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Why is disability culture a crucial component of the disability rights movement? The question is addressed by Finkelstein, a psychologist by training, tutor in Disability Studies at the Open University and Visiting Senior Research Fellow in the Centre for Disability Studies, Leeds University. Finkelstein has a disability.

LONDON DISABILITY ARTS FORUM

Disabled People and Our Culture Development

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1. INTRODUCTION

I have been asked to talk about disability and culture, not merely our need, our right, to participate in the cultural life of our country, but our need to develop our own cultural life, to create a cultural expression of our lives. This is not easy, for two reasons. Firstly, there is a great deal of uncertainty amongst disabled people whether we do want 'our own culture'. After all, we all have had experiences of resisting being treated as different, as inferior to the rest of society. So why now, when there is much greater awareness of our desire to be fully integrated into society do we suddenly want to go off at a tangent and start trying to promote our differences, our separate identity? Secondly, at this time, even if we do want to promote our own identity, our own culture, there has been precious little opportunity for us to develop such a cultural life. Certainly, few of us would regard the endless hours that disabled people used to spend basket weaving under the direction of occupational therapists in institutions and day centres as an artistic contribution that

disabled people made to the cultural life of humankind.



Anne Rae and Vic Finkelstein

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So, if it is difficult to say what a disability culture is, what can I say? We must, first of all, remember, that culture is not about individuals, it is about the life styles of population groups, whether large or small, national, or local, or even international. Therefore, one thing, at least, is clear: if we are to make our unique cultural contribution to society then this must come collectively from the people, it cannot be imposed on us by leading disabled individuals **from the top down**, any more than it could, or can, be imposed upon us by occupational therapists, art therapists, or any other therapists that are forced upon us in the future. It must arise out of the spontaneous desire of disabled people to share our feelings, experiences and desires, our loves and hates, our pleasures as well as

our sufferings, **amongst ourselves**. In other words, we have to make the choice that we want to identify ourselves as disabled people. We have to be willing to express our separate identity. There can be no disability culture without this freely made choice.

(a) **The multicultural society**

We all have some idea about the multicultural nature of our society. We can recognise this in the presentation of Black arts and music on television and radio, television programmes and newspaper pages for women, the growth of women's theatre, working men's clubs, gay and lesbian journals, and so on. In all this diversity it is easy to recognise that society **is** made up of separate groups, each with its different contribution to society. It is also no big step from this to acknowledge the right of different groups to make their own contribution to social and political life, even if some political parties have difficulty accepting such rights at the present time! Even disabled people, we should not forget, are recognised as a separate group. If we did not have this recognition then there could be no such thing as '**special education**', '**sheltered employment**', '**disability allowances**', etc.

(b) **The dominant culture**

However, it is also clear that although there are many cultures in our society not all groups are equal. There is in fact a hierarchy with the so-called **White Anglo-Saxon Protestant Male** values and culture at the top. This is the dominant culture. When talking about culture, therefore, it is most important to remember that if we do not say **which** culture we are talking about then there can be confusion about whether we are referring to the dominant culture or to the culture of some other group. Does **British culture**, for example refer to the culture of the dominant group or to the multicultures of Britain?

This may all sound very abstract but it can be very important when we talk about disabled people participating, or gaining access to the arts. Are we talking about access to normal arts and culture, that is, to the dominant culture, or are we encouraging participation in a multicultural society? It is essential, therefore, for us to be clear, and to make clear to others, not only what we mean by **integration** into the arts, or society as a whole, but more importantly, what we are encouraging disabled people to integrate into. If we do not do this then we may well end up finding out that what we have actually been encouraging all along, despite what we thought we were doing, is integration into the dominant culture. This, I fear, is, with a few notable exceptions, mostly what has been happening with the campaigns to involve us in the arts up to now or, at the very best, left everyone confused about what we really want.

2. DENIAL

Because there is lack of clarity about the cultural world that disabled people are encouraged to join this world is mostly the dominant cultural world of able bodied people. There are two sides to the coin that is being presented in order to buy our entry into the able bodied world. The first encourages disabled people to want to join the **normal** world by concentrating on our **abilities** and not our disabilities. The second tries to encourage disabled people to concentrate on what we have in common with able bodied people. Neither side of the coin, however, can buy our entry into the able bodied world. In the end all that we have bought is the able bodied role model and for this we have exchanged our identity!

(a) **Emphasis on 'ability'**

The most notable example of recent attempts to foist **ability not disability** values on disabled people is the cancelled 1986 ARTABILITY Conference. The conference, as many disabled people now know, was arranged as a follow-up to the Attenborough Report which is largely concerned with access to able bodied arts. By concentrating on **ability** the organisers lost sight of disabled people and **our** view of the world. It was no accident, therefore, that the dominant cultural values not only determined the programme with its emphasis on able bodied people and how **they** can

improve **our** access to the dominant culture, or how they can improve and promote art as therapy for disabled people, etc., but some important parts of the programme were not even accessible to wheelchair users! The conference was cancelled by the organisers when these **ability** values were collectively criticised by organisations of disabled people.

Clearly by focussing on ability it is easy to lose sight of disabled people and when this happens the dominant cultural values, whatever the original intentions, are the ones that get promoted. Far from buying access to the normal (able bodied) world the side of the coin that displays **ability not disability**, and is labelled **something-ABILITY** (such as ARTABILITY or WORKABILITY), discourages our involvement in, and contribution to, the multicultural world. It encourages us to aim at able bodied standards and values rather than to create our own standards and refer to our own abilities!

(b) The people first movement

Historically, the problems we face have been interpreted by able bodied people as resulting from our disabilities (meaning our impaired bodies). Since our experience is the opposite, i.e. that our problem is trying to live in a world designed for able bodied living, there is a natural tendency for disabled people to want to shift the focus of concern off the disability (meaning our impaired bodies). However, instead of shifting this focus onto our society, with its disabling dominant able bodied culture, some people have mistakenly tried to remove the focus of attention altogether by asserting that we are all people first. An example of instant integration!

In this country the term **people with disabilities** has been coined to try and buy our way into the world like everybody else, to be accepted as people first. But what does **everybody else**, or **people**, mean here? Since we do live in a multicultural society there is no way that people with disabilities can think of ourselves as people first and at the same time be clear about the culture with which we identify. Thinking of ourselves as people with disabilities, surely, encourages us to lose sight of ourselves and when this happens, as we saw with the emphasis that people with able bodies (to be consistent) put on 'ability', then the dominant cultural values, whatever the original intentions, are the ones that get promoted.

Perhaps this fortunate promotion of dominant culture values explains why it is that people with able bodies, who also happen to be social administrators and service providers, are particularly keen to encourage us to think of ourselves as people with disabilities, as people first. The side of the coin that is labelled **people with disabilities** is, in my view, incapable of buying instant integration but instead it confuses us into accepting the dominant able bodied values without realising that this is what is happening.

I have suggested that it is logical for us to end up supporting the dominant culture, rather than our own, if we promote our **abilities and not our disabilities** or if we promote ourselves as **people with disabilities**. Let us at least try and be conscious about what we want and what we are doing. If we want to focus on our abilities and present ourselves as people first then how can we at the same time organise separately and try to develop our own culture? This is surely the question behind the justification of the PHAB club movement. Idealistic approaches which confuse our identity, however, will fail because as long as we are different no amount of denial can help us assimilate into a world designed for people with able bodies. Real integration, on the other hand, can be achieved on the basis of a full recognition of our differences and this in turn will depend a great deal on us making the free choice to identify ourselves as a social group.

3. WE, DISABLED PEOPLE

Let us come back to the idea that we live in a multicultural society and, from this point of view, ask ourselves whether we want to make a contribution, as disabled people, to British culture.

Events, such as this organised by the **London Disability Arts Forum**, and similar happenings in other parts of the country, show that there is already an identity developing amongst ourselves with our own cultural expression. This gives us enormous confidence in ourselves. However, at this time, it would be wrong for an individual to try and say what this disability culture is going to be. After all, we are still in very early days and culture cannot be imposed by an individual from the top down. It must develop spontaneously and creatively out of the collective experiences of disabled people. Nevertheless, we can say, in my view, that the willingness of disabled people to present a clear and unashamed self-identity and our ability to organise our own effective organisations for social change will greatly help the development of a disability culture.

(a) Self-identity

Firstly, we must be clear that it is essential for us to create our own public image, based upon free acceptance of our distinctive group identity, before we **can** participate in the multicultural world. Such a cultural identity will play a vital role in helping us develop the confidence necessary for us to create the organisations which we need to promote the social change that we all want.

(b) Collective identity

Secondly, it is essential that all disabled people join together in our own organisations so that there is a creative interaction between disabled people who are involved with the politics of disability and disabled people involved in the arts. It is this interaction which can be particularly fruitful in helping us to take the initiative in developing a new disability culture.

Over the centuries, and particularly during the past two decades, disabled people have been clearly portrayed as tragic figures whose lives are wholly dominated by difficulties and a desire to be **normal**. Even sympathetic media programmes choose clever titles, such as '*Does he take sugar?*', which reinforce our public image as people who are always concerned with what able bodied people think about us. Our public image, therefore, not only presents us as people mainly comprised of bundles of problems (people with disabilities) but also shows us constantly looking to able bodied people to solve our problems. Able bodied people are not just presented as our helpers, as our problem solvers, but as our role models.

Most of our lives, however, are not spent worrying about problems. This is not to say that being forced to live in a world designed for people with able bodies does not present us with massive problems and make us dependent upon able bodied people. Nevertheless, for the first time in the history of humankind there is the real possibility of making the world fit for disabled people and consequently we need to encourage a real change in the way **we** present our identity to ourselves and others. The development of our own distinctive culture to express a rounded picture of the reality of our lives will help us gain a place of our own choosing in the multicultural society. The celebration of difference, we will then discover, **is** the celebration of humanity, of being members of the human family.