An Untapped Resource?

Working With Volunteers who have Aphasia

Who are we?

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Content of Today's Presentation

- Issues in User Involvement
- The Social Model in Aphasia therapy
- What is Supported Conversation in Aphasia (SCA$^{©}$)?
- Volunteer Project
- Reflections

The Volunteer Project

- To provide training to all staff in use of Supported Conversation

- To establish a core group of volunteers with Aphasia, with a gradually developing and broadening role (based on service model developed by *Connect*)

- To evaluate the benefits of using former clients as volunteers in a healthcare setting

Why User Involvement?

- To provide training that is more meaningful and experiential for staff

- Intrinsic benefits of volunteering – develop skills, feel valued, put something back into the community

- Can address SLT intervention goals (e.g. 'adaptation of identity', 'healthy psychological state' – Pound, 2000)

"Practising what we preach"

- Client as 'expert' : Drive towards a patient–led NHS (e.g. Patient Self-Management Programme)
- Acknowledging / revealing competence in people with Aphasia

The Social Model and Conversation

- Schiffrin (1988) conversation is "a vehicle through which selves, relationships and situations are socially constructed"

- Kagan (1995) conversation is the means by which we reveal our "inner competence"

"Don't knock the weather; nine-tenths of people couldn't start a conversation if it didn't change once in a while".

Simmons-Mackie and Damico 1997; McAllister *et al* 2006

Transactional elements less important to Aphasic people than the *interaction of conversation*

The Social Approach To Aphasia

- Not impairment based
- Focuses on conversation as a whole
- Considers environmental barriers
- Aims to facilitate communication in naturalistic situations
- Addresses the roles and communication abilities of all those involved

Some Examples of the Social Approach

- LPAA – Life Participation Approaches in Aphasia
- Aura Kagan
- The Aphasia Institute, Toronto
- Connect, London and South West

What is SCA© ?

"Supported conversation is based on the idea of conversational *partnerships*."

"It provides...opportunities for genuine adult conversation and interaction, in recognition of the centrality of conversation in everyday life.."

'' SCA© involves training conversation partners to acknowledge the competence of individuals with aphasia and to help them reveal what they think, know, or feel''.

(Kagan, 2001)

Communication Ramps
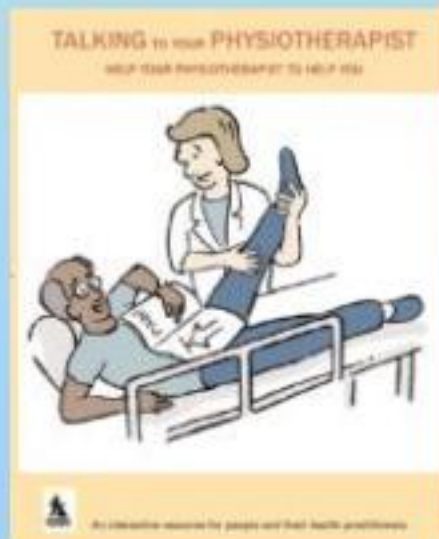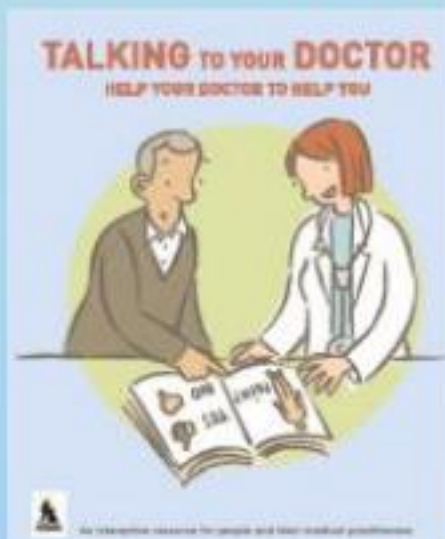
SCA© AND AAC

- Can be thought of as 'light tech' AAC
- Similar to Communication passports / Talking Mats, e.g. facilitating conversation through symbol use and written words
- Goal is to improve skills of conversation partner(s)
- A Caveat…symbol systems can have limited effectiveness with people who have Acquired Communication Disorder

Efficacy of SCA

- Kagan *et al* (2001) Controlled trial. Two groups, one exposed to people with Aphasia and other received training.
- Trained volunteers scored higher on ratings of acknowledging and revealing competence
- Positive change in "message exchange skills" of partners with Aphasia

Efficacy of SCA - Continued

- Rayner and Marshall (2003). Trained a group of volunteers over three sessions
- Drew on techniques of Kagan
- Questionnaire ratings showed increased understanding of Aphasia
- Volunteers' videos rated by SLTs – increased skill levels on 9 point scale
- Gains in participation of Aphasic subjects

Supported Conversation Project

The Volunteers

- 8 clients were contacted by letter.
- 6 ex- clients and 1 current client from Moor Green agreed to help.
- Clients all have Aphasia without significant underlying cognitive deficit
- Range of Aphasia from moderate to Severe
- Some clients already involved in Dysphasia Support, self-help or advocacy groups

Volunteer Preparation

- Letters of invitation – 2 sessions
- First session - getting to know each other, explaining the project, questions answered
- Second session - exploring issues in giving feedback, formulating a feedback sheet
- Practice Session – simulated conversations with SLT staff

8 November 2005

Dear

You are invited to become a **conversation trainer.**

We would like you to help us. We want to train staff at Moor Green, so they can have **better conversations with people who have Aphasia.**

We will ask you to have conversations with our staff, and then **rate the conversations.**

First we would like to **meet with you** to discuss the aims of the training and to agree what will happen on the day you have the conversations. We will run **2 conversation trainer sessions.**

Staff Training Session – Day 1

- What is conversation?
- What is Supported Conversation?
- 'Real life' examples of Supported Conversation
- Small group work alongside taught elements

Staff Training Session - Day 2

- Staff were given observation sheets
- Asked to note down what the conversation partner did or said to:
  - Support the conversation
  - Keep the conversation adult, balanced and neutral
- Each conversation partner also received feedback from the volunteers
- Whole group feedback and action planning at end of session

Staff Questionnaire

- Return rate around 60% (excluded staff who missed 1 of the sessions)
- When asked to rank different aspects of the training 80% of staff rated conversation practice as the most useful
- Some stated that more preparation would have helped, before doing the 'live' conversation
- Overall feedback very positive

The Volunteers' Experience

- Sessions were enjoyable
- Sense of doing something useful
- Fitted in with some volunteers' philosophy of self-advocacy and empowerment
- volunteers enjoyed being 'in control'
- Sense of shared purpose
- Fostering friendships

Our Reflections

- Positive feedback from staff
- Clear evidence of benefit to volunteers
- An initially positive experience encourages everyone to stay involved
- We have learnt about our own practice (e.g how good are we *really* at ensuring all information is Aphasia-friendly?)

Questioning Our Assumptions About User Involvement

"All users can and should be involved"

- Group dynamics
  - Volunteers' understanding of the recovery process
  - Inherent difficulty with subtleties of expression (Nieuwenhuis *et al*, 2006)
- Informed Consent
  - Who benefits from user involvement?
  - Can we make all information accessible?

"Users want to be equally involved in all decision making"

- Roles and 'empowerment'
  - Clients may prefer professionals to take an expert role (Symon, 2006; Griffiths, 2006)
  - Inherited role expectations
- Generation of ideas
  - Projects are usually generated by professionals
  - Co-existing cognitive factors

What would we do differently?

- Consider adjustment issues
- Decide what time to allocate for volunteer training (then double it)
- Spend time on feedback issue (e.g. volunteers rate invitation letter)
- Train all staff (need to be aware of different skill levels)
- Use bridging tasks
- Include a timely debriefing session / evaluation

Thank you for listening

Any Questions?