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Independent, Proud and Special: Celebrating our Differences

By Jenny Corbett

INTRODUCTION

I find the term "independent", like the term "empowerment", to be, at best, ambiguous, and at worst, misleading. We are none of us truly independent individuals, depending as we all do on the structures which support our daily life. To be fully alive as human beings requires a complicated inter-dependency upon networks of people and systems. Independence is not about coping without help of any kind. That describes a bleak existence.

There are three key issues which I shall be exploring in this chapter. They are:

1.   The need to distinguish between independence as a skills based process and independence as a mark of individuality;
2.   The need to recognise the delicate and subtle relationship between independence and inter-dependence;
3.   The need to respect individual differences and the ways in which the dominant culture can oppress marginalised sub-cultures.

1. WHAT DOES INDEPENDENCE MEAN?

The way in which I would define "independence" is in:

- knowing what you want and being able to express individual needs;
- having a strong sense of self which recognises personal boundaries;
- having as much control over your own life as possible.

Within so many special education programmes for disabled young adults, there is a significant emphasis upon teaching skills of empowerment and independence. Elements of such courses may well include sessions on assertiveness, self- knowledge, decision making and time management. Whilst there are clearly many techniques and practices which can be shared in these learning experiences, I would still wish to question whether "independence" is a skill which can or should be taught, without carefully contextualising it in a social and economic system.

In 1989, I wrote a paper for the then journal *Disability, Handicap & Society* called `The Quality of Life in the "Independence Curriculum"'. This paper emerged from my research into what were then termed, "daily living skills" courses, which had become very popular in further education colleges. These courses often extended over two years full time and were designed for students with severe learning disabilities, complex physical disabilities and emotional and behavioural difficulties. The rationale for them was that a mark of true adulthood was the degree to which we all become independent in our daily lives, being able to shop, cook, budget, clean and arrange our recreational interests.

Whilst this clearly makes sense, if we construe "normalisation" as all adopting similar behaviour patterns within the society in which we find ourselves and, thus, being able to assimilate and become part of the group, it does not necessarily mean that we all experience the same level of independent living. If the daily living skills of cleaning, shopping and running a home are easy for us to manage and take up little of our time, leaving us free to do other things, that is fine. If, however, they assume such importance in our daily lives that we are left with little free time to do anything other than complete daily chores, this becomes a rather limited form of independence.

Within a society such as ours, people tend to measure their level of independence in economic terms. If they are earning a high salary, this enables them to pay others to clean and manage their household chores. They do not require the marker of independent living skills which doing all the mundane daily tasks constitutes. When young people with physical and learning disabilities are trained to manage daily living tasks for themselves, this may involve them in laborious and even painful processes, which can inhibit rather than enhance their quality of life.

My hypothesis, within that earlier paper on "The Quality of Life in the Independence Curriculum", was that the expectations being asked of disabled teenagers were higher than those asked of their non-disabled peers. Adolescence is traditionally accepted as being an experimental and irresponsible period of life. Why, then, were disabled teenagers being asked to spend so much time on the kinds of daily living tasks which their peers would avoid if possible? Having an untidy bedroom and eating unhealthy foods are surely commonplace among adolescents. For some disabled young people, on college courses in the 1980s, they were the key elements on which they were assessed as being appropriately adult.

It is important to recognise that current thinking, in, for example, books like *Whose Choice?,* edited by Judith Coupe O'Kane and Juliet Goldbart (1996), is

more sensitive than in the recent past and issues of sexuality, empowerment and age-appropriateness are all explored and contextualised, acknowledging their problematic nature. The vital factor, in debating concepts like "independence" is that every person is different and will have their own form of individuality which requires a means of expression unique to them. In 1993, Sue Ralph and I wrote a joint paper for *Disability, Handicap & Society,* called "A Shared Presentation: two disabled women on video". In this, we were reflecting on two videos which we had separately made with our disabled women friends. We wanted to help them to present themselves and their daily lives as they saw things and not as others would wish to portray them.

From this experience, we learnt that what was important to them was not necessarily their ability to run their own homes without assistance - this may have been quite inappropriate in relation to the severity of their disability.

What they both found most important was to be able to pursue their specific interests and to maintain their network of friendships. In other words, it was an independence of mind which seemed to create a quality of living experience. This surely applies to us all. In our choice of interests, friendships and social networks we grow and develop and enjoy the rich inter-dependence which full living offers.

2. WHY DO WE ALL NEED TO CONNECT TO OTHERS?

It seems inappropriate to talk about independence without recognising the significance of our inter-dependency. We all need to connect to others, if we are to become active citizens. There are many connections which are valuable in their different ways, be they relationships with friends, lovers, family, animals or within wider social networks. We learn about ourselves through connectedness with others. It is part of our human nature to want to give to other people, be it in the form of time, company, support, affection or co-operative efforts.

Disabled people are often the recipients rather than the providers of care. They have as much need to enjoy the pleasure of inter-dependency as others but are so often confronted with attitudes which label them as incapable carers. In a recent Channel 4 documentary, "The Story of Julia", a young woman who is deaf and blind was shown in her battle with social services to keep and bring up her baby. Her desire to be a loving mother was evident but the severity of her disability meant that the caring professionals regarded her as a potentially high-risk situation. As it was so rare for a deaf-blind mother to bring up a child, this was something of a test-case.

The young woman was extremely independent in that she expressed her views clearly and frankly, telling some of the social workers exactly what she thought of their concern. Of course, she recognised that she needed considerable practical help in order to manage her daily routines. What she wanted was a level of inter-dependency which placed her views and perceptions alongside those of the "experts", whereby she could share her own mothering tasks in the way she wanted. It was notable that this particular young woman was regarded as "difficult" and "aggressive" because she was so adamant about the degree of control she wanted over her own life. Disabled people are often expected to be compliant and dependent. Life is easier for them if they are.

In my opinion, it is far more caring to let the other person take the initiative and direct actions which can then be undertaken by non-disabled supporters than to take over control from them. However, this kind of caring requires a high level of empathy. It also calls for humility, in recognising that professional experts do not always know what is in the best interests of their clients. They are experts in types - not in individuals. Placing a high value on our inter-connectedness involves trusting that those who are trying to become more independent can only do so with support from others.

The dilemma in the "care in the community" initiative is the lack of care and the lack of community. If de-institutionalisation means, in reality, that someone is living in one room in a lodging house in the community rather than in a hospital ward in residential provision, this can hardly be seen as anything other than locational integration. For it to become a much richer form of social inclusion, this kind of bleak independence has to be supported by wider social networks and friendships. It is quite evident, in looking around our major cities, that there are many isolated individuals whose independent living involves existing on the streets, dependent upon charitable donations from passers-by. Such people can be treated as non-persons. In order to avoid the discomfort of too close an encounter with homeless individuals, fellow citizens tend to walk by hurriedly, looking straight ahead and almost pretending that they are not lying there on the pavement. People who are perceived as socially dependent are often devalued as being of less importance than those whose citizenship is defined by occupational status and social standing.

I began this chapter by stressing the importance of distinguishing between independence as a skills-based process and independence as a mark of individuality. I think that the focus upon skills for independence in the training programmes for students with physical and learning disabilities is a way of avoiding confronting the hierarchies of individual differences. The basic living

skills which mark our progress into adult responsibilities might be regarded as a crude base-line for independence. It offers only the lower framework for what can become a fuller form of independent living. If we equate true independence of mind with a respect for individual differences, this requires a value system which is rarely found in our competitive society. There are definite hierarchies which delineate how and where and for whom individuality is acceptable.

3. DOES THE STATUS QUO VALUE INDIVIDUAL DIFFERENCES?

In any society, what constitutes "normality" is fluid and flexible, according to how the dominant value systems change and develop. Over the last twenty years in Britain, we have seen considerable changes in the ways in which - women, people who are black, gay or disabled are regarded. We live in an increasingly pluralistic society, in which many cultural groups co-exist. This might be seen by those wishing to preserve the status quo as dangerously insecure, leading to social fragmentation and loss of the cohesion which status quo from which we were missing.

In 1991, I wrote a platform piece for Disability, Handicap & Society, called "So, who wants to be normal?" in which I suggested that the normality of the status quo was not something I strove to emulate. I said that I would be insulted to be labelled as "normal", which I felt seemed "to embody confinement and restraint: a pinched, arid meanness". In 1994, I went on to write a paper for Disability & Society, called, "A Proud Label: exploring the relationship between disabililty politics and gay pride", in which I compared the process of "coming out" as gay with that of "coming out" as disabled. One of the essential features of "coming out" is that of expressing both individuality and solidarity at one and the same time. It is saying, "This is who I am and I align myself with this group of people". Of course, this is to simplify what can be a most complex process.

Many disabled people do not support disability politics or seek to join groups of other disabled people but try to blend as much as possible into a varied communal environment. Similarly, many gay people have no desire to support gay politics or to mix in predominantly gay social circles. Seeking solidarity is not compulsory. It is there as an optional extra for those who find it helpful and stimulating. If "coming out" can be seen as an expression of independence of mind, it is a reflection of the individual themselves deciding that they place value on their own difference. In the recent past, it was not uncommon for many marginalised groups, including those who are disabled black or gay, to be stigmatised as being undesirably different and to be encouraged to take on a

self-deprecating role. Thus was the label of pride born: taking the bigot's labels of "cripple", "nigger" and "queer" and turning them around to become badges of strength and solidarity.

It can be seen that there is a very real struggle between the need to join forces in marginalised groups and to draw power from cohesive and collective action and the simultaneous need to express individual differences. This can be seen in the women's movement, where there are so many different experiences which struggle to find common ground. It is also evident in the black and gay movements, where there are tensions between different factions who begin to fight among themselves rather than join forces to fight for a united sense of injustice. In the disability movement, one of the more recent struggles has been between disabled women and disabled men in the debate on the relative merits of a social model of disability and a recognition of individual differences and experiences of pain.

Whilst these tensions are very uncomfortable and threaten the power of solidarity within a fragile sub-culture which needs cohesion, they can also be seen as healthy, in showing signs of individual differences and distinct needs. It seems important to me that we don't run the risk of turning marginalised groups into forces for oppression which silence awkward expressions of individualism. If views are to be heard as independent voices, their right to be different from others who are proud of their own differences must be respected and valued.

CONCLUSION

In calling this chapter, "Independent, Proud and Special: celebrating our differences", I am deliberately celebrating my own experience of difference alongside that of my friends and colleagues. In my most recent paper for this journal, "Teaching Special Needs: "Tell Me Where It Hurts", I reflect on my own career experience and the complex reasons why I was drawn to work in special education. It is only relatively recently that I have been emotionally capable of revisiting the distressed and disturbed adolescent that I once was and helping her to feel calm and confident. In being quite unable at that time to accept, let alone celebrate, my gay identity (it was labelled by far more medical terms then), I took on the self-loathing role and gave myself a good deal of pain in the process. In now playing an active part in the disability arts group, "Survivors' Poetry: poetry workshops and performances by and for survivors of the mental health system", I am able to share and inter-connect with others who find poetry to be a valuable means of self-expression and catharsis.

I have definitely felt empowered by the love and support of other gay people. This does not mean that I want to live within an exclusively gay culture, nor to

align myself with radical elements of gay politics. For me, independence of mind is about deciding who I am as a person and what my deepest needs are. I appreciate that, as an academic, I have a certain degree of access to dominant "discourses. I am also able to move between varied and diverse social groups, whose value systems may be conflicting and even breed hostility. I am wary of fundamentalism, whatever form it takes. I feel that different views need to be listened to and respected, if we are really in the business of celebrating difference. Where they are clearly socially destructive opinions, they need to be heard in order to be properly challenged. I am not scared of others disliking my views and want to listen to perceptions very different from my own.

I end by asking if there is a political agenda attached to the celebration of individual differences. We need solidarity in order to build power in minority groups. As in any collective (like Trade Unions) there is a tradition of sublimating individual needs in order to foster the good of the whole. I suggest that this tends to be most necessary in the early stages of any political movement, when the oppressed need to join forces against their oppressors. It is surely a mark of maturity within a political group when they are able to allow for individual differences. It indicates a level of comfort and confidence, which acknowledges that expressions of individuality are healthy and just. There are clear differences within the disability discourses. The dominant group can be seen as those (predominantly white male) who have spinal injuries and whose voices are most often heard in academic debates. This leaves disabled women and those from other groups, like people with learning disabilities and mental health difficulties, on the edge of the dominant discourse, getting their views often marginalised. We might feel that it requires a revolution of sorts to relocate the sites of power and change the discourse arena before it solidifies as a mirror of the hierarchies within society in general. We might, however, feel that the struggles in minority groups merely reflect the perennial inequalities in all social networks and that they are to be expected.

As a final request, I would ask you to read beyond *Disability & Society,* excellent and stimulating as it is, and to explore the many disability arts magazines which exist on the fringe, in print and in the media. They offer a true celebration of individuality and difference which communicate directly at an emotional and instinctive level, accessible to all.

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