Community Integration - Myth or Reality?

Present day government policy indicates a preference for community based services for adults with mental handicap. However, the inadequacy of resource allocations and the apparent failure to address the implications of true comminants integration raise serious questions for all those concerned.

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INTRODUCTION

This article will discuss living in the community from two perspectives. Firstly it will consider what living in the community can mean from the point of view of the consumer. Secondly it will consider the issue of community living from the point of view of the service provider.

The second perspective is easier since it is written out of the experience of one involved in planning and providing community based services. The first task should properly be undertaken by a consumer. In attempting to describe some consumers' experiences, examples of Irish and British research will be called on as well as personal observation.

OVERVIEW

Before dealing with these two tasks, an attempt will be made to set the scene by giving a very brief overview of service structures as they are today.

Services for persons with a mental handicap usually have one of four origins:

1.   **Statutory Services:** These are provided mainly through the eight Health Boards, the Department of Education and the Department of Social Welfare. Such Services include residential centres, assessment services, special schools and income maintenance schemes. Funding is from the exchequer by the way of general taxation.

2. **Voluntary bodies:** These are religious orders and parents' groups organised as charities or limited companies. They provide a range of residential, community, employment and recreational services. Funding may be direct from government departments or through health boards. Funding also comes from public charity.

3. **Informal Organisations:** These are mainly smaller organisations relying heavily on charity and voluntary effort.

4. **Commercial Bodies:** These rely on direct or indirect payment.

The vast majority of persons with a mental handicap in Ireland receive services through the voluntary bodies.

GOVERNMENT POLICY

Present day stated government policy emphasises the preference for community based services rather than institutional ones. This policy has been stated and restated many times. The most significant documents are the *Commission of Inquiry into Mental Handicap* (1966), *Planning for the Future* (1984), Towards a Full Life (Green Paper on Services for theDisabled) (1984) *Health and Wider Dimensions* (1986), and the *Commission on Health Funding* (1989).

THE REALITY OF COMMUNITY LIVING

First one should look at the reality of community living. What does living in the community mean? At first glance it is a very simple issue, since we all live in the community. For most it is a normal style of life which may be taken for granted. What are the components of living in the community? A number of characteristics fundamental to living in the community can be enumerated. These characteristics can be described as benefits and costs.

BENEFITS OF COMMUNITY INTEGRATION

1. Opportunity to live where one chooses.
2. Opportunity for education and work.
3. Right to mobility - access to any part of the community.
4. Access to services and products (public and private).
5. Access to social networks and personal relationships.
6. Citizen rights - freedom of speech, political participation, protection of the law.

COSTS OF COMMUNITY INTEGRATION

1. Contributing to the support of the community i.e. taxation.
2. Obligation to obey the laws of the community
3. Obligation to accept social norms.

Those who do not conform to these obligations may be penalised by being removed from the community, i.e. prisoners. Many types of persons may be marginalised in the community - the travellers, the homeless, persons with a mental illness or a mental handicap. Persons with a mental handicap can find themselves marginalised in the community. In many cases they can not receive the benefits of community living while being obliged to pay the costs.

In a sample of forty five families studied by McConkey (1989), 75% of parents opted for their son or daughter to remain living at home when they reached adulthood. This contrasts with the opinions of the persons themselves. The study indicated that 53% of those asked expressed a desire to leave the parental home. The reasons given by parents indicate protective attitudes: "The family are more used to him; they can handle him better", or: "His sisters wouldn't let him go into any home; he wouldn't be looked after as well as by ourselves".

EMPLOYMENT

Most adult persons with a mental handicap attend day centres or sheltered employment centres. In 1987 there were 6,500 persons in this form of work (McConkey, 1989). Approximately one third were community based, the remainder were in large residential centres. What do these people do? Some 58% of adult centres engage in contract work. Most of this work is tedious and repetitive e.g. packing refuse sacks, labelling and so on. This work is carried out under conditions of employment that would not be tolerated by any trade union in Ireland today.

The weekly income of persons in sheltered employment varies from IR£8 per week to IR£20 per week. Clearly IR£20 per week is 50p an hour - IR£8 per week is 20p an hour. Of course most people attending sheltered employment are in receipt of the Disabled Persons Maintenance Allowance (DPMA) of IR£47.20 per week and benefits in kind. This fact is often used to rationalise low pay in sheltered employment. It should be stressed, however, that DPMA is a statutory right, although it is subject to means testing. Persons with a mental handicap have a right

to a reasonable income. It could be argued that many persons with a mental handicap could, earn substantial amounts of income and contribute in a meaningful way to the community, if they were paid according to productivity. Unfortunately our social welfare system is structured in such a way as to trap people into low income groups.

It is worth noting that at the present time workers in the shanty towns around Sao Paulo in Brazil have an average income of twenty pence per hour. One wonders where the third world really is! In Flynn's survey of persons in independent living in Britain (Flynn, 1989) the average weekly income for those with a mental handicap was found to be IR£39 per week when the average industrial wage was IR£150 per week. In Ireland the average income is around IR£47 per week when average industrial wage is IR£180 per week.

OPINIONS OF PEOPLE WITH MENTAL HANDICAP LIVING ON LOW INCOMES

"............ we feel that we could do with some more money you know. Like £42 doesn't really go far these days. What we buy out of that is like food, which takes a large part of it, like clothing. I just find that I've not bought any clothes for the past three years. What I've been doing is I've been going to the Oxfam shop and I've been getting things fairly cheapish there........."

"..........I'm only on £35.70 and I don't think that's enough for me. Where do you expect a person to live in that way? It wouldn't keep me going with this place as well.......when me Mum was alive I used to get more than that, a lot more..........it's very hard isn't it?"

COMMUNITY ACTIVITIES

The most frequent leisure activities of persons with a mental handicap is watching television, accounting for 67% of leisure time (McConkey, 1989). This may be related to another issue, that of social relationships. The Research in Dublin has shown that the majority of persons living in the community do not have significant contact with other persons living in the community. Contact is limited to other family members, their peers and professionals.

Research has shown that the opportunity for persons to develop personal relation-ships is also limited. One piece of research indicated that over half of those interviewed expressed an interest in personal relationships, whereas over three quarters of the parents said they would not like their son or daughter to have a per-

sonal relationship. This highlights another fundamental problem. There are often differences between the needs and wants of parents and the needs and wants of the person with a mental handicap. Whose needs and wants do we actually serve?

VICTIMISATION

An even starker picture of the reality of community living presents itself. This is the issue of victimisation. It is a dimension of people's lives which has largely gone unresearched. Flynn (1989) examined the incidence of victimisation among a group of adults living in the community in London. Out of a sample of one hundred the following events were reported:

INCIDENCE OF VICTIMISATION REPORTED BY ADULTS WITH MENTAL HANDICAP N = 100	
EVENT	**NO.**
Intimidation from children	22
Property Stolen	17
Intimidation from neighbours	15
Property damaged	12
Exploitation by non family member	10
Exploitation by family member	6
Mugging/physical abuse	2
	Flynn, 1989

Could this be happening in Ireland? To date there has not been any work carried out to examine the extent to which persons with a mental handicap are victimised in the community. One can be certain that most service managers and professionals can recall events and experiences from their own client groups that indicate that significant victimisation is happening.

CITIZEN RIGHTS

Citizens rights for those with a handicap have largely gone unnoticed in Ireland. One wonders how many persons with a mental handicap are helped and encouraged to cast informed votes at elections? Do policy makers and professionals see persons with a mental handicap as citizens with the same rights as non-handicapped citizens? They are our clients. The beneficiaries of our long years of learning and expertise; the recipients of our wisdom.

At present there are three hundred persons in the Eastern Health Board area not

receiving a day service. How many parents would tolerate the absence of a school service for their non-handicapped children? Why is it that we accept deficiencies in service for persons with a mental handicap more readily than deficiencies in services for other citizens?

ISSUES OF SERVICE PROVISION

Reference has been made to stated government policy on the development of community services. The reality as reflected in government expenditure is very different. In 1987 the government spent IR£113.5 million on services for persons with a mental handicap. (Department of Health, 1989). The breakdown is as follows:

GOVERNMENT EXPENDITURE ON SERVICES FOR PERSONS WITH MENTAL HANDICAP (1989)	
Residential Centres	IR£77.3M
Psychiatric Hospitals	IR£28.6M
Day Services	IR £7.6M

Since 1976 expenditure increased from 7.6% of total health expenditure to 10.1% in 1987. This increase is mainly due to the growth of residential centres which are largely institutional in character. The figures illustrate the contradictions between stated policy and actual expenditure.

WHERE DO PEOPLE WITH A MENTAL HANDICAP LIVE?

DEMOGRAPHIC PROFILE, 1986

LOCATION	NUMBER
Psychiatric Hospitals	2,031
Residential Centres	5,099
Group Homes	773
At home	3,962
Total	11,865

Department of Health, 1987

According to Brennan (1987), of the 2,031 in psychiatric hospitals, 1,600 could live in the community or in residential centres. Of the 5,099 in residential centres 1,900 could live in the community.

THE COST OF COMMUNITY CARE

One of the arguments against community care is the cost of service and the lack of resources. Brennan's study shows the following costs per annum:

COST IN IR£ PER ANNUM			
Level of M.H.	G/Homes	Res. Centres	Psych. Hospitals
Mild	4,600	8,300	12,500
Moderate	9,200	10,500	12,500
Severe	17,800	16,500	19,000

Department of Health, 1987

CONCLUSION

So what should be done? The evidence available to us suggests that a number of issues need to be addressed if we are to be committed to the ideal of persons with a mental handicap living in the community in a real and meaningful way.

1. Persons with a mental handicap must be involved in decisions about their lives. Most case conferences and programme meetings still take place without the person or a representative being present.

2. Structures must be put in place to ensure a reasonable quality of life for those already living in the community. These must include: An adequate income; meaningful work and meaningful remuneration; proper monitoring of living conditions by the state; emphasis on real training programmes which give real skills; access to services as a citizen right; and, development of supports to cope with isolation and loneliness.

3. Adequate resource allocation must be made available to community services. Community care is more cost effective than residential care and is more attractive if properly organised. One caveat worth noting here is that for some, community care really means care by the family, especially the mother. The philosophy of community care has not taken into account the changing structure of our society. Moloney (1990) has noted that policy makers do not consider how family relationships have changed or how there have been major changes in mothers' expectations of their own lives.

4. There ought to be a willingness on the part of those who hold power i.e. the state, parents and professionals, to change. There is a need to consider other ways of providing the necessary support for those who are disabled.

5. The power to make decisions about their lives must be given to the individuals themselves.

There is a need for a fundamental reconsideration by society in general, and government in particular, of their priorities with respect to those who are handicapped. The provision of adequate resources is essentially a political decision. The shifting of resources from institutional facilities to community care supports is a political decision. The decision to transform the concept of community integration into a reality is a political one. The allocation of resources is not just about economic limits, it is about making choices. The choices made by government are influenced not only by the resources available but by the pressure exerted on it by citizens. This includes the professionals, parents and those who have a handicap.

Let me leave the final word to Kathleen Jones, Professor of Social Administration at the University of York. She writes:

"To the politician community care is a useful piece of rhetoric; to the sociologist, it is a stick to beat institutional care with; to the civil servant, it is a cheap alternative to institutional care which can be passed to the local authorities for action - or inaction; to the visionary, it is a dream of a new society in which people really do care; to the social services it is a nightmare of heightened public expectations and inadequate resources to meet them. We are just beginning to find out what it means for the old, the chronically sick and the handicapped".

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