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Abstract

A brief but powerful paper containing some insights into the history of institutions and the gradual closures of such places. The author notes that although the standards of care and comfort have risen, there is still little evidence of participation in home and community by people who have been moved from institutions. He stresses that to heal the great institutional damage, people must have many more choices and be given more control over their own lives. **Keyword: Self Determination**

Must moving out mean moving on?

Moving people out of institutions to towns they have not chosen to reside in is not the way to heal the damage of the past argues David Brandon.

I've just finished my latest book which is about the history of the mental handicap hospitals. I wrote it because we have a completely new generation of residential staff who know little about the history of services. Such ignorance is dangerous because what we have achieved is extremely fragile and easily lost. It has been lost once before. The book is called *Strange Places* and it traces the history of the hospitals - mental deficiency colonies as they were known - from their origins in the mid nineteenth century. It includes five further chapters taken from tape recordings of former hospital patients.

The Victorian dream turned eventually into a huge nightmare; the best of intentions was transformed into the worst of outcomes. Our great grandfathers began with a dream of tranquil settings in which people with learning difficulties could acquire increased social and occupational skills and return to the community as useful citizens. Music, dance and warm generosity would attend their days. They took thousands of people with disabilities who were rotting in the workhouses and gave them a better life. Their intentions were similar to our modern visions.

By the turn of the century the nightmare had begun under the huge pressures of medicalisation and the institutionalisation of services driven through the moral panic of eugenics. Then most of us believed 'mental defectives' bred more vigorously than ordinary people and that they produced large numbers of 'defective' children. Quasi-Nazi thought dominated the United Kingdom.

The huge colonies became grim places as they were more and more oppressive. The 1913 Mental Deficiency Act was the highpoint. It insisted on the primary nature of institutional care. The right place for most people was thought to be inside the institutions. By the 1960s the scandal period had begun, amply illustrated through the personal experiences of the five individuals whose stories form the main part of *Strange Places*. However, the institutions are now rapidly closing down. The mental handicap hospital will be the only institution to mainly open and close down in the same century. By the year 2000, if we keep our nerve, there will be less than 10,000 hospital patients from a maximum of more than 64,000. It will be a glorious day when they close down entirely, and I hope it happens within my life time.

The five people in my book bear eloquent witness to the poor quality of services as well as the personal kindness of many individual staff. There was the boring grind of the daily routine; the cleaning; the eating rituals; sleeping in dormitories; the uniform clothing; the harsh relationships; the threats of punishment including the notorious punishment blocks and refractory wards. Staffing ratios were extremely low. It was common to have only two staff onwards with 60 patients, many in wheelchairs and with multiple and profound disabilities. Morale plummeted. Training and management were generally poor. Violence and theft were common. Many female patients, sectioned as 'moral imbeciles', were sexually abused.

Many thousands of people, including staff, were intensely damaged by this process. I still live with memories of more than thirty years ago, seeing 'troublesome' patients get the wet towel treatment in bathrooms. I could do very little. 'Community care' must mean a healing process for us as well as the former patients. We also need help and support.

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Former patients are frequently ambivalent about moving out into the community. They might have hated the institution but they missed the people. Huge chunks of their lives were spent there with large emotional investments. Most people they had grown to know intimately lived there and are now scattered over various north western towns and cities. Financial and management considerations still dominate placements. They are separated from people, both staff and residents, who had been regarded as close friends. Sadly, one woman I know still has an unopened Christmas present for a staff member who will probably never visit her.

Although standards of both care and creature comfort have risen dramatically in the staffed group homes, there is still little evidence to suggest we are learning the important lessons of participation. People must be given more control over their lives; they must have many more choices. Most people are being moved out to towns they did not choose to reside in and many are unwilling to leave the hospitals. They move to houses they had no part in selecting; they live with staff they have never met before and they live alongside people they did not know well or even at all before leaving hospital. Those are not the ways to heal the great institutional damage which was all about a multiplicity of abuse and gross non-participation.

We must hold firm to our visions of life in the community. A life where people with learning difficulties can make real friends; be treated with dignity; learn to trust, like and love. They must have the power and control this time. We must never repeat the mistakes of the 1913 Mental Deficiency Act, shrouded in the fantasies of eugenics. Only by knowing our history can we have a clear and practical vision for the future.

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