**The Way Back**

**by Maggie Hines (1983)**

If you are severely physically impaired and need the help of another human being to survive, you have all the potential for incarceration in institutional care. We live in a. society which is built on the assumption that the family is the right and proper source of help. Institutions operate as a social defence mechanism to protect this general assumption. Inevitably in a society which provides minimal family support services, the stress on families operating as sole carers leads inexorably to breakdown and the incarceration of the person who is physically impaired.

It may seem strange to commence an article about housing for physically impaired people with a statement about care. But the fact is that the more severe the impairment, the greater the likelihood of dependence on other people and the less likely that housing per se will satisfy the conditions for social integration. Housing, however well designed, however well equipped with gadgetry, will never meet the needs of dependent physically impaired people. Housing and help are inextricably linked and must be consistently perceived in this way if physically impaired people are ever to achieve a secure base for full participation in our society.

In my case, following the accident which led to my own physical impairment, the question of family breakdown under the stress of caring for my needs did not actually arise. One parent was dead and the other too frail to cope with my needs. Then, as now, there were no adequate domiciliary support services. Apart from the community nurse, help provided by the Local Authority was purely discretionary, since my accident was before the 1970 Chronically Sick and Disabled Persons Act. Indeed, before my accident I was working as a nurse and never challenged this situation. I assumed, like most do, that our social welfare provision was sufficiently all-embracing and that if people did end up in institutions by virtue of their age, mental or physical condition, then surely this was the right and proper place for them. The only time I ever encountered the suggestion that the way we did things was not the perfect model was while nursing in the Lebanon, where dependent family members were contained within the extended family rather than in more formal social solutions. By and large my attitudes were those of the average professional in health and social welfare; those physically impaired people I encountered were seen as cases or patients based on the medical model and not as people who just happened to have a condition.

My awakening began in a very real sense when I found myself on the other side of the fence. I found myself on the receiving end of the very same attitudes and perceptions I had been carrying around with me. I can't say I liked it very much. However, having survived the acute stage of my paralysis in hospital, further rude awakenings were in store. There were no houses for people like me, no flexible system of domiciliary supports comprehensive enough for anyone as physically impaired as me. Since my family could not cope and indeed, my wish was not to go back to parental care, I was swept neatly into the nearest institution. It was there that I really began to wake up to the oppressive social relations existing in society and its impaired members. I hadn't realised that in a split second I could be switched from being an able-bodied first-class citizen to a disabled second class citizen with all the implications that carries with it.

Institutions were places people like me died in. The longer I lived there the more I realised I was one of society's social out casts thrown onto the ultimate human scrapheap. I resented the devaluing and dehumanising regime. It was impossible for me to accept this form of accommodation and care as being an acceptable substitute for housing and help in the community. Society had incarcerated me because they thought and still do - that institutions were the right places for people like me. For me the natural place was out there in society playing an active part, as I had always done, in the community. We are social beings, it is offensive and wrong to remove us from society and treat us as sub-humans. It was like being sentenced to life imprisonment without trial, and in this case, life means precisely what it says for most people, with no chance, for parole or remission for good behaviour.

The way back was long and tedious. I had begun to see along with many other physically impaired people, that we needed to come together, get organised and develop unity of purpose. When Paul Hunt publicly suggested that we should come together in this way it was a lifeline to me. The Union of the Physically Impaired Against Segregation was formed and, as it developed, many things about my situation came clear to me. I could see that I and my fellow inmates were victims of other peoples' prescribed solutions to our problem. What was needed was that physically impaired people should define their own problems and their solutions out of their own direct experience of disability. We needed to get back into society with real control over our lives. Of course we need help, but I could see that existing service providers (among whose number I had so recently been) must become a resource to be drawn on by those in need of help. This would mean a radical change: the professionals' prescription of stock solutions to our need of help had to be replaced. But the idea of our service providers actually lending themselves as a resource under the direction of their so-called patients or clients is still a long way off.

The solution to my immediate housing / help needs had to be struggled for in advanced of these required changes. When I met my husband-to-be, we set about devising our own alternative to institutions and the principles on which it ought to be founded. That we were able to achieve what we wanted says a lot for the individuals with whom we worked along the way. Our answer was a small development of housing units, some of which were designed with the architect to meet the specific needs of their potential tenants identified in advance. Other units were to be let to non-disabled tenants who were willing to supplement the help available from local domiciliary services in meeting our need for support. This quasi-collective solution against the institutional reality forced on us by other people.

The Grove Road Scheme in Sutton-in-Ashfield has subsequently offered a pointer to other people seeking an alternative to institutions. The approach is simple enough: it rests on the premise that physically impaired people should be fully participating citizens integral with their local community. It shows that there is nothing particularly special required except a willingness on the part of the service providers to work with us in designing and developing 'independent living' arrangements. It suggests first, that the basic design of a house should be evolved out of the dialogue between architect and disabled person. Second, that aids to independent living should be provided with the housing to reduce artificial dependency on human resources. Thirdly, that a system of help is required that 'spreads the load' so that no one source bears the sole burden of care.

Statutory sources of domiciliary help can have a valuable underpinning and stabilising effect providing that they are responsive to the requirements of the disabled person concerned. But it is essential that support systems are socialised further than this drawing on the resources available out of normal neighbourhood relations. This has the effect of removing from the family the burden of being the sole carer and increases the general level of awareness of the community about the needs of the disabled person and the needs of the carer. In this respect, the ideas of DCDP are very important. Practical progress is already being made towards a county-wide Care Attendants' Register - at the time of writing a pilot project at Clay Cross is in the final stages of planning. How far Social Services see this Register as a part of a spectrum of domiciliary help rather than a convenient method of shedding, as opposed to sharing, the load, remains to be seen. But there is no doubt integrated independent living is [on] the way and will provide a real choice for the first time for even the most severely physically impaired person. It's the start of a process which will spell goodbye to the segregated residential institutions as we have known them as they are thrown into the garbage can of history.

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