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Abstract

The author argues that we have to find ways that genuinely root people with disabilities in their neighbourhoods rather than segregated and lonely lives and which develop structures to give people real power to influence services around them. Service brokerage ideally provides people with disabilities and their families the opportunity to manage their service money, which gives greater independence from professionals, helps give individuals respect and power, and facilitates the development of non institutionalised services. Brandon provides examples and discusses weaknesses of the scheme such as the tendency to over individualise services and that in reality people will continue to be without real power. **Keyword: Individualisation**

Money for a change

People complain they are 'owned' and controlled by the services meant to serve them. Giving them money to buy what they need rather than services into which they are expected to fit would reverse this process and root people in their neighbourhoods rather than in segregated communities. David Brandon argues that we should drop the term 'community care' and start thinking about interdependent living'.

We are supposed to be moving, in the current jargon, from a resources-based to a needs-led service. That is supposed to mean that people with disabilities under the new Care in the Community legislation will get an increasingly tailor-made support system. Currently they complain that they are:

- 'owned' and controlled by the services meant to serve them.
- not treated as full citizens.
- encouraged to be passive and grateful.
- forced to fit in to hostels, day centres...
- given few choices.
- not given continuity of support, often dealing with many different professionals.
- not treated with dignity and respect.
- supported by poorly trained staff.

Segregated

It is difficult to see how any major assault can be made on these problems within the vague idea of 'community care'. For example, many residents of mental handicap hospitals and psychiatric hospitals are the victims of **transinstitutionalisation**. They are not moving into what might be described realistically as the 'community' but chiefly into other sorts of institutions like different hospitals and hostels. They still reside in congregated and segregated services, but because local authority social services departments run these hostels and day centres, they are defined as somehow part of the 'community'. This is nonsense. Those services are just as separate from ordinary neighbourhoods (Mind, 1981). In these formal systems, service users are often encouraged to become heavily dependent on paid workers - frequently distant missionaries, no more members of the neighbourhoods surrounding the services than are the residents of these community institutions. Recent research suggests that

even group homes, now the dominant forms of residential care for people with learning difficulties, are micro institutions. Sinson suggests that institutional management practices and the implications of block systems of catering, cleaning, hairdressing in group homes, considerably erodes ordinary living (Sinson, 1993).

We need to develop structures that give people real power to influence services around them.

We need to develop structures that give people real power to influence services around them, backed up by the relevant legal rights protecting against exploitation and negative discrimination, as well as through providing effective advocacy. It may be much better to ditch the much barnacled term 'community care' and focus on the more precise concept *independent or interdependent living*. This would involve a planned move away from segregated and congregated support systems. Why should people have to tolerate

twentieth century facilities like old people's homes based on modernised versions of the 1843 Poor Law Amendment Act and indoor relief? Why should people who are elderly, disabled, mentally unwell or with learning difficulties - *have* to live in systems which are based on sharing accommodation and day facilities with 'their own kind'? What and who is their own kind anyway?

Somehow we have to find ways that genuinely root people with disabilities into their neighbourhoods, rather than into living segregated and lonely lives - direct purchasers, employing local people in valued situations rather than as objects of pity. They must have the opportunity to hire and fire their own staff, local people able to give a flexible and empowering service.

Four years ago, the Canadian service brokerage system developed in the mid-1970s was almost unknown in this country. By now it is well known as an unusual form of case management but often completely misunderstood. For example, a recent article entitled *Brokerage in Action* describes the work of the Radnor housing care and repair project measured against an outline of Canadian brokerage elements. It concludes that the housing scheme is 'not an independent brokerage service' (Harrison and Means, 1993). Not surprisingly for

the innovative Radnor scheme contains not one of the essential elements. Worley mistakenly describes service brokerage as a process whereby case managers 'assist clients in gaining access to housing, therapy, and health care, finances and vocational and social skills training or employment... There is generally an emphasis on advocacy and a vigorous outreach service underpins this type of case management'. (Worley, 1989).

The Care in the Community legislation stressed the greater participation of disabled people in decisions about their support services. The Government White Paper wrote of giving 'people a greater individual say in how they live and the services they need to help them to do so'

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(HMSO, 1989). Service brokerage fits in well with those stated ambitions. The basis of the Canadian system lies in *individualised funding*. Users can have control over the amounts of money equivalent to providing the services. That money lies under their control to be spent on services to support them as people with disabilities. Unlike our Independent Living Fund, people with

disabilities have a detailed entitlement (Social Work Today, 1992).

Direct payments

Individualised funding was developed by parents of profoundly handicapped children in the Woodlands Hospital near Vancouver in the mid - 1970s. Instead of government money filtering through the hands of high earning senior managers and into block treatment facilities like old people's homes and hostels, it goes directly to users. In a 1991 British survey, 23 per cent of local authorities responding to a survey made payments to disabled people who then employed their own helpers. The majority of these arrangements were made as a result of individuals putting their case directly to social services departments (Morris, 1993). Such direct payments to clients are illegal. Making the individual a trust and paying the cash to that organisation usually circumvents this obstacle.

In 1979 a group of severely disabled people living in a nursing home run by a voluntary organisation approached their local social services department and asked a simple question: 'If we move into our own homes in the community *will* you let us use the money you currently pay the nursing home to buy and organise our own assistance?' The authority agreed. In time, everyone moved into

their own homes and bought and organised the services they required. Each person now has the home and life of her choice (Mason, 1992).

In general, people with direct finances do not employ distant missionaries or purchase statutory services or their equivalent. They purchase from the informal sector. In one recent study, 28 per cent employed relatives for some part of their paid care (Kestanbaum, 1992). The money gave them greater independence from professionals. They gained respect from having money and power. It facilitates the development of non-institutionalised services and gives real meaning to user power.

Price of intrusion

To help in the purchase of these services, they may need optional and independent sources of information from an agency. The new care management structures are already recognising the need for vastly improved information systems (Hayes, 1993). The Canadians invented what they called a *service broker*. This is a figure independent of service systems and responsible to a community based Brokerage Board, consisting of local people not salaried from health and social services so reducing any likely conflict of interests. Part

of the cost of receiving help has been the price of intrusion into the clients' private affairs. Much social work interviewing has been based on a subtle sort of blackmail where state and voluntary help is paid for by allowing the professionals to intrude (Doyle, 1917).¹

¹ Andrew Doyle commented on the Elberfeld system in Germany in the early 1870s: 'It is assumed by the framers of the English Poor law and is still assumed by those who continue to take any interest in administering it upon the principle upon which it was founded, that no real test of destitution can be devised except the test of the workhouse. As the application of that test is as yet no part of the Elberfeld system, it will be asked what is the substitute for it? *In the first place the applicant for relief is subjected to an examination so searching, so absolutely inquisitorial, that no man who could possibly escape from it would submit to it...*' (quoted in Mary Richmond's Social Diagnosis).

In sharp contrast, people approach brokers with their individualised monies and get help in designing the service to match their needs. Like travel agents, service brokers are not obligatory and make no decisions. They carry out people's instructions in so far as they are legal and in accordance with the terms of financial contracts laid out by the funding agencies. They are fix-it figures who work out how to turn the dreams and visions of users into a pounds and pence reality. They have skills in costing; in negotiating, in making contracts; in finding out and presenting information. They are professionals under the direct control of users and materially different from social workers, psychiatrists, nurses ... who work for a service providing/purchasing authority.

This process involves a major shift in the centre of power. People with disabilities have the opportunity to manage their service money and have access to independent sources of information under their control. Major planning tasks are taken out of the control of senior social service professionals and put under the control of individuals and their families. Even if they do not choose a service brokerage system, the fact that they could do would have a major impact on traditional services like adult training centres and hostels.

All that runs the very considerable risk that staff, particularly those who are female, poorly trained and poorly paid, will be still further exploited. Service users cannot benefit, in the long term, from a poorly trained and unstable work force. One method of protection lies in constructing funding contracts, which include protection clauses for staff - for example, minimum hourly payment rates and training packages. Every legal finance contract negotiated by brokers should

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include a standard list of protective clauses like entitlement to pension rights.

Another function of service brokers might be to work against some of the excesses of individualism built into brokerage. Services are rightly moving away from an enforced congregation which herds' people with disabilities together in hostels, hospitals and day centres. A brokerage scheme has an inbuilt and opposite tendency to over-individualise services. Users may land up powerful and alone. There is also a danger that the funding benefits of some people choosing

to share may get lost. It might be advantageous for some people to pool their money and gain from the extra facilities that their combined purchasing power brings. Brokers could work to develop co-operative schemes as an option so that they become a viable choice for some individuals with disabilities.

The **first stage** in the development of these ideas comes with ad hoc pressure from determined individuals, mostly those with physical disabilities, to opt out of the traditional framework and run their own services. Through the 'special case' committees of social services committees, this first stage is now well established. More than 300 individuals in Britain already have financial packages that make them effectively Directors of Social Services. They appoint the staff and say how their service will run. It seems to work well. A recent RADAR survey suggested that 23 per cent of local authorities make direct payments and 74 per cent of authorities would welcome legislation making it legal as it is in Scotland (Social Work Today, 1992). Recent research suggests that such individualised schemes are cheaper and the government minister concerned agrees about their cost effectiveness (*Care Weekly*, 1993).

The **second stage** is the development of pilot

schemes, which take the process beyond the single determined individual. The Norah Fry Institute at the University of Bristol has just finished a pilot brokerage scheme for individuals with learning difficulties. It seems to have gone well. Althea Brandon is setting up another pilot scheme in Cambridge.

The **third stage**, as in the province of Alberta, Canada, lies in planning both individualised funding and service brokerage as mainstream services. Individuals then have a complete entitlement to such schemes.

One vital by-product of Canadian developments has been to weaken the grip of the particular client groupings. Pots of money which are labelled - mental illness; physical disability; old age; make the particular label assigned to a client very important. You either qualify for particular monies or you don't. Clients who are potentially eligible for two or more money pots cause difficulties for the systems; for example, as in the 'challenging behaviour' group. Where finance systems become more individualised, particular labelling to match specific money pots is not nearly so important.

In the post April 1993 period, it is really difficult to see how service users will do much better. They will continue to be without real power. The 1981 Special Education Act

spawned a statementing process involving education psychologists. More than ten years on, this slow and cumbersome system simply does not work. Professionals are forced to write educational statements, which do not reflect the 'needs' of the individual child but summarise what resources are available. 'Thousands of parents are regularly lied to by educational psychologists who dare not reveal the full extent of children's problems in case they demand extra help' (Hugill, 1990). There is a basic conflict between the control of the agency, which employs them and their attempt to describe the real needs of children with special needs. Comparing community care and education structures,

...'Community care' can very easily lead to incarceration within the four walls of the home - a new version of institutional care

Cornwell argues pessimistically that 'the pressure on resources is likely to intensify the dynamic of reliance on professional assessments to legitimate bureaucratic decisions, creating a process which facilitates the emergence of a class of professional bureaucrats' (Cornwell, 1992).

One recent care planning study reports: '... the practitioners I observed ignored directives to record unmet need. They

were unwilling to confront the issue in assessment, and were cynical about policy directives which urged action with no way to carry it through' (Ellis, 1993). The departments, which employ them, are heavily institutionalised, strapped for cash and want severe restrictions on possible service demands. How can we learn from the experiences following the 1981 Act? Perhaps the Canadians offer a better vision? (Brandon and Towe, 1989 and Brandon, 1991).

So called 'community care' can very easily lead to incarceration within the four walls of the home - a new version of institutional care. Genuine interdependent living with power over the provision of services, particularly about the hiring and firing of staff, can lead to real integration and mixing with others. **'People used to Western democracies were horrified by the practices of totalitarian states where citizens were told to live, where to work, how many children to have, what to think and so on. Yet in our country it has been accepted that caring professionals should run the services by which they control every detail of a disabled individual's life. Today, disabled people are saying this is no longer acceptable'** (Mason. 1992).

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