

Communication Facilitation and Person Centred Counselling

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People with severe communication difficulties can find it difficult to achieve control in their lives, and may experience barriers to success, for example in the area of the 'five accomplishments':

- being respected
- having relationships
- making choices
- developing skills and potential
- sharing places (eg daily living arrangements, access to education & community)

They may need support and/ or facilitation. What kind, and from whom?

Is advocacy the best answer?

If there are barriers and difficulties, advocacy can help people to say (and get) what they want in life.

Teachers and therapists in the field of augmentative communication generally concentrate on ensuring that the person's communication system and skills are the best they can be, so that they can *self advocate* as effectively as possible. In practice, this means focusing on the vocabulary available, the method of accessing, speed of communication and user skills and strategies, along the lines of Janice Light's model of communicative competence for individuals using augmentative methods of communication.

Recognising that fully independent communication is not always possible, provision of communication facilitation and independent advocacy services may be helpful.

But what if someone does not really *know* exactly what they feel and want? What if their ability to make choices and decisions and to follow through with them is impaired by a lack of experience of the world, or by a difficulty in understanding how other people think and behave? What if negative emotions such as anxiety, anger or unhappiness cloud their ability to take in information, think and take decisions?

There can be a need for a different kind of support. Counselling comes to mind. There are areas of overlap and areas of differences between advocacy and counselling. Both help people to be clear about what they want and to develop the confidence to speak up. However, advocacy is action orientated, while counselling is inward and private and is more about helping people explore and express their feelings.

Madeleine

Madeleine has cerebral palsy, uses a wheelchair, has no speech and communicates by direct pointing to Bliss symbols on a board containing about 500 symbols. She has not found any technology yet that is acceptable or useful to her, mainly because of accessing difficulties and an unwillingness to use scanning and switches. She is a good Bliss communicator in that she can make her personality felt and can get her message across effectively much of the time, but she is highly dependent on having a good communication partner who can 'co-construct' messages with her. She generally uses only two or three key symbol phrases, not always in grammatical order. For Madeleine, someone who is a good communication partner is someone who:

- has known her a long time (and knows a lot about her family and friends and past and present personal life)
- knows her communication system well - how the Bliss symbols work and how she uses them.

Does Madeleine need an advocate?

Madeleine does not really need an advocate because one of her strengths is a determination to make her views heard. Her team of helpers are willing to consult and to listen to her. She always asks for a communication facilitator to be present at meetings. She is able to insist that people take the time to listen to her views. Her problem is being sure what her views *are*.

Madeleine's situation

Madeleine is currently facing very major choices and decisions in her life about where to live and where and how to spend her time during the day. She is finding all aspects of decision making agonisingly difficult. She is uncertain about what she really wants and she is in distress. She feels pressurised by the way professionals expect her to make up her mind quickly, sometimes on the basis of very little information. She feels confused and angry about being expected to stick to her decisions and not being or allowed to change her mind. She is automatically resentful and suspicious of attempts to influence her decisions. She is having trouble coping with, and making sense of the very strong feelings that she is experiencing.

Any form of change involves doubts and fears for all of us. It is noticeable however that all Madeleine's carers and support workers always try to stress the positive and 'jolly her along' - no space is allowed for her doubts, fears or other negative emotions.

Perhaps because of her high degree of dependence, Madeleine often suppresses her true emotions in order to keep approval from others, especially her close family. Family too always stress the positive and actively try to avoid negative emotions.

This situation and these problems are probably common to many augmentative communication users.

Counselling may help. It can be done!

Although it has not been widely explored as an option for AAC users, counselling may help. It is doubtful if there are any statistics on how many people attend counselling and what percentage of those are people with disabilities, or with communication disabilities in particular, but one might imagine that it is very low proportion indeed.

One of the common features of all the various forms of psychotherapy and counselling is the fundamental and central role of **communication**. By definition this would make access to counselling a challenge for people who use augmentative methods of communication.

Madeleine's experiences show how it is possible to attend and to benefit from person-centred counselling sessions with the support of a communication facilitator. The aims of person centred counselling for Madeleine were:

- that she become clearer about what she feels, needs and wants.
- that she become more able to accept the things about herself and her past experience that she cannot change.

How does it work?

Privacy and confidentiality are central to a counselling relationship, so it is usually inappropriate for another person to be present. However, in this case, the presence of a communication facilitator was essential to getting the counselling process started at all as the counsellor did not feel counselling was possible without this support. The aim was to see if facilitation could be faded out later on.

The presence of a third person during the early stages of the establishment of the counselling relationship has both negative and positive influences upon the counselling process. The most positive influence has been that it has kept anxiety levels (client's *and* counsellor's!) down, which allows the relationship to develop and effective interaction to take place. The most negative influence is the sometimes obstructive role that the client-facilitator relationship plays on the counsellor-client relationship.

The communication facilitator carries out a number of functions:

- reading off the symbols/ words, and construct these into meaningful and more or less grammatical phrases and sentences as she indicates them, which means that the counsellor is free to watch Madeleine's face and body movements closely and establish eye contact .
- Spotting when she is using symbols in unusual ways, and thus being able to signal to the counsellor areas where there may be further 'unpacking' to be done.
- Having identified an area where Madeleine is deficient in vocabulary, or where an ambiguity or misunderstanding has arisen, quickly drawing up a supplementary symbol chart for immediate use.
- As well as decoding Madeleine's symbols, because of background knowledge of her life, spotting connections to past and present events, and - as 'authorised' by Madeleine - providing the counsellor with 'chunks' of history / background information.
- At the end of each session, checking with Madeleine what she would like fed back to staff

and family at the time of ordinary communication support visits.
 (Unlike many clients in counselling, who would not want to tell others, for Madeleine it can be huge relief if she manages to uncover and put into words in a session things she has been wanting to talk about with others for ages, but has never felt able to communicate adequately.)

- Outside sessions, sometimes sending through to the counsellor written notes with factual information, names, news, feedback from home conversations etc. - as requested/authorised by Madeleine.

Interestingly, Madeleine is never stuck for something to talk about in counselling sessions (unlike other, non disabled clients). An impression comes through that Madeleine is in some senses communication-deprived. Silence is a waste of her time!

Communication Issues

There is a special quality of attention and listening in the counselling situation that is quite different from ordinary conversations, however serious. This has illuminated and enhanced understanding of Madeleine's use of her AAC system as well as of her inner feelings. Madeleine is aware of this special quality. She has called counselling "*hear, listen- time - (for) me*"

In the course of this very special process, communication issues that have been highlighted include:

- *different qualities and levels of listening and decoding of the AAC user's messages*
 We have been struck by the value of having two simultaneous listeners - a practical problem-solving listener (ie the communication facilitator) and a deeper level listener (the counsellor) who is to some extent free of having to 'decode' the surface of the message. (Does this imply that the AAC system - or indeed any form of language - is in some senses a barrier to communication?)

These two listeners can consult freely with each other and with Madeleine to confirm that the message they are building is accurate. This process is in itself valuable to Madeleine as a different kind of feedback.

- *different semantic field boundaries*

AAC systems are not just ordinary spoken language 'translated into' an alternative modality. The way the system is constructed, accessed, and taught has an effect on how similar or how different it is from conventional spoken language use.

Overloaded words

Most speaking adults have a vocabulary of one or two hundred thousand words. When you only have a few hundred words to express many thousands of meaning, each word can carry a huge 'baggage' of extra, different meanings (to the point where they may become overloaded and difficult to 'unpack'.) Listeners - who often just read the word above the symbol and do not know much about the meaning of the symbol itself - are often not expecting short and apparently simple words and phrases to be highly charged with emotion, and so may miss their real meaning.

For example, Madeleine uses the word *play* a lot. Inexperienced listeners sometimes take this in its simplest and most positive interpretation as '*game*', '*relax*', '*have fun*' - much the same as '*opposite work*'. But in fact we have gradually realised that in Madeleine's semantic system, it more often means something much less frivolous like '*unprofessional*'; '*not competent*'; '*not doing work properly*'; '*working at the wrong level*'; '*inappropriate*'; '*playing / messing (someone) around*'; '*wasting time*'; '*not taking it seriously*'.

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she play speak means 'she tell lies'

She says

⊥₁ ↑ ^

I opposite work - which people took to mean "*I want to relax - I don't want to work*" but actually, when she had the chance to explain fully, meant "*I want to work but I can't because I'm*

distracted by the noise that the other residents make, and by the TV being on all the time”

Underloaded words

The opposite side of the coin to the above is that sometimes concepts and experiences are impoverished by a lack of adequate vocabulary to describe them. Due primarily to lack of space, Madeleine’s symbol vocabulary for feelings is very limited (*happy, sad, upset, angry, excited, sick*). She has difficulty identifying (and therefore experiencing) other feelings. Of course, we have supplied symbols she seems to be needing eg. *anxious, depressed, frustrated, confused, disappointed, guilty, irritated*, but although she knows the spoken word and can identify the new symbols, it has taken a good two years for her to really recognise those words as matching and representing her own emotional experiences.

- *grammar difficulties and potentially misleading messages*
With Madeleine, we need to be aware that her difficulties with higher level language functions might be masked by apparently grammatical sentences. For example she often uses a simple declarative (eg. “*She (is) angry*”) but it eventually turns out that she is actually meaning something much more hypothetical / subjective and conditional eg. “*I am worried because I am thinking that perhaps she will be angry (if...)*”
- *the use of repetition*
Madeleine has always used repetition a great deal which had been problematical in her home setting. The counselling perspective - that “clients repeat things if we miss them first time round” has been illuminating and it has been helpful to pass this on to home staff. We now conclude that Madeleine is in fact saying “*there’s something in here that hasn’t been picked up the way I want it to be, that I still want to talk about*”. At other times, she is simply perhaps stressing how important something is.
- *juxtaposition of apparently unconnected messages / carrying conversational reference points over a far longer time frame than a single ordinary conversation.*
Madeleine re-uses certain names and collocations of words and sentences and apparently irrelevant stories to illustrate whole ‘packages’ of emotions. For example, in the middle of talking about something completely different (or nothing in particular) she may be talking about herself and then may suddenly start talking about a nonspeaking child at school many years back, and say that she feels sorry for his Mum. Her counsellor (unlike ‘ordinary listeners’, often) is able to make this leap with her and make the connections with the emotional messages.

We don’t know whether this is consciously done, as an AAC strategy, to try to control the topic and ‘trigger’ listeners into the same mind set as her, or whether it is an unconscious conversational event (fairly common in counselling).

- *sophisticated use of the facilitator*
Madeleine will often get the facilitator to tell the counsellor a piece of factual information. The counsellor then helps Madeleine to express her feelings about it. It takes the very special skills of the counsellor to pick up on which thing(s) it is that Madeleine wants to focus on.

For example, Madeleine may say “*I child, school C*” to trigger the facilitator into re-telling the well-worn story of her introduction to Bliss symbols, at 4 years old. The facilitator now knows to ‘fast forward’ through it until she starts to give eye contact and become animated, and then to slow right down on that section to let the counsellor pick up the key bits that Madeleine is trying to draw her attention to, and so she can ask the right questions to draw it together with how Madeleine is feeling now.

- *talking in scenes*
Madeleine started using Bliss symbols at the age of 4 years (she is 27 now). She seems to think in images and ‘scenes’, rather than in language, and uses and re-uses these as a sort of shorthand to describe feelings and thoughts. For example, she will say:



Tuesday night car

when she means ‘*completely losing control / having a temper tantrum/ anxiety attack*’ (because that was the notable occasion some years ago in her sister’s car when it first happened). It is interesting that this talking in scenes is not unlike the series of images, superficially often unintelligible, of which dreams are composed.

- *the importance of keeping vocabulary that relates to the past available to the user*
Especially on low tech displays where space is so much at a premium, some support workers are so anxious to keep the AAC system vocabulary up to date and relevant to the current context that vocabulary is sometimes wiped the minute something or somebody has finished being a feature of everyday life. We forget that people may need to think and talk about the past in order to make sense of the present and to plan the future.

But is it REAL Counselling?

Purists would say that with a third party in the relationship, it can't possibly be 'real counselling'. We believe it is, although perhaps not at the deepest level. A more important question, we feel, is "***Is it useful (to the client)?***"

There are certainly differences between what takes place between Madeleine and her counsellor and facilitator, and between client and counsellor in a more traditional types of counselling.

- It takes longer to establish a counselling relationship, but it *is possible* to establish this.
- It takes much longer to communicate; sessions need to last one and one half hours instead of the traditional 50 minutes - 1 hour
- it is harder than usual for the counsellor to 'read' the body language and facial signals of the client
- it is harder than usual for the counsellor to know what silences mean - whether they mean, for example, that the client has not fully understood what has been said, or whether they mean that she is thinking / processing. There are no clues.
- It is sometimes hard to untangle what the client really means to say from interpretations the facilitator generates.

In spite of being very different, our conclusion is that as well as being therapeutic for Madeleine the client, the *essence* of true counselling is being achieved. A true counselling relationship is one where there is ***psychological contact between the counsellor and the client.***

What does being in psychological contact mean? It will include:

Empathy

Empathy means understanding what it feels like to be inside the client's world and experiencing it in the same way as the client. Communication in the counselling relationship often goes beyond words - a kind of intimate and almost spiritual 'feeling connected'. Successful empathy in counselling consists of feeding back to the client in such a way that she *knows* the counsellor has heard and understood. Madeleine has said several times

P $\hat{\circ}$ \perp_1

Pat hear me

Congruence

This means being present and engaged in the relationship as herself, and being willing to be open with the client about her own feelings and experience. This is an area that was difficult for the counsellor to achieve at a deeper level while the communication facilitator was there as a third party in the relationship. In time, since the facilitator stopped coming to every session, this area has been developing.

In Madeleine's case, as well as understanding her frustration at having such a limited means of communication (empathy) the counsellor is willing to share with her the frustration and anxiety that she experiences in not being able to understand her more easily (congruence).

Unconditional positive regard

This means fully accepting and prizing the client as a unique human being and offering non-possessive warmth and acceptance whether or not one agrees that what she decides to do is in her best interests. Counsellors offer this but clients often do not experience it, especially at the beginning of counselling. A sign that the counselling relationship is progressing is when clients start to feel accepted by the counsellor and gradually start to become more accepting of themselves. Madeleine has recently started, for the first time in her life, occasionally coming out with statements about herself, as if she is starting to see herself and experience her feelings more clearly. She has said



I, me -woman -opposite -rest (I am a tense sort of person)
Madeleine's Progress

The counselling experience, week by week, is in itself an enactment of one of the main issues for this client - namely the frustration at having such a limited means of communication and having to work so hard at being understood.

Madeleine has gradually developed strategies for handling the counselling situation. She primes her day support worker in discussion beforehand, so that sessions will often begin with this staff member saying "Madeleine asked me to tell you that she has been feeling / thinking about / wanting to ask...." Although the support worker sits outside in a Waiting Room throughout the session, there has so far been no occasion when Madeleine has wanted to call her in for any reason.

One year after the beginning of Madeleine's counselling, she indicated that she felt able to manage on her own with the counsellor, without the presence of the facilitator and she now attends regularly on her own. It is clear that trust has been established. After few months of this, she then asked about resumption of facilitation. After discussion, it was agreed that she would go on her own some times but the facilitator would come every so often, about one in 3 or 4 sessions, to be a sort of 'backstop' to clear up any dangling misunderstandings, to give feedback to both counsellor and client, and to link with home workers.

A Question of Degree

This was very much 'uncharted territory' at the beginning and it felt at times that *everything* was different about the counselling process with someone using augmentative communication and a communication facilitator. In practice it has turned out that there are more similarities between Madeleine and clients in counselling who have no communication disabilities than there are differences. Many people don't know what's going on, for themselves. Many people without disabilities cannot express what's going on for them. Many people feel that they may be the only ones to experience certain feelings. Being understood by another person is not straightforward for anybody.

These issues and difficulties were essentially the same for Madeleine as for non-disabled people, only significantly *more extreme*. Because of her high dependency, the pressure (spoken and unspoken) upon her from others is more powerful. Because of her limited experience and restricted communication system, exploring and understanding her feelings is slower and harder.

Conclusion

Advocacy was not the answer for Madeleine, though it may be, for others. There is a danger that society goes from having *no* expectations of people with disabilities, to creating a myth that AAC or advocacy (or whatever) will enable people to fulfil *all* their hopes and expectations.

It does not follow that because Madeleine's experience has been beneficial, that counselling is possible and right for everyone - this is plainly not so. But we hope that Madeleine's experience may help to plant the idea that for some people counselling may be a possibility, even where there are severe communication difficulties and only limited forms of AAC available.

The truth is that negative and painful things happen. Even if someone is enabled to have a fulfilling life there may still be grief, anger, frustration and sadness, and these need to be acknowledged and given expression. Counselling can help people to accept and live with the unchangeable.

Madeleine has proved that with learning difficulties, an extremely limited vocabulary and slow communication it is nonetheless possible to discuss feelings in a very powerful way, to feel truly understood, and to grow in the direction of psychological health.

Sally Millar
Pat Butson

Notes

Stopping Counselling

How long should counselling last? There is no set period. Many agencies work to a time limited contract of, say 8 sessions (which may be increased, on a negotiable basis, to a maximum of 16).

With a client with communication difficulties (and associated communication deprivation), it sometimes feels like counselling needs to go on 'forever'. But this is not a realistic possibility. In Madeleine's case, attendance has to a large extent been influenced by the issue of funding. Overall, counselling, which is due to stop at the end of 1998 will have covered a period of 21 months, with discussion and 'warning' about the termination of counselling starting well in advance, to give Madeleine time to come to terms with it. Madeleine is currently worried about stopping: she says "*I need Pat*".

Funding Counselling

One of the greatest barriers to obtaining counselling can be the issue of funding. Most counsellors work privately on a fee paying basis, and many people with communication difficulties have low incomes, so access to counselling is difficult.

In Madeleine's case, she was lucky enough to receive a grant from a local charity, whose express purpose is to support payment of counselling for those who need it who are on low incomes. In Madeleine's case this means that the counsellor charges £20 instead of £25 per hour, Madeleine pays £3.00 per hour and the charity pay the difference (to the counsellor). This particular charity is Edinburgh based, but other areas may have something similar - it is worth checking it out (the people who will know of the existence of such trust funds are likely to be the counsellors practising in your area.)

Otherwise, people should try approaching their GP (whose practice may have a link with a counselling service, usually for cases of depressive illness), or Social Worker (who may be able to arrange for help in the case of worries about life choices and decisions).

Finding the right counsellor and the right facilitator

It's doubtful whether just being a good friend to someone and working hard at listening and understanding them is the same as, or as good as, counselling (though it can go a long way). If you feel that someone you know is in emotional distress and would benefit from counselling, it would be wise to try to find a properly qualified and experienced counsellor. This kind of counselling set-up will only work if the right kind of people are involved. The best way forward might be to identify the facilitator first, and then get that person to set about finding a suitable counsellor who is open to trying to work in this unusual way. As with advocacy, ideally, neither person should be a relative or a member of staff in the client's immediate daily environment.

The following may be able to supply lists of qualified practitioners in your area:

PCT Scotland
40 Kelvingrove Street
Glasgow G3 7RZ
Tel: 0141 332 6888

COSCA
64 Murray Place
Stirling FK8 2BX
Tel: 01786 475140

British Association for Counselling
1 Regent Place
Rugby
Warwickshire CV21 2PJ
Tel: 01788 578328
Email bac@bac.co.uk