen**, who not only encourages clients to participate but offers to accompany them to their first meeting. Carolyn herself commends the group's "great support networks as they accommodate the most active of participants as well as those 'feeling their way' in the beginning."

Members suggest therapists could join more online groups so that they are really aware of what is most concerning people with communication difficulties. They also hope therapists tell people about organisations such as the British Stammering Association. They would



On a Voyage of Discovery in Dundee with the British Stammering Association

like speech and language therapy students to attend self-help groups to broaden their knowledge of the lived experience of communication disability.

Whether people prefer an online forum, a Telephone Support Group – both particularly useful for people in more rural areas – or face to face contact, it is clear that in time those who benefit turn their attention to supporting newer members, and gain confidence and insight as a result. I attended a British Stammering Association Open Day in Dundee, organised as a mix of speakers and workshops catering for children and young people who stammer. Dr David Lilburn explained that he worked through the theory of stammering with his speech and language therapist "but I had to put it into practice – to tame this beast that was taking control." He went on City Lit courses, "taking care of myself, getting out there – and so much changed." According to David it is important to take risks, as "the most rewarding time can be when you go out on a limb". But he doesn't believe you can do this alone, and advocates self-help groups which offer social chat and support, and participation in the British Stammering Association – "where people actively embrace you because you stammer".

Another speaker Claire Pirnie had a revelatory moment when attending a European group in Holland. Far



John Mann of Safety in Stumblers scales Ladhar Bheinn for the British Stammering Association

from trying to hide their stammer – as she had always done, even in speech and language therapy groups – she noticed that "everyone just got on with it". As a result Claire stopped trying to hide it, talked about it and started public speaking to spread awareness – and found it gave her a real buzz.

The impact of these speakers was clear during speech and language therapist Liz McConnell's workshop on teasing and bullying, when one mother told me it had given her real hope for her son's future. Meanwhile the young people clearly relished the opportunity to have a laugh brainstorming potential solutions with their peers (bury them alive, put their head down the toilet...!)

The British Stammering Association open day was held at Discovery Point, a non-medical venue. When the Speakability-affiliated Speakeasy group was formed in Aberdeen for people with aphasia, those involved were also determined to meet in a hotel not a hospital.

Speech and language therapist **Annette Cameron** has been associated with the group since its inception. She believes that the focus of speech and language therapy is now different in the early stages of stroke – actively listening to the client's agenda, revealing competence and providing signposts. Some clients may wish to participate in a self-help group at an early stage. However, she also sees there is still "a long way to go" in providing opportunities that people will want to take up. Any established group can be a daunting prospect for new people. Speakability suggests that people who already know each other can be referred to attend their first meeting together as one way of overcoming this.

Code *et al.* (2001, p.45) noted that membership of Speakability's 50 groups "comes from a relatively well defined section of the aphasic population". This includes people who are mainly ambulant, living at home and with access to transport. They also tend to be relatively young and have a long-standing and relatively less severe aphasia. People who take on leading roles in such groups are more likely to have professional and managerial backgrounds.

At different stages the Aberdeen Speakeasy group has concentrated on the communication support; enabling people to tell their own stories; campaigning; and now social support. One successful initiative was to set up computer classes, so some members can now produce invitations, menus and lists of meetings. The group members themselves initiated the classes, and the speech and language therapist - Annette - conducted training for the staff who provide the computer classes. Annette has observed that many factors can change the course of a group – personalities, deaths of members – and that the speech and language therapy link has to be very flexible as a group changes. Annette cautions that there is a danger of a speech and language link therapist being overly protective of a group. "It takes courage to stand back and let it take its course, remembering that they are adults with responsibility for their own lives". The therapist's concern is that the group may fold, but another group can emerge. Klein (2000) talks about four basic developmental phases of successful groups. Phase one is exploratory, where people are sussing the group out, seeing if they can trust it and if it will meet their needs. Phase two sees a growing sense of closeness where people begin to feel more confident about revealing themselves. Phase three gets to the heart of the matter, searching for meaning

and uncovering coping strategies. Finally phase 4 looks to the future, with people leaving, or the group re-evaluating its aims. Throughout, Klein describes the facilitator's role as shifting "from leader to cheerleader" (p.17).

Annette finds great satisfaction in "seeing people whom you have worked with from the onset of their communication difficulty move through to a stage where they don't need you any more". However, she constantly questions "at what point does a specific aphasia need / identity become a broader need which no longer requires input from the speech and language therapist? And are we then meeting the needs of other people with aphasia?" She has seen situations where people want to develop and use certain skills but group dynamics at the time were not conducive.

Code *et al.* (in press) point out that

Self-help in aphasia is still evolving and, like other human groups, things do not always go smoothly. Misunderstandings may arise. Arrangements for meetings and outings can be casualties of impaired communication. Members may have different expectations of their groups and some may go away disappointed. Some members may be unwilling or unable to recognise the need for facilitation and support. As in other groupings of human beings, leaders may be insensitive or over dominant which can impact on the development of autonomy in members.

For Annette the most rewarding part of her involvement with Speakeasy has been supporting members to effect change. Recently members have been involved in

two projects using Talking Mats. This approach not only encouraged communication skills, but also developed their confidence and self-esteem. The first project was part of the Grampian Disability Action plan. Members gave their views on GPs and hospitals, rating aspects as good / bad / indifferent. These views were then incorporated into the action plan. When a local MSP helped to set up a meeting with the First Bus Operations Director, Annette again used Talking Mats to help members think through, discuss and prepare their views. The Operations Director was delighted to find that this included positive comments and some practical suggestions, and he came back to the group with feedback. As these projects needed commitment from the speech and language therapy department and a determination not to lead or bias proceedings, Annette was particularly pleased when the manager of the Managed Clinical Network for Stroke who viewed the Talking Mats commented, "That looks really empowering."

And there you have it in a nutshell. Working together, clients, carers and speech and language therapists have opportunities to set up and nurture groups and online forums or blogs. Such initiatives can "open up the doors" to a powerful vehicle for adaptation and change.

*"... I do appreciate you being round.
Help me get my feet back on the ground..."*
Lennon & McCartney (1965)

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Resources

- Afasic www.afasic.org.uk
- British Stammering Association www.stammering.org/selfhelp_groups.html
- Expert Patient Programme www.expertpatients.co.uk
- Safety in Stumblers www.safetyinstumblers.org.uk
- Speakability www.speakability.org.uk
- Talking Mats www.talkingmats.com

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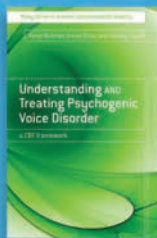
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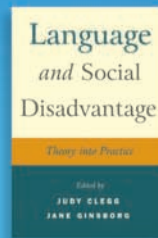
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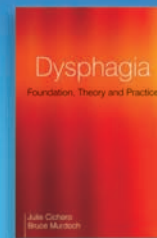
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