

Meeting the needs of people with severe disabilities

the person, the helper and the process

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This article aims to provide an account of the counselling process involved when working with a person with a severe disability: Within the confines of this article, the term severe disability pertains to a person with an intellectual and/or developmental disability which hinders learning..

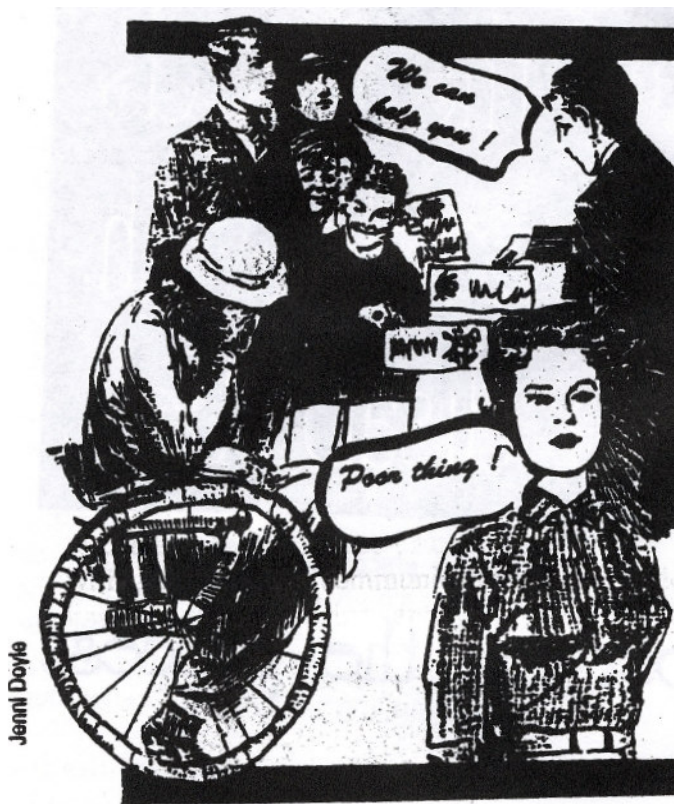
For instance, this person with a severe disability has no verbal communication skills and she is unable to express her needs and wants in the language that is acceptable to the general community. She has no formal mode of communication for expressing her thoughts and has not learnt to use alternative communication modes eg. COMPIC (computer pictographs), manual signs and other forms of pictorial representations such as photographs.

This person, if physically able, might grab at objects in order to communicate her needs and

wants. She may only have limited receptive language skills which could contribute to her inability to relate to her environment. Consequently, the person is unable to express her concerns, thoughts and so forth and at the same time is unable to comprehend and process much of the information that is received from the environment.

This person may have multiple disabilities. As well as an intellectual disability, she might also have a physical disability affecting her mobility, dexterity, communication and sense of control This subsequently places the person in a position where she develops a high level of dependence. She may have a poor sense of self-worth. The combination of these factors could manifest itself in challenging and inappropriate forms of behaviour.

In order for a person with severe disabilities



member of the community, it is common to hear that she will be 'behaviourally modified'. In so doing, we ignore the notion that she has something to say, and hence repress her from further attempts to communicate her thoughts through preferred actions. If behaviour is a form of communication, then we could surmise that a person with a severe disability does indeed wish to express her wants and needs.

In the past, some professionals believed that people with severe disabilities could be excluded from educational services designed to enhance communication. However, all individuals have the capacity to communicate. Perhaps it is the responsibility of people working with the person to interpret what she is communicating and the thoughts underlying the actions.

Some people with severe disabilities are taught to use alternative modes of communication. Even with these modes of communication, people seldom listen to their thoughts, and only when they are communicating 'acceptable' thoughts and wants do they act upon them.

Communication is essential in order for people to transmit information about themselves, their world

and others. Relaying this information is necessary for all people in order to achieve a level of independence and to function effectively in the environment. Communication is essential to growth, enabling people to develop a degree of control and autonomy. Aiming to encourage independence should be considered in all levels of communication.

Some of the identified modes of communication are listed below.

1. Verbal and written language.
This requires the person to be able to express thoughts and understand others through words, and also the ability to pronounce these words in a comprehensible manner.

2. Augmented communication systems.
These are designed to assist a person with limited verbal language skills. If a person is unable to express her thoughts, needs and wants in verbal language, systems such as COMPIC, sign language, pictorial representations and word boards could assist.

3. Non-verbal communication (body language).
So many thoughts are expressed through non-verbal behaviour, such as facial expressions, body movements, eye contact, action or non-action. Therefore it is important to be sensitive to the behaviour of the other person and recognise that the verbal message can be supported, confirmed or contradicted by the non-verbal behaviour.

Other than verbal or written language, the general community does not seem to have much tolerance of alternative modes of communication. Even within the accepted communication mode the community expects a high standard in its use. People who speak too quickly, or conversely, too slowly are frowned upon and considered poor communicators. If a person cannot verbalise the words clearly or articulately, it discourages the listener from continuing to attend to what the person is saying. There seems to be an unspoken rule of how to communicate. People who deviate from this standard would find it hard for their thoughts and ideas to be heard.

All these factors are pertinent to the problems encountered when attempting to counsel a person

with a severe disability. Problems arise when the expectations of the counselling process cannot be achieved because of the person's disability. The counselling process in general is perhaps intolerant to people who are unable to partake in the process.

In the course of this article, we seek to challenge the concept of counselling as we traditionally relate to it, when used in the context of working with people with severe disabilities who are non-verbal. It was daunting to be asked to write on this issue as so many of our learned responses are challenged when putting pen to paper. Much of the work we do in this area is based on instinct and trial and error.

The Role of the Counsellor

Traditionally, the role of counsellor is one of providing a service to another: person based on skilled help through interaction and communication and usually pertains to an equal relationship between both parties. This sort of counselling would focus on feeling, thinking, and action skills and consistently encourage personal responsibility and self-help. It would both support and challenge the person to attain more of their potential. The counsellor is to assist the person to recognise the limitations that she has placed upon herself, which have disabled her from further personal growth. Regardless of the origin of the problem, she must take an active role in managing her own problems, including the search for and implementation of possible solutions.

The ideal outcome is for the person to take control and manage her own life. For this process to occur, she must be able to communicate thoughts, feelings, actions, to have developed a receptive language, and to possess some ability for self analysis and insight. The interaction in this situation, between the person and the helper, is on an equal basis.

When working with a person with a severe disability who is non-verbal, the traditional approach to counselling needs to be re-worked or redefined. It fails in this situation as the person has poor expressive or receptive language skills. Her experiences are severely limited due to lack of exposure to a variety of situations, difficulty in abstract conceptualising, communication barriers and little or no insight into self or self analysis.

Counselling in this context can be redefined as a form of education, as a means of presenting options (if possible). The first step is to develop a mode of communication with the person: This can be achieved by developing a one to one relationship, by increasing opportunities for communication and enhancing sensitivity to all forms of non-verbal communication. The nature of the education process changes, as most of the input of information or communication is from the helper to the person. In this situation it is common for the counsellor/educator to feel like an interrogator. In order to obtain information, which the person cannot volunteer, the helper needs to elicit as much information as possible by becoming the dominant party in the relationship. This approach demands a shift in power from the person to the helper, who is then responsible for the movement and direction of the encounter.

Communication is generally a process of sharing, a recognition of each other's communicative expressions, an understanding of the topics, the purpose of each other's communication and a knowledge that communication is purposeful and reciprocal. Therefore the expectations of the counsellor/educator must also adapt to this particular situation.

Recently, a worker from one of the sexual assault units in Sydney came to see us for advice. They are getting more and more women with severe disabilities at their clinic for sexual assault counselling. Many issues were raised : around consent, around how to best 'counsel' the person, how to diagnose their needs. This is such a difficult area. It really brought home to us how many helpers are struggling in this area. The most obvious point which came out of this consultation was the need for the worker to rethink her expectations of the outcome of this 'counselling' as compared to her expectation generally with other clients. The area of sexual assault is difficult as the law is so rigid around leading or guiding victims without the use of resources, eg, anatomically correct dolls, (but that is another huge area and not to be covered in the confines of this discussion.) The function of this worker's sessions would therefore more appropriately be one of education. As she said 'clients often don't know why they are here.' How can people begin to appreciate the far reaching consequences.

of a situation if they have no previous understanding of the issues?

Sexuality and Education

When assisting someone to understand the concept of sexuality or sexual expression, the issues are much more complex than teaching a tangible concept. As educators, there are certain premises we aspire to regarding what we expect people to learn. We generally believe that, with a certain input from us, people will raise their awareness of their own attitudes and values and those of others, increase their knowledge of sexual issues and gain confidence in discussing sexuality issues.

People with severe disabilities, however, challenge this view of sex education as being pertinent to their needs. A more appropriate role seems to be improving their quality of life by contributing to an understanding of their sense of self and assisting the growth of the person. The difficulty with this, as educators, is that it no longer matches up to our expectations of the desired outcome. In this area of education we will always fail with our accepted agendas. It is a whole lot easier to see people with severe disabilities as asexual than to confront the prospect of educating them on sexual issues.

In some cases, you may think that a person with a severe disability and no verbal skills is uneducable, and therefore cannot take in terminology or participate in formal training. This is a limiting and restrictive view. If we are to regard sexuality as an intrinsic part of the whole person and their personality, then it can be argued that sexuality cannot be taught as an academic subject. From this perspective, sexuality is existential, which involves the person's personal experience and how they relate to their reality (even if they cannot communicate this to you). Because we like to see sexuality as a tangible learning experience and people with severe disabilities often cannot learn in this way, we again view them as asexual because it is convenient and more comfortable for us to ignore this area.

Self-esteem

Many people with severe disabilities live in a closely supervised environment with little privacy. They have very little personal power and are dependent on others for care in the areas of eating, bathing, toileting, etc. Often they have learnt to

disown their bodies. The way they are handled varies according to individual carers. Sometimes their only experiences have been negative ones. Due to their communication difficulties, carers are often unaware of a person's needs or their discomfort. A most important beginning in a one to one education process is to encourage the person to reclaim their body by experiencing it in a pleasurable way. This can be done in a non-threatening way with the use of different textures and sensations on the skin, eg, baths, satin sheets and so on. People with severe disabilities have very little variety of experience when it comes to sensation. For those people who have been institutionalised this is even more the case. Within a trusting relationship between the helper and the person, experimentation in this way is possible. This may also encourage: the person to explore their own body parts and to enhance their self-esteem by promoting self-awareness and some sense of personal power. The level of a person's disability determines how possible or practical this process may be.

The attitudes of carers will also have a major impact on the self-esteem of a person with a severe disability. Through carers they will see themselves mirrored as an individual or a label, a sexual or asexual being.

Commonly, people with intellectual disabilities have low self-esteem due to their disability, their lack of exposure to the socialisation process and the environment in which they live: often within institutions this is repressive, while living at home may be over-protective.

At present, the community is still not ready to acknowledge those who do not fit into the stereotype. These environmental factors contribute to the creation of a reality that fails to promote a healthy self-esteem in individuals with disabilities. Many of these individuals still function within repressive environments and yet the expectations placed upon them have changed dramatically in recent times. This dichotomy creates confusion for the person with a disability and frustration for carers and helpers because they have higher expectations, which the person may not achieve. In such a scenario, teaching self-esteem in the context of body awareness and the pleasure that can be derived from oneself would be severely undermined.



disability. However, the underlying issues of reluctance and resistance would not be addressed.

We would like to emphasise here that the main purpose of informed consent is not only to protect the person with severe disabilities from harm and abuse. It is also to respect the person's status as a valued member of the community, and to ensure their choices and wishes are respected. To some members of the community, obtaining the informed consent of someone with severe disabilities is tokenistic and seen as a wasted effort. Making decisions for others is often seen as less problematic and more practical. This discounts the person as a worthy human being. Obtaining informed consent is not the only means by which a person's dignity and choices are respected. If someone were to partake in the counselling process, with or without their informed consent, it is the responsibility of the helper to be sensitive to any feedback or communication from them regarding their willingness or unwillingness to participate.

One of the most important aspects of conducting any form of sex education and counselling is to be aware of your own attitudes and values. These

attitudes and values will bias your delivery of information and the non-verbal messages that you give. People with severe disabilities and no verbal skills are very sensitive to non-verbal messages in order to compensate for their limitations in communication. This is compounded by the inconsistent attitudes of carers towards sexuality and also by the attitudes that you carry when you enter a counselling situation. For example, most sexuality education counselling is heterosexist in nature in that it assumes that sexuality is only expressed between people of opposite sexes. It excludes other expressions of sexual preferences including celibacy, bisexuality and homosexuality. No one is able to change another's attitudes. However, it is possible to identify and challenge the attitudes that you hold. By doing so you may inadvertently create attitude changes for yourself and those around you.

People with severe disabilities have the right to have a place of value in this society. At present we, as a community, are demanding that people with a disability conform to our expectations and standards and imply that it is their responsibility to move towards these standards. This ideal does not work in the best interests of either people with disabilities or society. It is not succeeding in its aim of integrating them into the community. One possible failing is that we have placed the whole responsibility for change on people with disabilities and we, as a society, have failed to recognise that we have the responsibility to change with them. To further enhance the achievements that people with disabilities have attained so far, perhaps society needs to question its own responsibility and move towards setting up standards of accepting people for who they are rather than what we expect them to be.

