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Inclusion Through Participation in Support Groups

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ABSTRACT

As part of the requirement for my Master of Arts Degree I wrote a thesis, as an insider, on the value of support for members of a small community. I was particularly keen to tell our stories. It was evident how our struggles and problems were not that dissimilar from other groups, for example, the emancipation of women and the plight of indigenous peoples. My discipline in social anthropology is located within the humanities and provides an ideal base for studying the interconnections between oppressed groups.

Several years previously I was fortunate enough to join a motivation group, initially, it was facilitated by a field worker and then the group managed its own program until it disbanded. I was curious to know why the concept was successful. A small group of adults with disabilities, were drawn together. What was it, camaraderie, bonding, communitas or all of them? Perhaps being with others who have shared similar life experiences is enough.

I started exploring models used by humankind for millennia, such as apprenticeships, where the more experienced members of a group drew newly arrived individuals to the centre and thought them skills..

This paper will explore how support groups work and how they can be sustained. Also how, the tertiary education environment can lend itself to co-mutual self help support groups for students with disability. It will include a model, "communities of practice" that would work successfully within the tertiary environment. It will also explore the importance of encouraging students to belong to support groups—either in the institution or the community.

1. INTRODUCTION

In this presentation I am going to speak about a support group concept and both explain and show how the idea is well suited for the development of inclusion of disabled students within the tertiary education setting. I will advance the argument that peer support is used across the life span and is effective for people of all ages as an aid in helping them cope in our society. The basic premise is advanced by neo Vygotskian educators regarding his concepts, of young children being effective agents in their own learning process. This is also described By Victor Turner, a social anthropologist who studied pre-industrial cultures in Africa on the

integration of any members into their own community. I will also show some analogies with other marginalized groups indicating some of the oppressions that they face within their own environment.

2. WHO AM I?

I have never the liked the word disability, the term seems pervasive and an all-encompassing word to me. I went through the stage of saying that I was a person with an impairment, but that is, a medical descriptor of part of my condition. The experience is disability and is a social construction. It is in the eye of the "other". Disabled people deal with a lack of access to resources all the time. This is some what taken for granted by the majority in society, which restricts equal access to those resources. That is a part of maintaining exclusion. I have Multiple Sclerosis, it is with me all the time but it doesn't consume my whole being. Most of the time I am ordinary, well I look ordinary, God I hope I am. But multiple sclerosis is an incurable and debilitating neuro-spinal condition and the most prevalent neurological problem for young adults in the Western world. I was diagnosed here in Sydney back in 1980 when I was part of the way through my Big O.E. It never seriously affected me physically till about 10 years ago. Was that the time, I succumbed and didn't manage my condition, at all well, against an uncompromising environment? Not long after I returned to NZ from the UK, I decided that I needed to retrain and I sought a qualification in social work.

3. AND WHY AM I STANDING HERE?

Since 1994, I have been very much a full time student at Massey University in Auckland, apart from last year when I took some time to be of service to my fellows. For my masters research I observed and participated in a small group of men with MS. I studied them as an insider and constructed an ethnographic thesis called, *Men with Multiple Sclerosis: A Study of a Mutual Self-help Support Group*. I am now researching access-ability issues in the tertiary educational setting and about to start writing on inclusion for students with disability for my PhD. Why I started to explore in this area, developed from my own healing experiences back in the early 90s, when I was invited to join a newly formed group of young to middle aged adults with physical and sensory problems. This group, bandied together, called themselves the "motivation group". I'll now read you the first paragraph of my thesis.

It was a Friday morning when I joined the "Motivation Group" for what was to be one of life's little enjoyable episodes. It was here that I was to find out that other guys were having similar experiences to myself. Just being in the company of others who shared the experience of multiple sclerosis was enough; we didn't have to bleat about our own problems, we understood. It was here that I came to realise the value of gaining knowledge from more experienced members of that group. That helped me to adjust more easily to society's demands. They showed me how to access the vital resources that would make my life more comfortable. It was this process of guided

participation in the support group environment that now forms the basis of this thesis.

(McCool 2000)

From a simplistic analysis of my reflections, you can see I was already starting to benefit from being in a group of people who had experienced similar episodes as myself. I thought thank God, I am not going mad, there are others like me.

Levine et. al. Psychologists devised a working definition of social support that proved useful in this understanding. The six areas of support include:

1. *Emotional support. The opportunity to share and express feelings, coupled with empathetic feedback concerning the authenticity and appropriateness of pressing emotional experiences.*
2. *Esteem support. The experience of being accepted and valued by people who are willing to listen reflectively and empathetically instead of judgementally.*
3. *Informational support. The opportunity to collaborate with people in order to gain information, advice, and guidance are (sic) potentially helpful in clarifying problems, generating options and developing workable solutions.*
4. *Companionship. Enjoyment of the friends which emerge in the course of pleasurable social activities.*
5. *Motivational support. The availability of encouragement and reassurance, offered in an atmosphere of hope. This enables the recipient to endure frustrations and to persist in the solution of long term problems.*
6. *Status support. Some mutual aid groups may produce positive changes in self-perception and social recognition by offering the individual a meaningful role and a valued identity within the larger community.*

(Levine et. al., 1990: 188)

This was my first experience of attending an unstructured peer support group meeting. I had been a member of other clubs and societies, like the diving club, St. Vincent de Paul society and freemasons. But somehow this seemed, different perhaps because I was a little older. I was able to see links between the different benefits and drew many parallels from freemasonry and social support. We began developing a community of practice. It certainly didn't take long before we had struck a close friendship. Here was a group within a group of men that had been relatively high achievers in their work life. They had come to a transitional phase in their life, due to disability they found that they were without the security of a job and had new issues to face such as an inability to drive, fatigue, and managing others perception of self. Then we learnt together ways of adapting to our changed life style.

4. HOW DO SUPPORT GROUP'S WORK

The motivation group was effective for all of the reasons highlighted by Levine et al. Probably at the time it was thought that it was successful more from a position of luck, more than judgment. The concept has been transposed to other groups that formed later, one of them called "boyz-R-us", mainly men with MS, of which four of us had been members of the motivation group in the past.

4.1 Bonding

I was reminded of other experiences of bonding, the mateship formed in the early days of starting work. I worked for the CBA Bank, now part of Westpack. Just after I left school in the late '60s, I was sort of indentured. We had to pay $20 for the privilege of joining The Bank's service. It was very similar to becoming an apprentice. You were not shown by the boss, how to do the job. It was the junior (now not so junior as you were the junior) who showed you what to do. He had moved up the run to the next job and it was his duty to keep an eye on you. So learning was partly by instruction, partly by observation, metacognating, or thinking about thinking and practice. I didn't start off as the bank manager. I was the postage clerk. Training through apprenticeships has a plethora of similarities to peer support groups like "boyz.R.us" as mentioned earlier, in fact they use the same processes, it just that in the work situation they have a more formal structure.

4.2 Size

Size is relatively important for support groups, the smaller the better. A group may be just two people. They can benefit from supporting each other. The literature has indicated that even men's mutual peer support groups operated in a nonhierarchical relationship between its members and this was similar to women's groups. The motivation group probably had about 30 members initially, but it didn't take long before it fractionated into smaller groups, I am reminded of the saying "birds of a feather flock together". Although disabled people represent nearly 20% of the population they are not a homogenized group of people. They follow their own interests. They have other interests that they would rather be involved in. I suppose the concept of disability issues, revolves around being a political movement to gain equal access and opportunity.

4.3 Shared life experiences

Support groups generally worked more effectively when individuals shared similar life experiences. It is in the finding of that shared space that camaraderie is found. In New Zealand, when Maori meet a stranger they try to find connections between themselves, their shared ancestry and present family relations and common relationships and interests. They call this whakawhanaungtanga. But I think this happens in all successful communities. Even in our own local communities we attempt to find common interests. We lost some thing, when we became industrialized and urbanized. The maintenance of social relationships are so difficult when we are individualist, forever trying to make ends meet, servicing

our extraordinary debt. We are so busy, we can't afford the time, we need to concentrate on our own issues so we ignore our neighbours and live in a state of anonymity. We used to see it much easier 40 or 50 years ago. When I was a kid I spent a lot of my holidays time in the country with my grandparents, uncles, aunts and cousins. In a small community, people are interested, (it is not that they a nosey) they are all connected, and interrelated. Through this industrialized process of individualization people with disability are left adrift minus the supports available to prior generations. The support group provides the small community ethos or community of practice.

5. WHY THEY WORK

These beneficial processes in mutual aid groups can be looked at in terms of satisfying the needs of their members through:

1. overcoming the effects of isolation and instillation of hope-groups consist of people at various stages of dealing with their condition.
2. universality-a belief that members are unique in their experiences.
3. imparting of information-participants learn a vast amount on a great variety of topics.
4. altruism-opportunity to receive for oneself through giving.
5. collective emotional experiences-authentic emotional expression, the "no bullshit" factor and being in a psychologically safe environment.
6. group cohesiveness and commitment to each other.

Robinson et. al. (1995: 71) point out that, 'By sharing the experiences and coping strategies of people facing similar situations, people with disabilities (as well as those that assist them) may learn to add the + plus to their own coping styles'.

5.1   Some theories on why

Vygotskian theories, and these have been highlighted aptly in a book published by Wink and Putney (2002) called, *A Vision of Vygotsky.* Vgotsky died in Russia in the early 30s. As a psychologist who was formally trained in linguistics he made a valuable contribution adding to documenting the learning process. Although he spoke mainly about children there are far reaching implications for all of us. This concept was advanced by Lave and Wenger (1991). It proposed that particular communities of practice act as powerful mediums to accomplish real collaborative work through guiding participants from the periphery to the centre of the community. According to Lave (1991), learning takes place as a function of the activity, context and culture in which it occurs. Learning is thus "situated" within a definite social and cultural domain. Social interaction is a critical component of situated learning in that newcomers develop an identity within the community and acquire skills through collaborative interaction with established members. Learning in this context is usually not directly taught, it is unintentional, occurring through active participation in working together with other people. These ideas are what Lave and Wenger (1991) refer to as the process of "legitimate peripheral

participation". Vygotsky coined the term "zones of proximal development"(ZPD) to describe the learning process when relating to metacognition explained early in my experiences. This process of collaboration between the slightly more advanced student who advises and demonstrates their own experiences helps the novice to think about and develop a rationale of mastery of an issue.

Within the context of any support group, the "community of practice" framework holds promise as an anthropological perspective for understanding the conditions necessary to promote effective coping strategies amongst those who are students with disability. Support Groups that use an "apprenticeship model" for guided participation for both males and females include structures, for example, like that combat fear of flying or dealing with addictions like Alcoholics Anonymous.

By becoming separated in their learning, peers have unique experiences, Victor Turner shows how these relationships develop within a separated state which he calls liminality. This camaraderie between its fellows was both apparent between members of both peer support groups and apprentices or indentured juniors.

5.2   An analogy

Applebee (1998) used an analogy of poverty and work, that we can use quite well to illustrate similar problems that many disabled students endure. Although she was describing experiences of families in the north of England there are too many similarities between disability and poverty to exclude this quote:

... for the effects of social exclusion and poverty - disempowerment, feelings of low self-esteem and lack of confidence - create an almost insuperable barrier for educators as they seek to help people living with these effects to reach their potential. The impact of this social exclusion and poverty is being coped with day in day out in schools across the land and manifests itself in poor attainment and attendance, increased behavioural problems and escalating pupil exclusions - many of you know the effects better than I.

Poverty shares almost a synchronic relationship with disability and being a student, so often being poor and a disabled student can be tantamount to failure. Most of time you can't fail at being disabled, but you can lose the plot and not mange your condition very well. Depression is so often part of the experience, and when something has got to give, often the studies as being the easier of the options.

6.   A MODEL

Co mutual self support groups that are (1) short lived seem to be most effective, that is to serve a need. They must be (2) peer led, although it could be that facilitation might be necessary to start them off. And, (3) size is important, one-to-one contact often leads to both parties helping each other very efficiently. In my own research about seven members seemed a comfortable group when all were able to "eyeball" each other. Learning at tertiary level is generated from

within the student and uses as much the same as Vygotsky's idea of zones of proximal development for the process. Scaffolding and structures for development are better coming from their peers. In other words the disabled student needs to have ownership of the process.

Applebee (1998) goes on further to say:

The cultural glue, which gives meaning to every area of life, bonding people to one, another is rapidly dissolving. An example of this is what has happened to the socialisation of young men in such communities. Work provided an important support to parents as their teenagers grew to be men. It provided the means by which young, daft boys became sensible young men to whom young women were prepared to commit themselves (and we see the knock-on effect on family structure where men tend to be absent). The workplace provided older men and a hierarchy through which boys learnt skills, discipline and self-control. When the paid work disappeared, so did the contribution it made to this process.

Applebee shows that apprenticeships, as with the support group concept, are effective for both members and trainees in developing structures for survival and learning that move beyond just training. Although on the surface, much of the training of individuals was operative in apprenticeships. In the support group environment the lessons learnt from peers is more symbolic, in actual fact both are learning how to become more acceptable socially. It increases the self-esteem of members of both groups so that they feel they can become productive members of society.

7. ENCOURAGING STUDENTS TO BELONG

Well how do you do it? When we often deal with disability in isolation. There is an old Irish saying 'it is in the shelter of each other that the people live'. Co-mutual support groups are self-help groups. They help self-esteem. The groups can only be inclusive of students or staff that have impairments. Role models are important, but healthy disability coordinators have no currency. They may empathize, but generally they don't have the experience of the discrimination and prejudice that many disabled students, or disabled staff, face day in day out. We all join groups or clubs out of self-interest. Some don't want involvement with disability because of the stigmatization. The idea is right, self-determination may eventually be the goal of those who need to successfully adjust. For disabled students sharing of concerns through their peers is instrumental in developing a motivated self to put it back into confidence, assuredness and esteem.

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