Safeguarding Community Care: the American Experience

This paper is a report from a seminar run by Michael Kendricks, Director of The Safeguards Project, and Cathy Costanzo, Centre for Public Representation, while visiting this country from Western Massachusetts, USA. The seminar was held at the King's Fund Centre on 11 July 1986, and chaired by Dr D Towell, Fellow of the King's Fund College.

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This paper is a descriptive account of the seminar and attempts to accurately reflect the views and opinions of Michael Kendrick and Cathy Costanzo so that the reader can determine their own response to the ideas presented.

The Safeguards Project

Michael Kendrick is the director of the Safeguards Project, a diverse training/education and social change project in Western Massachusetts that was established in 1980. Its aim is to act as a values-oriented project to safeguard the quality of community living of persons labelled as mentally handicapped, mentally ill or physically handicapped. Its ideological basis is rooted firmly in the work of Wolf Wolfensburger and the principles of normalisation.(1)

The project is financed largely by the state, and was initially funded through the efforts of a sympathetic hospital administrator. Its remit is to cover all client groups with a long-term disability.

Michael Kendrick sees the role of the project to act as 'trouble shooter', to keep the service providers 'on their toes', and to be continually asking uncomfortable questions. Their work has been mostly with staff, looking at the effects of certain systems of care on the quality of lives of people with a disability. There has been much involvement of users of service in this role. The role of the project is also educative, creating a standard of 'morality' for the region and promoting engagement in discussion on values. A recent initiative 'Education in the Community' has arranged events, weekend courses, for families, friends, neighbours, etc., to highlight the role of a defined values system to ensure quality of life for people with a mental illness.

The project has lived through six years of intense controversy; but has gained support and respect because it is:-

1) Seen to be accurate!

2) Seen to be 'for' users, and fully involves them in the projects work.

3) Above the political process.

4) It has bought people of very high quality to the Region.

In short, not everyone agrees with the project, but it makes sure that the vital issues are constantly addressed. The project is evaluated bi-annually by an independent group to ensure the continuation and fulfillment of its stated values, aims and objectives.

The Legal Advocacy Project

Cathy Constanzo has worked for the Centre for Public Representation for over 10 years. This project is a legal advocacy project involved in both personal and systems advocacy in Western Massachusetts, principally for persons labelled as mentally ill who have been resident in Northampton State Hospital.

This work is grounded in one-to-one contact with individual clients, (rather than 'class' or groups of clients) and consists of:

a) conventional legal work

b) 'trouble shooting'

Through attending regular meetings in the hospital; Cathy Costanzo is able to identify those clients who don't 'seem to be going anywhere' and who may need individual citizen advocacy. The involvement of the project facilitates change in the situation as staff respect, (and are in some awe of) the project, which has a clearly stated values system as a base for its advocacy work.(2)

Themes common to both projects:

Both projects see themselves as 'influential mosquito's worrying the big beast'. They see their work as bringing people into meaningful involvement with people with a disability. Both projects pay special attention to families, being aware of the fact that professionals see families as a group, whereas each family thinks of itself as having a specific individual problem. Educational and support events for families need to be economic with time, and mindful of their level of education. Both projects feel that they have to work with families on what they (the families) want; often not much can be offered to them, and it is important for professionals to recognize and accept this limitation.

The History of Community Care in Western Massachusetts

Western Massachusetts has a community mental health service that caters for over 90% of clients in the mental health system. This high level of community care was initiated over 10 years ago by a Court Suit brought against the Government by the Centre for Public Representation. The Action claimed that patients' constitutional and statutory rights were being violated by institutionalisation; and that less restrictive alternatives, suitable to their needs, should be pursued.

The action never became an actual law suit, and was conducted in a spirit of cooperation with the hospital administrators. It resulted in a Consent Decree whereby the Court instructed that Western Massachusetts initiate a comprehensive system of appropriate, less restrictive treatment, training and support services for each person defined as 'mentally disordered', who had been, were, or may be resident in Northampton State Hospital, (the regional asylum).

The principles for creating and maintaining such a Community Programme were defined by the Court as follows:-

"A. A comprehensive community mental health service and retardation (mental handicap) system consists of three distinct components:

1) Residential environments which are the least restrictive and most normal settings appropriate for each resident or client:

2) Non-residential treatment, training, and support programs which are geographically separate from community residence and which provide a major daily activity for those clients whose residential environment does not provide the total treatment program, as well as for other (members of the plaintiff class) clients who live independently in the community; and

3) Management services to adequately develop, coordinate, administer, monitor, and evaluate this network of environments and programs.

B. The provision of appropriate treatment, training, and support services to residents and clients will not deprive other persons currently receiving mental health or retardation services from (the defendants) staff, from continuing to receive such services for as long as they are determined to be necessary, according to professionally accepted standards. (That is, the introduction of community services would not detract from services already being offered to clients, nor would they in the future).

C. The determination of client service needs will occur through an individualised screening, evaluation, and service planning process, including annual reviews of individual service plans.

D. The determination of the appropriate residential and non-residential placement for each resident and client will be made so as to guarantee that all persons are placed in the least restrictive alternative which will provide them with appropriate treatment, training and support.

E. In light of the profound effects of the long term institutionalisation of many of the (plaintiffs) clients, and the practical problems in making available the most suitable setting, some residents and clients may be placed initially in the more structured alternatives; however, they will be provided with the necessary treatment, training, and support to enable them to move, as quickly as possible, and in accordance with their capabilities, into less restrictive, more open settings and programmes.

F. Since the residential models are designed to be the most normal and least restrictive environments appropriate for the residents, smaller apartment units are preferred to larger group homes, although either may be appropriate depending on the particular circumstances.

G. Community residential and non-residential services will be offered to the maximum extent feasible and entirely if possible, on a voluntary basis and with due regard for the client's dignity and personal autonomy.

H. All residential and non-residential services will be offered by providers of services on a non-discriminatory basis, without regard to a resident's or client's degree of handicap or ability to pay.

I. Community residential alternatives and nonresidential programs will be integrated in the community and operated in the most normal manner appropriate to the needs of their clients.

J. Standards for all residential alternatives and non-residential program models are necessary to insure the health, welfare, and dignity of all clients of such programs. Licensing procedures are necessary to enforce these standards and serve as the primary monitoring device to insure program adequacy.

K. An evaluation process is required to assess a program's quality and effectiveness in meeting the needs of its clients.

L. Adequate residential and non-residential services will be provided in appropriate, less restrictive alternatives to all residents and clients for as long as determined necessary to meet their individual needs, according to professionally acceptable standards."(3)

As a result of the Consent Decree and the consequent introduction of community care, the largest community residential unit was 8 people in 1976, it is now 4 people in 1986. The ratio of staff to client ranges from very intensive (2 staff per client) downwards. The number of beds in the institution dropped from 500+ to about 140; there has recently been a rise to about 200 beds, reasons for this will be discussed below. Early on in the programme some very 'difficult' clients were moved out of hospital and thus a) proved it could be done and b) established the 'psychology' or ethos of working with people who had been institutionalised. Ninety percent of the community placements went ahead without community resistance. Notably, resistance was strongest in the districts whose population was mainly the 'young upwardly mobile middle class,' (yuppies).

Ten Years On:

Ten years on, the changes in the mental illness and mental handicap services can be summarised under the following headings:-

Positive Aspects of Change

1. The Service has tremendous flexibility

2. The Service can command a lot of local 'power'

3. Most of the agencies providing care are very small, so they are close to clients and have a better chance of knowing what they want.

4. The proliferation of small agencies means that agencies can 'specialise' with particular people/problems.

5. The schemes provoked international interest and provided a world-wide feed-back of ideas/examples of good practice.

6. There was the facility to incorporate local 'generic' services into clients care programmes.

7. The system could fully utilise the strengths of local leadership.

Negative Aspects of Change

1. The emphasis on planning for individuals tended to shift over time to individual profession or agency interest.

2. Life for individual clients became in some cases one continual programme, or set of programmes.

3. The programmes were often not, in reality, controlled by the community, but by the Government/Central System.

4. The local generic services were not always included in clients programmes.

5. There was a growth of idiosyncratic 'models' of care which, again, were in danger of losing sight of individual client needs.

6. In some cases there was a fall back to an institutional ethos. People with a mental illness sitting around waiting for the next programme, inducing a sense of 'community-based custody'.

7. The prevailing culture became based on a hospital versus anti-hospital conflict. Community programmes had to vigorously defend their position in this debate and so became unable to 'admit to their sins'.

Reasons for a recent rise in the popularity of institutions

There was clearly a tremendous amount of commitment, creativity and energy invested in the community programme. There was financial backing supporting this development, and failures were failures of imagination, not resources. However, there has recently been a movement advocating for a return to the institutions, especially from parent groups, and we in Britain can perhaps benefit from an analysis of why there has been a counterswing in public and professional attitudes in Western Massachusetts.

1. Firstly, there has been a hardening of attitudes towards minorities in the USA generally. A second term of a Reagan administration has meant that the 'innate conservatism' of the American people has become more overt and prominent.

2. The realities of life in the community are harsh for all under-privileged and oppressed groups, even more so in the current political climate. Life is not automatically a 'bed of roses' once discharged from an institution.

3. One of the major weaknesses has been the failure of professional staff to integrate _into_ the local community. Staff have set up agencies and run programmes with no consultation or involvement of the people who live and work in the street or locality in which staff are working. The Community programme is _in_ the community but not _of_ it.

4. Ten years on, the pioneers and idealists who initiated the community programmes have moved on to other jobs and other places. The staff there now are just 'paid to do the job'. This illustrates the need for systems of care to have a constant dynamic of change in their structure.

5. The role of the 'voluntary' effort was never fully developed. The limit of what can be 'rented' from human beings has been reached. Western Massachusetts needs to move on towards development of what is given freely; the service needs people to be involved out of interest, not simply because they are being paid.

6. The National Alliance for Mental Illness is a carers group, and the largest growing organisation at present in the US. It is similar to the National Schizophrenic Fellowship in this country, and advocates strongly as does the NSF, for a return to institutional care. It has become a powerful lobby at both local and national level, and has had great influence in the 'anti-community care' movement.

Perhaps the major theme running through these six points is the failure of services to effect a cultural change. The structure of services obviously changed radically but this has not been absorbed into mainstream public thought and attitudes. The changes following the Consent Decree, instituted a community service, but not always a community life.

Communities and families are not, on the whole, uncaring and deliberately devaluing in the way they treat clients. Rather, the community care movement, in its focus on the client, may not have addressed the needs of other lay people such as fear, ignorance, shame, and for families suffering and distress. A movement promoting normalisation then, should not neglect these considerations, and remember that devaluing attitudes can only change through normal and continued communication between clients and others. A client living in an ordinary house may never talk to his/her neighbour, especially if each day is spent on a 'programme'! (even if a community programme). Communication is only built up slowly through chats over the garden fence, in the pub, seeing clients working, in the local library, or cafe, queuing behind them in the Post Office, and so on, and it is in this way that devaluing stereotypes can be truly broken down.

Involving Users of Service

A community care service then, and a safeguards project, needs to create educational experiences for people by having users simply being there - being around and being seen. Opportunities should be provided for people to hear from users directly; users should be involved in conferences, meetings etc. The aim is to make people feel comfortable with people with a disability.

There are dangers though of professionals having a 'token user' around who may themselves turn into professional comsumers. Professionals can 'defer' to users opinions, but actually take no real notice of them. Users, like the rest of us, need help and training if they are to participate fully in planning and determining services. There is an example of good practice from Norway where users are primed on how to teach, how to be a part of a planning team, and so on, before they become involved with staff and lay people in these activities.

There is also the dilemma of the user once involved being expected to have 'greater morality' than the rest of us. They are assumed to be 'beyond reproof', and to have an almost 'childlike' innocence in the world. This is a most iniquitous form of discrimination, users must not be subjected to a romanticised perception of their lives by others who are still not prepared to view them equally.

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Michael Kendricks opinions on the current situation in the UK

Michael Kendrick thought that people in this country under-rated their potential to effect change, and did not have enough self confidence - clients don't need a cautious movement!

One of the major problems in this country is that community care is currently only at the level of concept and theory - not experience. People here are committed to community services, not community living. The idealisation of community care, in opposition to institutions, inhibits a development of a realistic notion of community living, as the ideas form only in conflict with something else, and do not flourish and stand on their own.

Existential Change vs. Structural Manipulation

There is a danger in Britain of normalisation being manipulated through 'social engineering'. What this means is that normalisation will come from state bureaucracies who make policy decisions, administer funds, and so on. This approach cannot tackle the normalisation of everyday life.

People in the UK interested in the ideas of normalisation are usually in higher status jobs, and so part of the service bureaucracy themselves. Normalisation may then become adopted as a service goal, and not become an existential movement. There are inherent limits in services, the most comprehensive services cannot give a comprehensive life for a client, this can only be achieved by the permeation of normalisation principles into every sphere of daily life.

Services alone cannot provide the satisfaction or quality of life that comes through personal individual involvement with another person that is lasting and valued by both sides. If commitment is externalised in the service structure, then this can prevent the passionate commitment of human beings to really change their relationships with clients. Also, the introduction of normalisation through a 'dissident liberal reform movement' of well-paid service providers will inevitably fail to achieve lasting radical change, as political history only too well informs us!

Safeguarding British Services

The UK has as yet little comprehension of the need for safeguards to be built into any community care programme, to protect clients and constantly monitor the services they receive. The experiences of Western Massachusets show how essential safeguards are to ensure and maintain quality and values.

There is a danger in this country that the abolition of institutions will become the major cause for the normalisation movement. If this happens then people in the movement become afraid to criticise the forms of community care. Such a defensive stance prevents a proper critique of how flawed the reforms may actually be; remember institutions were originally seen as a liberal reform providing a haven for clients, can we be so sure we are not equally fooling ourselves? Also in a small network such as currently exists, it may be personal friends who are running projects and this will again hinder a thorough critical analysis of their work. Doubt must be legitimised or we will simply be constructing a new form of oppression for our clients.

The value of a safeguards project is that it must be independent of the service system, and so provide an objective critique. It can also establish a national standard that is above reproach and ensure that, in theory at least, this standard is unchanged. This standard can be defined through establishing a standard of being truthful, about services, clients lives, (good and bad), and so on. In individual projects it is important that high standards exist at the beginning as they will inevitably dull and weaken with time. Replication of social models of care can become fashionable and plentiful; quality, then needs to be built in right at the start, and it would be an aim of a safeguards project to ensure that this occurs.

Self Advocacy as a Safeguard

Self-Advocacy can be over-rated as a safeguard in itself. It can become a single party approach, and other things are then overlooked. It can also become a process of socialisation whereby a person goes out every Tuesday morning with the self-advocacy group because she/he knows no-one else to go out with, this is clearly not a desirable outcome. Self advocates can become fashionable in 'trendy circles', but not in reality actually listened too. In Britain it is almost impossible to finance a national citizen movement as state funds are solely directed towards service provision. Holland provides an example of an independent client movement,(4) and whereas there are many local groups in this country they have few formal links or networks.

Thoughts on a future normalisation movement in Britain

Normalisation is the force of moral resistance to things in clients lives that cause unnecessary suffering. There needs to be a genuine movement of solidarity with clients, sharing their burdens, their powerlessness, and their triumphs. The movement should attempt to clarify the relations of oppression and seek to moralise people, not demoralise them. It is correct for a movement to acknowledge a superior way of doing things, but at the same time to realise that it is composed of ordinary people, (not Mother Theresa's) and indeed, it would be righteous for a movement to claim that it was actually doing things in a superior way. A normalisation movement, should have a clearly stated values system which implies a superior service, but not become elitist and inaccessible by assuming that its members are, in fact, superior to other staff working in the mental health services.

A movement also needs to create a 'think tank' atmosphere, and exploit creative ways of broadening the public debate on normalisation, should it, for example, be made a social policy or a civil rights movement? Whichever, operating in the public realm means publicly stating the movements purpose and intent. Authority, accountability and responsibility must be openly stated, and, as mentioned above, a national impersonal standard publicly declared. A cautionary note though, excessive revolutionary zeal may lead to the immediate impact of ideas, without the time that people need to internalise the values. The 'normalisation machinery' might whurr into action before the convictions are fully developed.

Building Alliances

Is it possible to further the movement through developing alliances with other oppressed groups? This is a difficult question to answer; different groups have different histories, and are at different levels and starting points for alliances. There is a danger of the movement talking to gays, blacks, women, etc, and not the clients themselves. However, perhaps the movement can learn from the process of change gone through by these groups. Perhaps the major factor has been that they have achieved change through a grassroots movement that has grown in confidence, power and solidarity. Change has often only been won through conflict and struggle - the lesson is 'it won't be easy', and neither can it be, if the change is to be meaningful and lasting.

Should the movement address all disability groups?

People should remain aligned to a single group within the movement, be it concerned with mental illness, mental handicap, physical disability or elderly people, rather than expect the movement to address all groups simultaneously. People have to represent the issues of their particular group, which will differ as the stereotypes differ.

The mental illness service perhaps more than the other services are profoundly anti-normalisation. Professional training in this area drives out peoples ability to find 'normal' solutions, and they may become less likely to accept normalisation. Tackling the issues and problems in this field requires an approach that will, of necessity, be inappropriate in other fields. Equally other client groups demand a response that addresses the unique ways in which they are stereotyped, devalued and treated by the service system.

Final Thoughts

The normalisation movement in Britain must be proactive in becoming a morally superior, relevant and public standard setter - if it doesn't then other 'opposing' groups will dominate the scene and may possibly swing public attitudes in a contrary direction. It should develop an identity beyond the current network of people, into a social movement with commitment and purpose; however, it will not be a quick road to 'fame and glory'.

Other groups, (such as the Women's Movement) have broadened the political agenda; but the pioneers in the normalisation movement may have to wait for future generations of workers to recognise, approve and change services in the direction in which they are fighting for today.

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References

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