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Abstract

Jitka Jilich, an educator, discusses the fact that for people who have disabilities their community seems to be restricted to those people who are some way personally involved in their care. She cites author Donald Schon, who in 1971 examined the process of new initiatives in the community becoming 'good currency' or seen as 'marginal good currency'. Jilich says that it takes time for new ideas and initiatives to gain the status of 'good currency' and gives examples. The article also shows that ideas which were once thought of as 'good currency' are now out of favour. **Keyword: Attitudes**

Disability And Community Attitudes: A Process Of Change

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In the promotion of health for the general community there is often very little recognition given to the needs of the individual who has an intellectual or other type of developmental disability. There appears to be a general assumption by those persons and organisations that widely promote and implement major health programs on topics such as drug abuse, smoking, nutrition, or other personal or social health related concerns, that such issues are not a concern for the individual who has a disability. Part of the problem arises from the fact that there is no clear statement about the needs of these people. Further, if one were to look at the general resources on health which were available for persons within the community, it would be difficult to find much that is aimed at a level which would suit the conceptual abilities of individuals who have an intellectual disability.

For persons who have an intellectual disability, their community seems to be restricted to those people who are in some way personally involved with their care. This includes parents, relatives or staff who work in the field of disability. The promotion of change in many service areas for these persons is very dependent on this select and limited community. However, this cannot be interpreted as meaning that this field has not seen any progressive changes.

Over the past ten years the staff working in the Disability Unit at the Social Biology Resources Centre has been involved in promoting, developing and implementing health and human relations programs for people who have intellectual disabilities. They have provided educational, consultative and counselling support to professional staff, direct care staff, parents and individuals who have intellectual and/or physical disabilities. It takes time for new initiatives or ideas to be accepted within any community; at times of exasperation it has not been unusual to hear other staff and parents (and sometimes ourselves) say that "nothing has changed" or "we're still in the dark ages". However a review of the past ten years demonstrates some very clear, positive and progressive changes.

New and controversial ideas or programs cannot exist in a vacuum, but rather within a social, political and economic context. If new ideas do not concur with the predominant social beliefs and attitudes, any immediate and overwhelming support and consequent follow through is unlikely. Donald Schon[1] in 1971 examined the diffusion of new and innovative ideas within the community and also examined the factors that might influence this process. He analysed diffusion of innovation in terms of new initiatives becoming ideas in "good currency" or popular belief. If new initiatives occurred within a system of other ideas they would be said to be at the stage of being in "marginal good currency" (ie, ideas held to be true by only a minority of persons or groups within the community).

Over the past ten years, (if Schon's terms are used,) the needs and rights of disabled individuals for human relationships and health and sexuality can be described in terms of "marginal good currency" gradually moving into a state of being in "good currency" - although not yet there!

It takes time for new initiatives or ideas to be accepted within any community.

During the 1980's within Victoria, we have seen a considerable change in the nature of services and support that are provided to people who have disabilities and in the way in which these services are provided.

In 1981 some of the ideas which might have been in popular belief or termed ideas in "good currency" (as described by Schon) would have included:

1. Intellectually and developmentally disabled people are dependent and will remain dependent on their parents or on institutional carers.
2. Intellectually and developmentally disabled people are best educated and supported in specialist and separate settings.
3. The health care and maintenance of individuals who have intellectual or other developmental disabilities is the responsibility of their care takers, and of specialist health workers.

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[1] Donald A SCHON. **Beyond the stable state: public and private learning in a changing society.** Melbourne. Penguin. 1971

4. The personal and social relationships of individuals who have developmental disabilities will be the responsibility of staff and parents (and sexuality will not be a component of such relationships).

Schon also described the way ideas could be "marginally" in good currency. This would occur where there were social and contextual factors which would repress their emergence in general "good currency", and consequently they would only be found to be strongly supported by minority groups, enclaves or elite groups. Some of the ideas around the time of the International Year of the Disabled Person (1981) which were certainly still marginal, included:

1. Intellectually or developmentally disabled individuals are entitled to the same social, educational and employment opportunities as non-disabled persons.
2. Intellectually or developmentally disabled individuals need education in social skills to be able to achieve acceptance by the general community. This education is best provided within mainstream services alongside their non-disabled peers.
3. Individuals who have intellectual or developmental disabilities may achieve the competence to live independently, and their parents do not always need to remain their protectors or necessarily even their guardians.
4. Individuals who have intellectual or developmental disabilities have sexual rights and feelings like other members of the community.
5. Individuals who have intellectual or developmental disabilities have the right and the ability to make decisions and speak for themselves.

New and controversial ideas or programs cannot exist in a vacuum, but rather within a social, political and economic context.

Schon postulated that such "marginal" ideas could become more powerful or could contribute to more effective innovations if a social crisis, or a series of events, were to precipitate them into good currency. In other words, there is a range of factors which could contribute to the coalescence and strengthening of such ideas, which in turn lead them to becoming successful and prospective good currency. Some of the events during the 1980's which have influenced the acceptability of personal and social skill development as an important component of the emotional, social and sexual health of individuals who have an intellectual or developmental disability include:

1. The International Year of the Disabled Person (1981) with the public emphasis on the need to accept that people who have intellectual or developmental disabilities have civil rights and the need to "break down the barriers" so that they can be accepted members in the community.

2. An active promotion of Wolfensberger's[2] principle of normalisation for people who have disabilities, within residential, educational and occupational contexts. In 1982 the then Mental Retardation Division of the Health Department of Victoria began running intensive staff training workshops based on this principle (as did many other organisations). Individuals and organisations were encouraged to critically analyse the way in which they were providing services to persons who have an intellectual or developmental disability.

3. The demonstration of the political power of advocacy groups on behalf of persons with a disability. In 1981, the first union (called "Reinforce") of persons who have intellectual disabilities was established as a result of the 2nd South Pacific Conference on Mental Retardation. Two state wide advocacy groups which have developed are The Action Group For Disabled Children and STAR - Victorian Action on Intellectual Disability.

4. Equal opportunity and anti-discrimination legislation. The sexual relationships and reproductive rights of people who have disabilities was tabled in the Disabled Persons Act, 1987. This act publicised and supported the personal, social, economic and health rights of people who have disabilities.

5. The establishment of the Guardianship And Administration Board in 1987 within the state of Victoria. This Board works towards ensuring that the rights of all disabled people are maintained. It has the power to overrule decisions made on behalf of individuals who have an intellectual disability which it considers are not in the best interest of the person. It

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[2] Wolf WOLFENSBERGER. **Normalization: the principle of normalization in human services.** Toronto. National Institute of Mental Retardation. 1972.

assumes that all individuals have the capacity to make their own decisions unless it is proven otherwise. Where decisions need to be made by a guardian they need to begin at the "least restrictive alternative" for that individual.

6. The tabling of two reports by the office of the Public Advocate namely: **Silent Victims** (May 1988) and **Finding the Way** (April 1987).
7. The development and launching of the Ten Year Plan by the Office of Intellectual Disability Services (1989) which is to guide the direction of Intellectual Disability Services in the State of Victoria over the next ten years.
8. The funding of the National Self Advocacy Kit Project which actively promotes both the self and group advocacy of people who have disabilities.

Most of those ideas which were in marginal good currency in 1981 were occurring along side these events. Many of them have clearly attained the status of being in good currency in 1989.

In 1981 I was at the "receiving end" of human relations staff education which was provided by staff of the Social Biology Resources Centre. In 1983 I became increasingly involved in providing this education to other staff, and in 1985 I was formally employed by the Centre. During this period there have been changes in the content of staff education about health, relationships and sexuality for people who have intellectual disabilities. While many of the topic areas remain constant, in the early 1980's there appeared to be a subtle but strong emphasis on "convincing" course participants that it was important to address the personal, social and sexual health of individuals who have disabilities. To use the same approach in 1989 would, in most cases, be "preaching to the converted". Most participants acknowledge the importance of health, human relationships and sexuality education for persons who have intellectual disabilities. The emphasis of staff education now appears to be on the "how to implement" rather than "why do we need such education and support". In particular there is emphasis today on:

- How to effectively reinforce concepts and ideas presented in client education or counselling on a daily basis.
- Identifying the available resources and strategies that will help staff to implement human relations and sexuality programs.

Change is a process, not an event.

In the early 1980's there was a strong tendency to be "reactive". That is, staff in the Disability Unit at the Social Biology Resources Centre were responding to expressions of concern by professionals, direct carers and parents. The major concern was the need to provide individuals who had disabilities with the personal and social skills to decrease their risk of exploitation and sexual abuse, and where possible, to modify behaviours considered to be inappropriate (such as indiscriminate touching) as these were increasing their isolation within the community. While this is still important, in the past five years there has been a much stronger pro-active emphasis on teaching and supporting people with intellectual disabilities to actively acquire the skills for developing and maintaining genuine friendships and to learn to relate to people in a range of different contexts. It is believed that this will enhance their quality of life and will assist them to be more readily accepted as members of the community. There is also an emphasis on developing decision-making skills as well as the ability to assertively express their feelings and needs. There is a greater understanding by many workers, parents and advocates that the deficits in the personal and social skills of the individual are only partially (and sometimes not at all) related to the disability itself. Rather these deficits may be much more related to the life experiences of that individual as a consequence of the disability.[3] This has led to the development of a more preventative approach, especially when working with children, adolescents and young adults. These changes are indicative of ideas in marginal currency which are "moving" into a status of good currency. However I do not believe they have truly achieved the status of being in "good currency". One of the major indicators of the achievement of this goal will be when government service bodies develop health, human relations and sexuality policies. For example, the Office of Intellectual Disability Services is yet to develop such a policy.

Another major indicator will be when concerns about the personal and social health of individuals who have intellectual disabilities are accepted within the community via the general services that the

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[3] Susie SMITH. "Developmental consequences of disability" in **Proceedings of the Conference of the Association for Scientific Study of Intellectual Disability.** Perth. November, 1987.

community provides. This means that education and counselling support needs to be provided within and by the community in the same way in which it is provided to all other persons in the community. This will also be evident when the organisers of major community health programs recognise the needs of the disabled community and begin to actively include them in both their functions and program implementation. It takes time for new ideas and initiatives to gain the status of "good currency". The old adage that "change is a process, not an event" is an important one. Change has occurred, and as long as there are groups and organisations who continue to advocate on behalf of all persons who have an intellectual disability, we can expect that there will continue to be progressive changes.