

Facilitated Communication: Issues for Parents

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This paper seeks to explore the issues that facilitated communication raises for persons who wish to introduce this, or have it introduced, to their sons or daughters. These children or adults may be non-verbal, have some expressive language skills, be very articulate but echolalic, or have other physical or language disorders which are found amongst people with cerebral palsy, Down syndrome, etc. They may be in alternative care situations rather than living at home.

The writer had informal discussions with individual parents regarding the impact facilitated communication had on their family lives and any suggestions they had to offer. Permission for the use of anecdotes was gained from parents and facilitated communication users. Names have been changed for confidentiality.

This paper covers the following areas: issues related to attitudes; the importance of validation; observations and suggestions on facilitation training for family members and caregivers; and obtaining support for parents and their sons and daughters.

ATTITUDES

Every parent will clearly recall the words spoken when a diagnosis was given regarding their son or daughter. "I am able to tell you now that our tests have shown that ____ is severely retarded. It is unlikely that he will ever be able to ____ or _____. We don't know what the future outcome for him is but it is unlikely he will develop at the same rate as his peers, etc., etc.,"

Some parents will seek second and third diagnoses, spend large amounts of money traveling overseas to clarify the condition and seek alternative treatments. Some will expend enormous amounts of time following training programs and learning about behavior modification and various drug regimes and in the process gather an extensive vocabulary of educational, psychological and medical terminology. They may become more expert than the "experts." They may experience enormous strains on their marriages, their sanity and their careers, particularly in the early years.

Eventually, they may come to terms with the restrictions, life-style and seeming inevitability of their child's disability. They may keep abreast with the current research; they may become resigned to the status quo and choose to enter a "survival-of- the-fittest" mode, whereby they invest their energies into what will bring the most return -- the rest of the family, their careers, their homes, their families, or themselves. From time to time they may come across some new treatment that sparks their interest and may struggle with decisions as to whether to pursue yet another treatment that may be as inconclusive as ones already tried.

Then they see a documentary on television and watch in awe as children just like their child appear to communicate as never before. Not only do they appear to communicate, but they appear also to be more intelligent than ever any tests revealed, or than they gave any observable evidence of. It looks too good to be true, but is it?

So begin the questions that parents ask themselves as they contemplate what could be the most traumatic readjustment to their lives and the life of their child since that first diagnosis. Some of the questions (Ashe, 1992) they may ask are: Are those children really autistic or intellectually disabled? Who is really doing the typing? How do those children know how to read and write? Why haven't I heard of this before? Does this mean they have been really listening to and understanding everything, but couldn't say anything about it until now? What will they say now they can say it? Concerning major quality-of- life decisions, if I open the door and there is something behind it, how will I cope? If I don't open the door, how can I live with the guilt of never knowing and never trying? Who will believe me? Who will believe my child? What if my child communicates demands for his future or present circumstances that I cannot fulfill? What if the child I "know" is not the real person at all? Do I have to start from scratch? Do all my knowledge and expectations that I have come to terms with have to be radically changed? Do I have the energy to start? Do I have the courage?

The expectations that parents and teachers alike hold regarding the abilities of these successful users of facilitated communication have to be radically revised within a very short space of time. As research results are published, further examination of professional expectations and methodologies regarding diagnostic criteria may need re-evaluation. At this stage, however, it is principally the parents who will be examining their attitudes. According to the parents interviewed, the process of changing attitudes is both shocking and exhilarating.

Care-taker language:

One of the areas they may choose to examine is the type of language they use in conversing with the facilitated communication user. Remington-Gurney (1992) refers to "care- taker" language, and states that "modifying speaker behavior may be the key to better interaction with speech impaired individuals." Some aspects of caretaker language are contained in intonation, patronizing politeness, raised volume in the belief that the person will be more likely to understand the message, and naming adults as "good boy!" or "good girl!" Not only does such

language need to be eradicated in interactions with facilitated communication users, but Remington-Gurney suggests that it has no place in any interactions with people with any disability. It has a disempowering effect and does not enhance free communication between user and facilitator.

Choice and decision-making:

The user of facilitated communication now has the opportunity to make choices about the everyday things in life. Such arbitrary decisions as "She'd like a chocolate milkshake" cannot now in all conscience be made. Nor can the choice of reading material, television programs, recreational activities, clothes, friends, meals, or, in fact, anything that affects the facilitated communication user, be made on their behalf, if facilitated communication is to be fully incorporated into everyday life. Perhaps for the first time in their lives, facilitated communication users have legitimate power, and every opportunity should be made to present the user with time and appropriate facilitated communication aids to make these choices. Motivation is surely the greatest key to learning, and positive reinforcement of choices made and followed up on enhance the potential for the user to see facilitated communication as a valuable tool in moving from being an observer of life to being an active participant.

Educational extension:

Initially, a user needs a facilitator. Parents have expressed concern as to how they can get facilitators for their children in classroom settings. Training volunteer facilitators appears to be the only remedy as yet in New Zealand as the technique is so new that most teachers have little or no exposure to facilitated communication. There is also no government funding available for this type of support yet.

Where there are no trained facilitators in the formal educational setting of a user, parents will need to advocate for their sons or daughters. Parents have expressed that they experience some difficulty in weighing up whether they are able, given their own work commitments, to be their child's facilitator, to pay for someone to learn, or to canvas for already trained facilitators. Some schools overseas (Biklen, 1992) have adapted to cater to the needs of facilitated communication users by way of setwork-type activities, training peer facilitators, and acknowledging the level of support required by users whose disabilities may encompass behavioral, neuromotor, and emotional, as well as expressive language dysfunctions. There are isolated pockets of expertise in New Zealand where teachers are adapting to the educational needs of facilitated communication users, but things are still very much in their infancy.

TRAINING

The primary requirement of parents is for support, information and assistance as they request it. Some parents do not feel adequate emotionally for the task of facilitating their own child, and have said that they have found it helpful to get support from other parents as well as experienced

facilitators. For some parents it may take months of agonizing inability to facilitate their son or daughter; for others it is a successful and positive interaction right from the start. Some parents choose not to facilitate at all. Whatever the situation, training is a vital ingredient in assisting parents to become competent and confident facilitators, or alternatively being given the support to come to terms with facilitated communication in their own time.

VALIDATION

Validation training for facilitated communication users is important if they want their communication to be taken seriously. This is an area of facilitated communication that should be clearly discussed with parents at the outset and introduced to users as their confidence and ability grows. Parents need to be reassured that not only does facilitated communication take time to develop, but there may also be a need for formal validation training, which may take the form of practicing message passing from the facilitated communication user to two independent facilitators (Baruch, 1992). Spontaneous comments, unanticipated responses and idiosyncratic use of words or spelling (Remington- Gurney, 1992) are other forms of unplanned validation that parents can take comfort from in the early days of wondering where the communication is really coming from.

SUPPORT FOR PARENTS AND FACILITATORS

Parents may wish to set up networks with others who are working in this area, creating opportunities to discuss their concerns and experiences. Mutual support by way of group training sessions from time to time can give much needed balance, especially in the early days of facilitated communication training when parents may be feeling quite traumatized by their recent experiences. Often only one parent will be able to facilitate, or want to be involved. This can put added strain on a marital relationship that may already be experiencing difficulties due to the nature of the user's disability. Therefore support from other parents is seen as mutually beneficial.

If communication of an emotional or controversial nature comes from the user, the non-family facilitator should not take on the role of sole personal counselor. If required, the person should be referred to a parent, support agency or other person and facilitated through the counseling. Facilitated communication can be emotionally draining on non-family facilitators, and the line between professional and personal support must be clear. Remaining objective and empathic is of greater value to all concerned and lessens the risk of a user becoming emotionally dependent on a facilitator other than a family member. Parents have expressed that they felt threatened that someone who hardly knew their child was receiving communications, sometimes of a personal and emotional nature, when they had been struggling for years with no meaningful response. Non-family facilitators need to be sensitive to the special relationship between facilitated communication users and parents, and communications of this nature need to be validated by experienced facilitators.

References

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Mark's father remarked: "When I watch you facilitate Mark and hear how you speak to him, it's made me realize that I have to change the way I speak to him too. He is clearly not stupid and I have been using inappropriate words and tones when I speak to him." The father also noted that he would not be buying any more babyish books for his son to read, but would buy more age-appropriate reading material.