



**Building Community Strategies
Working Paper No. 1**

**Australian Intellectual
Disability Services
– Experiments in
Social Change**

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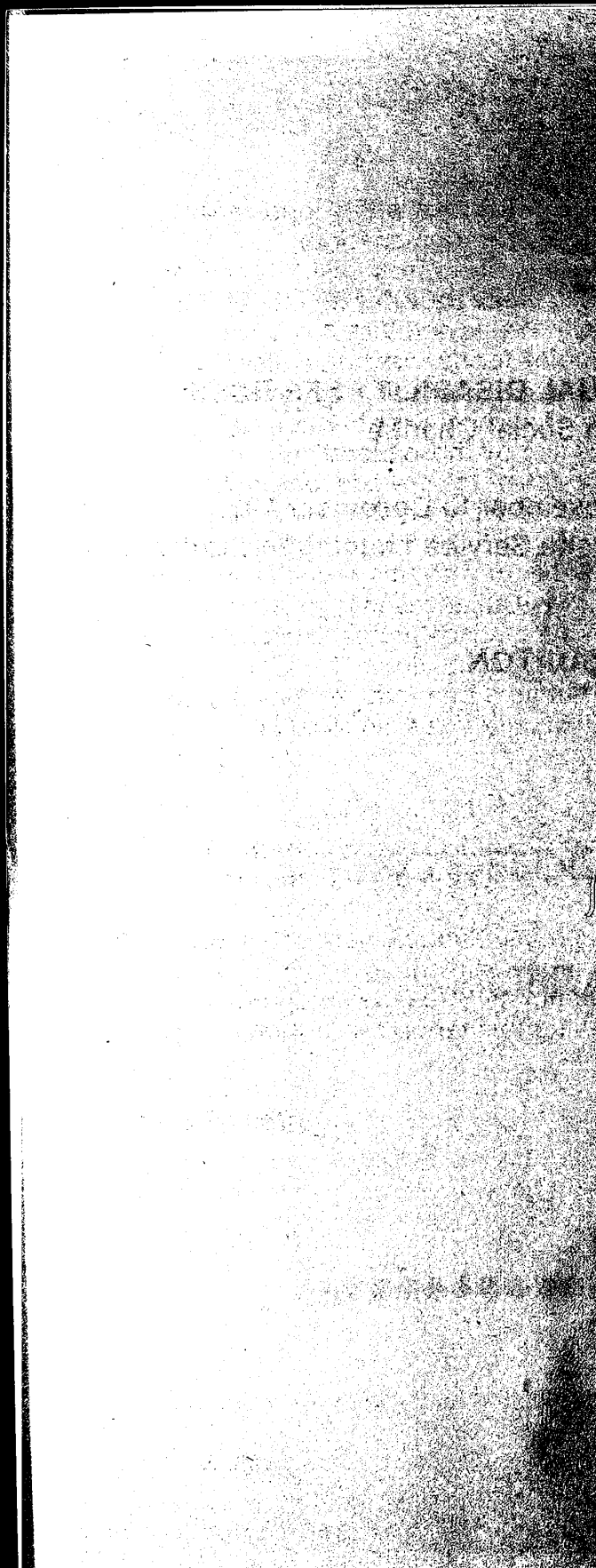
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AUSTRALIAN INTELLECTUAL DISABILITY SERVICES:

Experiments in Social Change

Report of a study tour, November to December 1987
supported by the National Health Service Training Authority

MARK BURTON



PREFACE

At the end of 1987, Mark Burton visited Australia with support from a NHSTA Travelling Fellowship to study programmes for the resettlement of people with learning difficulties from institutions into community settings. This report of his study provides an interesting account of how two states, New South Wales and Victoria, have gone about establishing large-scale strategies for de-institutionalisation and the governmental leadership this has required. More importantly, Mark's analysis of the Australian experience draws attention to the magnitude of the social changes implied by these resettlement programmes which, at their most fundamental, are concerned with 'including the excluded in the process of everyday life'. He argues that change of this nature requires both a broad alliance for reform and a vision of the future which can give coherence to this social movement. His analysis suggests however that these alliances may prove insufficiently robust as the pace of change accelerates, current visions may have failed to think through the full implications of social integration for service delivery and public bureaucracies may not be sensitive enough to achieve the individually focussed local action required.

Mark has himself been an influential leader in local service development in Manchester and a contributor to the important strategy promoting an ordinary life for people with learning difficulties in the North West as a whole. He is well placed therefore to draw out the lessons from these observations for people thinking seriously about how best to achieve principled and large scale change in the United Kingdom. Through its 'Building Community Strategies Working Papers', the College is therefore making this report more widely available.

March 1989

David Towell

ACKNOWLEDGEMENTS

This report, and the study tour on which it is based could not have happened without the support and encouragement of the following people.

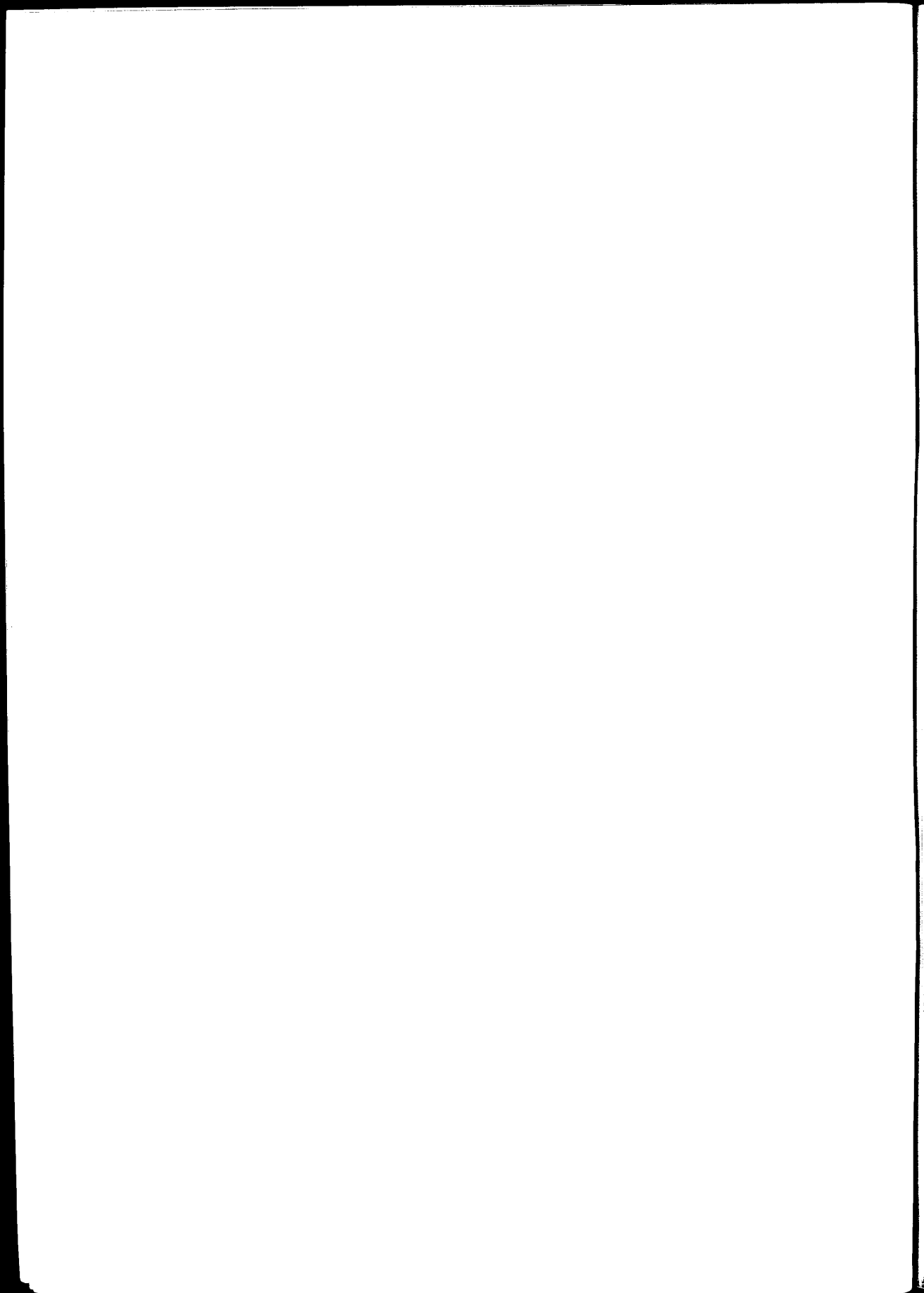
Britain First and foremost, thanks go to Carolyn Kagan for staying behind with two lively young children who are ordinarily demanding, but far more so when by yourself and they are missing their Dad. Thanks too for your encouragement with, and interest in the production of this report. To Helen Mortimer for willingly working longer hours with them during that period and to Amy and Anna for the phone calls and welcome home.

Thanks are due to the NHS Training Authority for an award of a Travelling Fellowship that made the visit financially possible. To Elaine Leaver, my Unit General Manager at North Manchester Health Authority in drawing the fellowship to my attention, and providing me with leave of absence and encouragement for the visit. To my colleagues in the Community Support Team for their forbearance when their manager was absent for five weeks, and to Robin Dony in particular for covering my responsibilities. To David Towell for filling in some of the gaps in my information gathering with regard to Victoria, and for providing me with some keys to understanding what I was seeing in Australia.

Australia Thanks are due to all the people listed in the itinerary, for their time and effort and interest in hosting my visit, but particularly to Simon Hasleton, John Dewhurst, Marcus Taft and Joe and Teesh Forgas in New South Wales; to Alan Hall and Frankie Gregson in Victoria, and to Errol Cocks in Western Australia.

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INTRODUCTION

In November 1987 I travelled to Australia with the aid of a National Health Service Travelling Fellowship in order to study resettlement programmes for people with intellectual disabilities*. My main focus was on the two major Eastern states, New South Wales and Victoria, but I also visited Western Australia which provides a number of contrasts with the East.

My aims were stated (in the grant application) as:

1. To study the resettlement of people with a mental handicap to community services in the states of Victoria and New South Wales, Australia.
2. To draw comparisons with policies and practices in the UK, with particular reference to the North Western Region.
3. To learn from these programmes, which are further advanced than our own**, both about pitfalls and good practice.

Why Australia?

In the search for ideas, models, lessons, or frameworks that might help us to provide more effective services there has been a considerable interest in developments in North America. This has been manifest not only through visits to North America by people from this country, typically followed by a report and/or talks about what was seen, but also via a number of visiting North Americans. This contribution has been valuable, but there can be considerable difficulties in interpreting what has been seen in a country with a very different system of welfare provision from that found in the UK. This is particularly so if the task of reforming services is seen as a principled and ambitious change in service systems rather than merely an adoption of models that have developed under somewhat different conditions. I must also confess to a degree of irritation with some of the enthusiasm for things American when we cannot ignore the very uneven nature of service provision there (Braddock 1985).

My interest in studying developments in Australia was based upon the notion that in many respects Australia represents an 'intermediate case' between Britain and the USA. This would certainly appear to be so in relation to its systems of welfare provision (including Health

*This is the term now generally used in Australia, and one which is in my view more respectful than 'people with a mental handicap' used here, and more accurate than 'people with learning difficulties' which seems to be increasingly used in the UK.

**This belief, it transpired, was correct in certain respects but not in others. This will become apparent from reading this report.

Services), but perhaps also in relation to less tangible cultural characteristics — a dimension that is of the utmost importance in considerations of social change (which service system change of this type certainly is), as well as in any serious examination of the issues involved in shifting the locus of support of disabled people to the community. I am also familiar with Australia, having worked there for most of 1980, so it would take less time to adjust to it than if I were visiting an entirely new country. This is a matter of some significance if the most is to be made of a short visit of one month.

Resettlement as social change: key issues in reshaping services to people with intellectual disabilities

The resettlement programmes that have developed in this decade are not simply concerned with moving a number of people from institutions to more appropriate accommodation in the community, although this is, of course a central element. What resettlement programmes are for, in the longer term is to replace the large institutions with a new service system, dispersed throughout the territory concerned, such that, in future, people requiring a service can be supported without having to leave the localities where they live. So in terms of service provision, a modern resettlement programme involves not simply helping people move out of the institution, but also providing alternatives to future admission by both resettled people and those lucky enough to have not used the institution. This includes providing community-based alternatives for short term breaks (often termed respite), for investigation and assessment, as well as for the occasional need to respond to difficult behaviour. Such a broadened definition of a resettlement programme is explicit, for example, in the current definition of 'the total resettlement task' employed in the North Western Regional Health Authority. *From the perspective of service provision, then, resettlement programmes involve considerable change in the way that welfare bureaucracies organise their resources.* In comparison with any industrial restructuring this is ambitious.

Moreover, viewed from the position of a person with an intellectual disability, the change involved also goes beyond the movement to new accommodation. The moral imperative behind resettlement is that people who are disabled belong with the rest of us, sharing our lives — our activities, our time, the places where we go, our acceptance, trust and respect. *Ultimately, resettlement programmes are here to change the social relations of intellectual disability: they are about including the excluded in the process of everyday life.* They are here to change not just the experiences of people traditionally seen as recipients of services, but to connect those experiences with those of the rest of

humanity, thereby changing all of our experiences. This might change our understanding, not just of what disability means, but perhaps also of what an ordinary life means.

Dramatically altering the manner of service provision to enable people with intellectual disabilities to participate in ordinary life is by any criterion an adventure in social change. There is a 100 year and more history of legitimated exclusion, whose dead weight has profound consequences in terms of the structures, practices, and ideologies of our human service agencies. It is also the starting point when we seek to work towards their inclusion in everyday life. We, and those unconnected with people with intellectual disabilities have been used to living our everyday lives without them. Success will mean more than changing organisations, it will mean profound changes in basic social relations, and in the value placed on human beings of all descriptions.

Before we dismiss such ideas as utopian, it must be recognised that such changes take time, and that there are steps on the way. However, it is a reasonable hypothesis that our ultimate goal should be clear, and also that by knowing where we are going, we will use means that embody our ends, so learning about those ends before we approach them.

There is no one way of describing the key elements in a programme of social change such as this. David Towell (1988) (writing in the British context) identifies three dimensions of a concerted strategy for change:

1. Establishing the strategic framework.
 - policy leadership
 - political backing
 - principles and vision
 - financial policies
 - management arrangements
 - personnel policies
 - staff training and support for innovation
2. Managing contracting institutions
 - co-ordination arrangements
 - staff consultation and participation
 - redeployment policies
 - individual client relocation
 - retrenchment planning
 - maintaining quality and morale

3. Developing local services
 - multi agency collaboration processes
 - establishing shared visions
 - participative planning linked to implementation
 - individual needs and representation
 - locality focus and community involvement
 - management and accountability
 - staff training and support
 - quality safeguards

Throughout the service system, Towell suggests, there are three key issues to address

- a). The development of new services should be based on explicit values and a positive vision of the opportunities which should be available to people with learning difficulties.
- b). Comprehensive and effective local services can only be planned and delivered through real collaboration between the NHS, local authorities and other relevant agencies.
- c). Region-wide initiative needs to be complemented by strong local leadership and widespread participation in achieving change.

This emphasis on vision, values, collaboration, and participation, parallels the understanding of the nature of social change that I will use to interpret what is happening in Australia. That framework for theorising the relationships between collective social action, ideology, and reforms will be presented below. For the present, I suggest that a successful resettlement programme, understood broadly, rests on 4 related spheres of activity:

1. *Establishing a vision of what ought to be.*
2. *Deepening the vision and gaining popular support for it, often through developing 'prefigurative' examples of what might be possible.*
3. *Developing the capability of the organisation(s) that will have to 'deliver the goods', and*
4. *Learning both about the means, but also more about the ends as the vision becomes less of a fantasy and the organisation(s) begin to operate to enable its realisation.*

It will be in terms of these spheres of action that I shall be attempting to analyse current developments in the three states that I visited.

Ideology and social change, some assumptions

Wolfensberger (1969, 1972), has argued persuasively that the forms that human services take reflect some basic ideologies that ultimately rest upon assumptions about the nature of people whose vulnerabilities occasion their reliance on such services.

I have argued (Burton, 1983), that Wolfensberger's account, while helpful does little to examine how such ideologies arise, or more importantly, how they can be changed. There is not the space here to enter into a lengthy review of the theory of ideology, but if as suggested above, the 'full resettlement task' is actually to bring about what amounts to some major social change, and if that depends upon the articulation of a clear vision and sense of values, then the political literature on the role of ideology in social change (or come to that in preservation of the status quo) is likely to be very relevant.

One of the most influential schools of thought concerning ideology stems from the work of Gramsci (e.g. '1971', Simon 1982). This framework is complex and the following account will inevitably distort and oversimplify it. A key idea is that in the western democracies, most social control is not by coercion or the threat of force, so much as through consent. Much of what passes for 'common sense' — i.e. assumptions and expectations about the order of things — is socially constructed. Our consent to certain social arrangements is partly because we expect the world to be like that, or indeed believe that it should be that way. Many of the assumptions about the place of people with disabilities have this quality: "she ought to be in a home", "he ought to be in hospital". In the Gramscian view, ideology acts as a kind of 'social cement', unifying a bloc of varied social groups and interests. In relation to social change, a collective will is the result of 'a cultural-social unity through which a multiplicity of dispersed wills, with heterogeneous aims are welded together with a single aim, as the basis of an equal and common conception of the world'. Gramsci's concern is the relationship between class and politics, but we can apply the analysis to other social movements and the ideologies that unite them.

A further key concept is the notion of 'hegemony'. A hegemonic social group exercises leadership and power, not through ideological domination, but rather through the combination of elements from the ideologies of those social groups that form an alliance or social bloc with it. Normalisation theory, for example, combines notions about autonomy and self determination, social integration and equal rights, the importance of human development and the relevance of

educational technologies. These themes are present in the ideologies of the social work profession, anti-discrimination activists (including many people with disabilities), and psychologists/educators. For Gramsci the welding together of such ideological strands and their related social groups is not an intellectual exercise but is carried out through collective social action. When ideological hegemony is established 'common sense' reflects it and it becomes difficult to think of the possibility of alternative social arrangements: of course people with disabilities belong in the city centre — after all most of the shops, road crossings, and toilets are adapted for their access. So ideology, social change, and social reality are closely linked, and have to be if coherent social change is to occur.

While the above account uses the metaphor of ideology as rooted in the interactions between various social groups, it may be noted that some recent and influential literature within organisational and management theory also emphasises the role of ideology, philosophy, or culture in both the maintenance of organisations and in their change (e.g. Brunsson, 1982; Handy, 1985; Pettigrew, 1987).

In viewing the Australian scene, then I took a special interest in the extent to which explicit ideology underpinned the resettlement programmes and plans, the breadth of the alliance or social bloc that by and large adhered to it, the efforts made to maintain this ideological and social leadership and support, and the extent to which strains were put on this hegemonic leadership by forces external to the alliance for reform but also by the consequences of the programme itself (in the form of a 'backlash', for example).

THE AUSTRALIAN CONTEXT

The Australian scene

Despite having asserted in the introduction that in many ways Australia is more similar to Britain than is North America, it would be very easy to make such a claim seem ridiculous. Australia is nearly as large in area as the USA, and is populated by some 14 million people, the vast majority of whom live in the coastal metropolitan areas of the South Eastern corner of the continent. While colonised by the British only 200 years ago, it was the home of a remarkable civilisation for some 50,000 years prior to that tragic event, a civilisation that is difficult to comprehend from a European point of view, but which was adapted to this extremely dry and inhospitable land (Blainey, 1976). When I was there the parallel was drawn by several people between the oppression of the aboriginal Australians and that of people with intellectual disabilities.

Australia is now a culturally diverse country, having been considerably enriched by immigration from Southern Europe and the Middle East as well as South East Asia during the post 1945 period.

There is a federal system of government, the Commonwealth of Australia having been founded by the Federation of the then colonies in 1901. State governments have considerable powers, with for example, their own prison departments, health departments, police forces, education departments, social welfare and housing departments. Local government has fewer responsibilities than in Britain, with the State level taking on many responsibilities that would belong to local government here. It is probably true to say, however, that there is a trend towards the increasing power of the Commonwealth government at the expense of the States, and a gradual increase in the responsibilities of local government.

State governments are funded through Federal taxation, and while, as in the USA they have the power to levy a State income tax, unlike the American States they do not.

The Australian welfare state

I have heard Australians complain that they are one of the most governed countries in the world. However, what is striking in comparison to welfare provision in the UK is the extent of 'welfare pluralism', or a 'mixed economy of welfare'. Unlike Britain, for example much of acute hospital provision is within the voluntary sector, although the Whitlam government of the 1970s did have some success

in replacing the insurance principle with 'an equitable tax supported medical care system' (Crichton, 1987). In addition, the Whitlam years saw initiatives in the community health field as well as in an emphasis on a more effective use of resources.

It is, however, only in recent years (1970s, 1980s, depending on the state) that Departments of Health have been set up at State level covering all Health provision.

Both State governments and the Commonwealth have departments concerned with social welfare. The Commonwealth is largely concerned with the funding of non-government agencies, while States provide direct services in agencies that approximate to British Social Services Departments (SSDs). There is a less strong social work profession than in Britain, with State welfare departments having nothing like the domination enjoyed by British qualified social workers in SSDs; other departments, such as Health, employ their own social workers.

As in Britain there has been concern about the high cost of institutional services in general, and a gradual build up of community based services across all client groups.

The Whitlam government also set up a Social Welfare Commission that controversially emphasised consumer involvement, and this has become a popular theme, at least in policy statements.

Other significant aspects of the Australian welfare scene are the far lower proportion of public housing (although there is some), and the very high rate of unionisation of the work force. This tends to be industry-based rather than craft-based, and has to be seen in connection with the existence of Labor administration in all of the States I visited in addition to the Commonwealth government.

Commonwealth policy on services to people with disabilities

When the Australian Labor party (ALP) returned to office in 1983, the new Minister for Social Security, Don Grimes, initiated a 'Handicapped Programs Review' focussing on 'the Commonwealth Government's programs of special services for people with disabilities and setting new directions more in tune with the aspirations of disabled people themselves'. A report, *New Directions*, was submitted in 1985, and its main message was that, 'wherever possible services for people with disabilities should be provided under a mainstream or generic auspice rather than in segregated facilities'.

Furthermore there was a strong emphasis on 'consumer outcomes', i.e. what consumers actually get and really want from service provision. The outcomes that were found to be the most important for people with disabilities were,

- a place to live
- paid employment
- being competent and self reliant
- participating in community activities
- feeling secure
- having choices in life, *and*
- having an image which is regarded positively by other people.

A final emphasis was on the rights of people with disabilities, including those with intellectual disabilities, particularly in relation to access to educational and employment opportunities.

The influence of normalisation is obvious, and this was carried through into the Commonwealth Government's Disability Services Act 1986. This legislation covers both the funding of services for persons with disabilities and the direct rehabilitation services provided by the Commonwealth Government. The Act replaces provisions of previous legislation with provisions that have the object of being 'more flexible and more responsive to the needs and aspirations of persons with disabilities'. Some of its key aims are to:

- ensure that services are available that enable people with disabilities to achieve their maximum potential.
- ensure that services
 - further integration of people with disabilities into the community, complementing generic services
 - enable people with disabilities to achieve the kind of positive outcomes listed above
 - are provided in ways that promote positive images and self esteem of people with disabilities.
- ensure that consumer outcomes are taken into account in the Federal funding of services.
- encourage innovation in service provision.

Associated with the Act is a statement of Principles and Objectives which provide more detail about the underlying philosophy (reproduced as Appendix 6 to this report).

The means by which the above aims are to be achieved, is of course through a funding policy. Under the Act, services will be approved for funding if they further the objects of the Act (in terms of the above list and the principles and objectives in Appendix X). Since service provision has tended to be based on other criteria in the past, it will take many agencies presently funded under previous legislation some time to reorientate their services towards these consumer — orientated objectives. To enable this to take place there is a 5 year period, to 1992, termed 'Transition', wherein agencies have to review their services on the basis of 'an analysis of what is required to produce a quality of life for clients of the service and how the service can provide the necessary supports to ensure that this happens' (DCS&H, 1987). A transition plan must be submitted by each service, covering, aims, objectives and intentions.

The Commonwealth Government mainly funds Non Government Organisations (NGOs), but can also fund State Governments. To give some idea of the scale of this finance, there is A\$151M (approximately £60M on a simple currency conversion basis) available across Australia. Western Australia, for example, which has just under 10% of the population receives A\$13M, and of this, maybe 60% is for intellectual disability services, although the proportion could be different in other states. In Victoria, the level of Federal funding is unusually low for historical reasons. Some demonstration projects are 100% Commonwealth funded, for example a supported employment program in Sydney for people with very severe intellectual disabilities. Programmes are generally jointly funded 50% by Commonwealth Government, with the State Government contributing another large part of the funding, together with a small contribution from other sources (e.g. charitable fundraising).

A succession of mini-budgets has, however resulted in a series of cuts in this budget. In 1987 when the ALP was re-elected the Ministries were reorganised and a 'Mega Ministry', the Department of Community Services and Health, was formed. Moreover, one view from an experienced observer (outside the Department) was that the present Minister lacks the commitment and vision of Grimes.

I met staff from the Department in its Western Australian branch and was impressed by their understanding of normalisation and related issues, which was by no means dogmatic. It is likely that their insulation from the day to day pressures of service provision encourages them to focus on the underlying principles in the Disability

Services Act, although this emphasis with its high expectations of services is not necessarily welcomed by service providers!

Both the New Directions Report (Commonwealth of Australia 1985) and the 1986 Act represents an exciting approach to the improvement of services in line with an explicit value base, and an emphasis on linking funding decisions to the real needs of people with disabilities. There were signs of embryonic attempts to define ways of assessing whether services indeed deliver the consumer outcomes that they intend to. It remains to be seen whether the vision can be sustained on the ground given the bureaucratic restructuring of the Department, and the cuts in funding (which reflect a deeper crisis in the Australian economy not dissimilar from that in the UK).

THE EASTERN STATES: New South Wales and Victoria

Introduction

New South Wales (NSW) and Victoria are home to respectively, around 35% and 27% of the Australian population. Their actual populations are around 5 and 4 million respectively, in other words of a similar order to that of an English Health Region.

They have always been the two dominant states, and there has always been keen rivalry between them and between their capital cities, Sydney and Melbourne (see for example Lacour-Gayet, 1976). The stereotypes are not altogether false: NSW — brash, arrogant, fast, invigorating, 'the premier state' say the car number plates; Victoria — more 'English', slower, more thoughtful, wetter and cooler, boring suggest some, 'the garden state'. I mention this difference because in many ways it also describes their different approaches to redeveloping their intellectual disability services.

Both States have a similar legacy of old hospital-type institutions, and both are embarked on ambitious resettlement programmes. However there are significant differences and these will be briefly mentioned here before describing each state in turn.

1. *Agency Responsibilities*

In NSW responsibility is divided between two government departments, Health, and Youth and Community Services. There is division of responsibility on the basis of severity of handicap.

In Victoria, an Office of Intellectual Disability Services is located within the Community Services Department. This agency is responsible for the institutions (now termed 'State Training Centres') as well as for people in the community.

2. *Separation from Mental Health Services*

This is a relatively recent phenomenon in much of Australia, which has a tradition of dual purpose institutions.

In NSW the intellectual disability wards in the hospitals were not de-gazetted from mental health legislation until 1985. It was only this year that the mental health and intellectual disability resettlement programmes were fully separated within the Department of Health.

In Victoria there seems to have been more specialisation in the construction of institutions, so it is only those in the country areas that are dual purpose. Organisationally, a separate 'Mental

Retardation Division' was created in the Department of Health in 1980, and this was transferred to Community Services in 1985. There is also separate legislation covering people with intellectual disabilities.

3. *Institutional Populations: the scale of the task*

In NSW there were in 1987, 1,960 people with intellectual disabilities in the 'Fifth Schedule Hospitals'.

In the smaller state of Victoria the population of the State Training Centres was 2,765 in 1987.

4. *Time Scale*

In NSW the Minister of Health announced in September 1987 that over a period of 7 years, there will be a reduction to 594 hospital beds, (i.e. a reduction by 1,366). However, (when I visited) the Department of Health was proposing to resettle no less than 750 people in the first year, and to have carried out the remainder of the deinstitutionalisation programme within 3 years.

In Victoria, on the other hand, although one institution was closed in 1981-2, consultation is currently under way over a 10 year plan to finish the job. There was some suggestion that 15 years would be a more realistic time scale for such service redevelopment.

NEW SOUTH WALES

Background

New South Wales (NSW) is the largest Australian State in terms of population (which exceeds 5 million). The main population centre is Sydney, which like all the large Australian cities sprawls for mile upon mile of single story, red roofed suburbia, reaching from The Pacific to the foothills of the Blue Mountains, a section of the Great Dividing Range that runs all the way up the East of the continent. To the West of these mountains lie sparsely populated plains, with a few country towns such as Dubbo, Orange, Wagga Wagga and Broken Hill. There are other population centres on the coastal strip, Newcastle and Wollongong in particular.

The present ruling party in the State Legislative Assembly is the Australian Labor Party (ALP) which has held power throughout the decade. However, persistent stories of corruption, an apparent preoccupation with prestige projects (such as a monorail) in the city centre, and other factors lead many to speculate that there could be a Liberal majority at the State general election in 1988. This is of some significance to the resettlement programme as we will see below.

Services to people with intellectual disabilities are run by a variety of agencies:

The Department of Health has responsibility for people with a severe or profound intellectual disability, people with less severe intellectual disability plus additional disabling health problems, and people 'who because of lack of alternative services have been inappropriately placed in facilities administered by the Department'. The Department has responsibility across the full age range, but there is, at present, a clear emphasis on service to adults.

The Department of Health runs the following services for people with intellectual disabilities:-

'Fifth Schedule Hospitals': i.e. traditional large institutions, of which there are 12, with some of these sharing the same site as psychiatric hospitals from which they have only recently been separated administratively. These institutions are located at or near (and 'near' can be relative) Sydney, Newcastle, Orange, and Goulbourn. At present these are home for 1,960 people, 5-7% of whom are aged 16 or under.

'Community Residential Units', universally known as 'CRUs', which are staffed group homes with up to (and typically) five residents, in ordinary houses bought by the Department of Health. There are at present 150 of these throughout the state. CRUs cater for both ex hospital residents and people accommodated from the community as an alternative to hospital. Some CRUs offer respite care.

'Community Health Teams', which correspond roughly to British Community Mental Handicap Teams. These are staffed at a level of approximately 2 front line staff per 80,000 general population (probably considerably lower than in Britain).

Some Day Services ('Day Activity Centres'), although the bulk of Day Provision is provided by the non-government Sector.

The Department of Health runs its intellectual disability services from a head office in Sydney, with Regional Co-ordinators in 11 Health Regions (3 of which cover Sydney Metropolitan area). Some of these Regions are further divided into Areas, which again have Area co-ordinators. Planning is highly centralised, although Regions differ in the detail of their implementation of plans (e.g. whether to have respite beds dispersed around a cluster of houses or to situate them in a core house). However program budgeting is only now beginning to supercede line budgeting.

The Department of Youth and Community Services (YACS) is a State Government Agency whose general responsibilities are somewhat analagous to those of a British local authority Social Services Department. In the field of intellectual disability, YACS has responsibility for people who are under Guardianship, i.e. they are the wards of the Minister for YACS: there are approximately 550 children (350 of whom are in foster care) and 350 adults. In the case of the adults the Guardianship order had been taken out so that the Department could provide a service. Unlike other Australian States (see the section on Victoria) there was no provision for selective Guardianship, although new legislation was in the process of being approved by State cabinet during the period of my stay.

YACS runs two institutions for 38 and 22 people and 23 Community based residential units (with an average of 4½ people [maximum 6] in each). There are plans to replace the 2 institutions with community based services. Casework support is provided to these people via local Community Welfare Centres.

There is 1 traditional sheltered workshop run by YACS, but the Department also has responsibility for licencing non-government sheltered workshops, day training centres and all residential services serving 2 or more unrelated adults.

YACS runs a Special Needs Adoptions Unit for children with severe and multiple disabilities. Interestingly, some planners in the Health Department seemed unaware of such a resource.

YACS has a Disability Policy Unit and the above specialist sections, but it tends to run its residential support services through its generic Community Welfare Centres. As in the Health Department there is a regional structure, but YACS Regions do not coincide with Health Regions. Furthermore Education and Social Security again have different Regions.

The Non Government Organisations (NGOs) provide a further component of the service system. The largest is the Challenge Foundation (originally the Subnormal Childrens' Welfare Association), and this runs a variety of residential and day services. The Steiner Organisation is another provider. Much of Special Educational provision was originally set up by this and other parent-based organisations.

The NGOs run day services, residential services (both traditional and CRUs under contract to the Health Department in some areas). NGOs are funded largely by the Commonwealth Government, but there is also State Government funding via YACS. There are also some private, for profit services.

Advocacy and related functions

Advocacy for people with intellectual disabilities comes from a variety of sources.

Citizen Advocacy is provided by at least 5 different local projects. The availability of Commonwealth Government funding enables such programmes to be developed and it is also thereby somewhat buffered from pressures from service providers at State level.

Corporate Advocacy is provided by **The New South Wales Council for Intellectual Disability**, a very effective umbrella organisation that has had a major role in promoting change. The Council represents an alliance of parents of people with intellectual disabilities with

professionals. It has been fortunate in having good communications with the machinery of government.

The Disabilities Services Co-ordination Unit; was set up within the State premier's department in response to a report from the State Anti-Discrimination Board. Covering all disability groups it provides a way of influencing government departments 'from the top'.

The Intellectual Disability Rights Service based at Redfern Legal Centre in Sydney's inner west, provides information on the rights of people with intellectual disabilities both to individuals and to organisations.

Self Advocacy is also established in NSW although I did not meet these groups (but see section on Victoria).

The History of Change

It is difficult to reconstruct the complex history of recent changes in ideology, service provision for people with intellectual disabilities, and in the opportunities and life patterns available to them. In attempting to do this here I have drawn on interviews with people employed by the State Government as well as those who were involved in corporate advocacy from outside, together with documentation available and discussion with observers in other parts of Australia. However, my limited duration stay meant that it was not possible to pursue every detail. Despite this, the broad picture should be substantially accurate.

The oldest institutions used to incarcerate people with intellectual disabilities in NSW were established up river from Sydney, and as in many other places there was little attempt to differentiate between intellectual disability and mental disorder/illness. While a Royal Commission recommended separate services as early as 1900 little was done to achieve this until the 1970s when wards for intellectual disability began to be 'degazetted', i.e. removed from the provisions of mental health legislation.

During the 1950s Non Government Organisations began to establish services. These were chiefly parent-based groups, setting up services such as special schools, day centres, and residential services for their daughters and sons.

1965 saw the establishment of the first Diagnostic and Assessment Centre at Grosvenor Hospital, and as recently as the late 1960s

Marsden Hospital was built — the Scandinavian architect winning an award for the design!

There was little mention of the 1970s by my informants except that Wolfensberger and others visited Australia and generated interest in normalisation and related ideas. The growth of some early intervention programmes during this period helped to change expectations of people with an intellectual disability. The NSW Anti-Discrimination Act was passed in 1977 and this outlawed discrimination on six different grounds, one of which was intellectual disability.

The early 1980s saw a quickening of the pace of change. In 1981 the NSW Anti Discrimination Board published a report; *Discrimination and Intellectual Handicap*. Among its recommendations was the establishment of a strong central planning and co-ordination function to be based in the premier's department. (This was eventually implemented in 1985 as the Disabilities Services Co-ordination Unit mentioned above). It also highlighted the issue of discrimination against people with intellectual disabilities, situating it within the broader concerns of discrimination against other oppressed groups, particularly in relation to the inadequacies of guardianship provision which meant incarceration in order to provide a service. This, then was official recognition of the legitimacy of the rights of people with intellectual disabilities. 1981 was also the International Year of the Disabled Person (IYDP), and in Australia, as elsewhere this led to a raising of consciousness about the civil rights of all disabled people. It was also the occasion for both State and Federal Government to review their policies and the services they were providing.

In the early 1980s it seems that parent activists and progressive professionals began to form the kind of 'social bloc' described in the introduction. There was what was described to me as a 'philosophical shift', towards a concern with less restrictive and community orientated service options and lifestyles. Together with this there was perhaps increasing recognition of the resources needed to provide appropriate support to people with intellectual disabilities. Some resettlement from the institutions was occurring in an ad hoc and under-resourced fashion, but such experiments gave increased credibility to the new ideology. At Stockton and Marsden Hospitals in particular there were positive changes in the nursing culture, including training, that sound comparable to the adoption of developmental and community orientated models within progressive factions in British mental handicap nursing.

The philosophical shift that involved the radicalisation of, for example, the parent activists of the NSW Council for Intellectual Disability and many professionals, together with realisation of the resource implications led to a heightening of corporate advocacy directed at the State Government in particular. The Richmond Report, commissioned in 1982, was an occasion for this advocacy to have a significant impact.

In August 1982 the Minister of Health announced that Mr David Richmond had been commissioned to carry out an inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled. Richmond was a senior civil servant and member of the Public Service Board, a key body in the government bureaucracy. The terms of reference were extensive and are reproduced in Appendix 7. Richmond's style was to engage in very thorough and meaningful consultation, and the social bloc was able to avail itself of this opportunity. Indeed, the NSW Council, throughout the preparation and implementation of the Richmond report was able to maintain a more consistent presence than that of the changing professionals and bureaucrats. It also has direct contact with the Minister and was able to exert a significant influence.

The Richmond report, adopted in March 1983, in what has been officially termed the Richmond Programme, made a large number of recommendations. These included the clear separation of services to people with intellectual disabilities from mental health services. In addition, it was recommended that as far as possible people with intellectual disabilities should be enabled to live within the ordinary community rather than in institutions. Indeed, services would be based on:

- (a) promotion of maximum development and education of each individual
- (b) pursuit of the objectives of normalisation and integration
- (c) promotion of the rights of people with disabilities

(principle (b) would in fact subsume both (a) and (c), see Wolfensberger, 1972). Furthermore, Richmond recommended that new resources be allocated and existing resources redeployed to set up a network of CRUs 'which would normally be ordinary houses each accommodating from 5-10 people'. Both long term and short term care would be provided as well as 'social and living skills training'. This programme would be directed at people resident in the institutions as well as those living in the family home and urgently in need of

alternative accommodation. Finally, the priority for funding this CRU programme would initially go to the Hunter and the 3 Metropolitan (Sydney) Regions.

At this point, Richmond moved into a position of significant power as Secretary to the Public Service Board, and this may have ensured implementation of the programme.

As a result, since early 1983, there has been an availability of seed resources as well as some transfer of funds from the Fifth Schedule Hospitals. The period 1984-1987, then may be seen as one where a new generation of services was established, and people were able to learn from the practice of developing these new patterns. In discussion with those leading the developments in late 1987, both at Head Office and in the Regions, it was clear that a great deal of their thinking about both the principles as well as the practicalities of community-based service provision came from direct experience in the period of implementation of the Richmond Programme.

A noteworthy feature of the publicity materials that were produced to explain the Richmond Programme was an emphasis on the implementation being a 'slow process of change which is being carefully monitored by the Government, consumers and the Unions'. In addition, all hospital staff would have their jobs protected.

January 1985 saw the publication of *Policies for Developmental Disability Services* by the Department of Health. This explicitly wrote the principle of normalisation into the policy of the department. It also followed Richmond in defining the client group to be served as those with 'Developmental Disabilities' rather than intellectual disabilities. This is a larger group, including those whose development has been compromised by physical disability or by brain damage during childhood. My impression is that it probably makes little difference in practice, and I have used the term intellectual disability synonymously in this report for the sake of simplicity.

In August 1985, the Public Hospitals Act was amended to finally separate intellectual disability services from mental health services in the hospital sector. As a result there are now two independent institutions sharing the same site in some places, with the intellectual disability part taking on a new name. However, in Head Office the separation of the two parts of the Richmond Programme did not finally take place until mid 1987. This has undoubtedly fuelled the confusion in the public mind between the two client groups.

A further development over 1986-87 was an Inquiry by a Ministerial Advisory Committee into conditions in the 5th Schedule Hospitals. This was precipitated by some deaths and bashings (to use the vivid Australian term) at a psychiatric hospital, but the initial inquiry was extended to cover the whole system. Apparently the report was so damning that it was not published except for the recommendations to Cabinet. Again, the NSW Council had representation on the Inquiry. The 27 recommendations were far reaching, recommending the eventual closure of all these hospitals over a five year period. Not all of the recommendations were accepted by State Cabinet, although the majority were. There seemed to be some reluctance to establish inter-agency task forces to look into particular issues, and while Cabinet, agreed to a major rundown of the hospitals some compromises were made, so that three hospitals for people with intellectual disabilities are now to be upgraded rather than closed.

As a result of this review, and its consideration by Cabinet, the Minister for Health, Peter Anderson, announced on 16 September, 1987 a A\$325 million eight year plan (sometimes described as a seven year plan in the same press release!) for the redevelopment of services for people with mental illness and people with intellectual disabilities. The actual budget for intellectual disabilities services within the above figure was not specified, but the following service developments were specified:

- 594 developmental disability beds in three first-class centres at the Stockton, Marsden and Grosvenor Hospitals;
- the establishment of 55 new respite care homes, 75 day activity centres, 60 full-time care residences, ten units for behaviourally disturbed people and 295 group homes for 1,344 people;
- the employment of 272 additional community staff and 2,040 extra residential care staff;
- the provision of 1,200 extra day places; and
- the establishment of a unit for severely handicapped children.

In 1987/88 it was proposed to establish '130 CRUs for 592 people; 529 day places; two special care units for behaviourally disturbed people; 30 day activity centres; 22 respite care homes and 15 full-time care residences.'

The programme was especially ambitious in the first 3 years, with a transfer of 1,366 people to the community from institutions, and the closure of 9 of the 12 fifth schedule hospital facilities for people with intellectual disabilities. 750 of these transfers were scheduled to take

place in the first year. (As a comparison, the North Western Regional Health Authority in England, which covers a population similar to that of NSW, proposes to close all its mental handicap hospitals over a 15 year period, resettling 150 people per year over that period).

A\$15 million was to be allocated for people living at home.

A task force chaired by David Richmond is to be established to oversee this programme, and again a variety of interests, including that of the NSW Council for Intellectual Disability, will be represented.

This brings us up to the present, and at the time of my visit the whole development was becoming increasingly politicised, as I will discuss in the next section.

To conclude this section on the history of change in NSW, it may be useful to draw out some themes and issues in this complex pattern of social change:-

1). A changing understanding of people with intellectual disabilities.

The philosophical shift described above drew upon a number of sources and experience, including:

- the longer range impact of social movements in the 1960s, concerned with civil rights and related issues, both as a general societal phenomenon as well as through events such as the passing of the 1977 Anti-Discrimination Act, publication of the 1979 Anti-Discrimination Board report, or the 1981 International Year of the Disabled Person;

- the mounting critique of institutions;

- the impact of the developments initially in Scandinavia and then in parts of the USA and Britain which pioneered firstly smaller and humane institutions, and later the use of ordinary housing;

- the development of such services in Australia, and their impact upon people with intellectual disabilities;

- the impact of early intervention programmes and behavioural teaching approaches led to a reappraisal of the capabilities of people with an intellectual disability;

- the growth of self advocacy;

- the impact of normalisation as an explicit philosophy.

Together with a shift in understanding about the humanity of people with disabilities, and a greater understanding about what might be possible in terms of service provision, there was,

2). A change in the power balance among the various stakeholders involved.

Elements of this change include:

- the decrease in the influence of the medical profession as intellectual disability services were increasingly differentiated from and separated from mental health services (this is not to forget that some members of the medical profession were, and are, important voices in the progressive social bloc);

- the increase in numbers and influence of professional staff such as psychologists;

- the redefinition in roles of staff such as mental retardation nurses;

- the development of an alliance between progressive parents and professionals (this has tended to be based around parents whose daughters/sons are not resident in hospital);

- the development of new forces such as citizens advocacy and self advocacy programmes.

Factors 1). and 2). have come together to establish,

3). A degree of ideological hegemony.

A consensus has been established between most professionals, the active parent organisations, legal rights activists, and significant parts of the bureaucracy and government politicians, about where people with intellectual disabilities belong and how to enable them to be there. This has become in many ways the established 'common sense', and it has acted as a way of galvanising this social bloc into action directed at turning the ideas into reality. The philosophy may be loosely described as 'normalisation', but what this actually means in NSW will be discussed below.

The implementation of policies based upon normalisation has been assisted by,

4). Political patronage

David Richmond's key role and position were discussed above, but in addition there has been a degree of commitment and even enthusiasm at State Cabinet level. Both Barrie Unsworth the Premier, and Laurie Brereton his deputy, are previous Health Ministers, associated with the

Richmond Programme. Moreover, Mrs Unsworth has an interest in intellectual disability while Brereton has a mildly intellectually handicapped daughter. It is of course difficult to assess the impact of such family interests. The present Health Minister, Peter Anderson is apparently an enthusiast for the Richmond Programme, seeing the issues as being about social justice. His statement announcing the 8 year plan in September 1987 said that implementation would provide services unparalleled in the world, and one of my interviewees suggested that Anderson wants to be known as the person who closed the institutions and set up the best service anywhere.

It is perhaps unlikely that such enthusiasm would have emerged without very good channels of communication with the activists in the progressive social bloc, and this definitely exists.

A further characteristic of this history that has led to ideological change and support for new forms of service provision has been

5). Consultation and debate

The Richmond Enquiry and Programme has been characterised by extensive consultation and debate. In some ways this has been misguided as for example when people have been consulted about people with intellectual disabilities moving into their neighbourhood, but in general it may have served to broaden the understanding of various stakeholders about the issues, and to build their consent to and support for change.

A final factor was

6). The capacity for model development

The availability of 'seed resources' has allowed practitioners to set up new services and explore the issues involved. This active development phase ('prefigurative action research', Burton, 1983) is clearly from where the present leadership of change in both the Department of Health and YACS, draws much of its theory and practice.

The above factors in the history of change in NSW corresponds very well to the theory of ideological hegemony by a social alliance or bloc that was outlined in the introduction.

The progressive bloc in NSW was able to initiate and sustain change from the late 1970s through to 1987. In the process the actors in this coalition of interests themselves underwent considerable transformation as the changes they had initiated in turn altered their

vision of what was possible, what had to be done, and what was the nature of the people with intellectual disabilities in whose interests, in the final analysis all this was. As the pace of change quickens it may be more difficult to maintain this ideological hegemony, as other stakeholders' interests come into the equation. In the next section I shall examine the present situation and some of the strains within it.

The Present Situation

In this section I will describe the situation in intellectual disability services as I saw it during my visit in November 1987. I shall not repeat basic information given above, but will try to go beyond the labels and official statements to describe what is actually going on. Naturally my observations are somewhat limited by the brevity of my visit, but I am reasonably confident that in broad terms the picture that follows is accurate. My itinerary and methodology are described in Appendices 2 and 5.

Service Provision

Hospital Services

The Fifth Schedule Hospital that I visited was the Strathallen Centre at Goulburn, a country hospital scheduled for early closure. It was until recently a dual purpose facility, but the intellectual disability side is now managed separately. It was noteworthy that the vast majority of nursing staff had qualified as psychiatric nurses rather than as mental retardation nurses, there only being 4 of the latter out of a total of 86 whole time equivalent. There were only 76 residents in the institution. One ward had been closed and replaced with 4 five person bungalows on the site, which were still run as a hospital ward and were linked by covered pathways. I was shown the ward where the people with the most difficult behaviour were said to live, and the people there seemed very similar to those that would be found on any fairly high dependency ward anywhere. There were 5 staff to 18 people by day.

Other hospitals have a larger proportion of mental retardation nurses. Among psychiatric nursing staff I met there was little or no awareness of modern training technology, nor of the notion of sharing activities with someone who could contribute to part of the task if not being able to fully acquire it. However, the standard of physical care appeared good. Staff concerns about resettlement included

- psychiatric pathology of residents: they felt that many of the residents were not only intellectually disabled but also mentally ill, and that in the community they would not have the benefit of appropriate nursing care. While their psychiatric background

probably led them to interpret much behaviour as symptomatic of psychopathology, I have some sympathy with their concern, since it does seem that in (rightly) separating intellectual disability services from mental health services, the problems of the minority of people with combined disabilities might have been overlooked.

- recognition of them as nursing professionals. It is not possible for nurses to work in the new generation of services as 'nurses'. It is possible for them to enter as qualified Residential Care Workers, but this is seen as an affront to their professionalism. They felt they had been trained to nurse (I couldn't get them to explain what this meant) rather than cook, mow lawns, etc. (The reaction is rather reminiscent of the reception of the Jay Report in Britain in 1979).
- a feeling of exclusion from the process and of not being heard.
- the likely isolation of community-based work, which is of course a real issue, particularly in the rural areas of the State.

When I visited, the State based nursing Trade Union had placed a 'black ban' on discharges and management were considering their next move in the light of this.

It seems likely that the picture is rather different at the hospitals in the metropolitan areas, and it is three of these that are being kept open, at least for the present. However, there are similar difficulties elsewhere, particularly in rural towns like Goulburn that rely on the institution as a source of employment.

Across the State the age distribution of people in hospital is as follows (I am grateful to Simon Hasleton for obtaining these figures).

AGE	NUMBER	CUMULATIVE FREQUENCY	%
>80	3	1960	0.2
>70	29	1957	1.5
>60	82	1928	4.2
>50	138	1846	7.0
>40	254	1708	13.0
>30	462	1454	23.6
>20	668	992	34.1
>10	292	324	14.9
<10	32	32	1.6

What is striking is the large number of relatively young people: 74% are under the age of 40. Staff estimates are that only 6.3% are likely to die in the next 10 years, and while these estimates could be optimistic, it seems clear that mortality is not likely to help the rundown of the hospitals greatly. Again this contrasts with the British context, (where estimated death rates are in the order of 3-5% per year) perhaps reflecting the generally younger population and selective migration of non-disabled people to Australia.

The Newer Services

I visited the Southern Metropolitan Region (Sydney south of the harbour, comprising the Eastern and Inner Western Suburbs). This Region includes some of the wealthiest areas of Sydney (the waterfront suburbs), as well as the deprived inner urban fringe, with its high ethnic population, unemployment etc. The Regional population is approx. 1M. There are 5 Areas in the Region, I visited services in the Eastern Area of the Region.

There is a Regional Co-ordinator, accountable to the Regional Director of Health Services, but responsible to the Director of Developmental Disability Services at H.Q. for the resettlement programme. The Area Co-ordinator is again primarily accountable, not through the Developmental Disability Service but through the Area Management of the Department of Health.

I detected some irritation from staff at Area level with the planning directives from H.Q., it was seen as inappropriate for the strategic management tier of the services to be so involved in the planning of the service programmes. There was also a feeling that the programme was trying to achieve its goals too quickly. However, there was a general commitment to the replacement of the institutions (albeit with some ambivalence about the most handicapped people), and some obvious expertise in areas of service delivery such as skills training and medical intervention.

The Eastern Area is perhaps unusual in that some local services were developed prior to the Richmond Programme. These comprise a day centre and a respite care hostel. The standard of the physical environment was not high, with shared rooms and toilets without doors, for example. (I was not able to watch the programme in operation, due to lack of time). In contrast, the staffed house (one of their 4 'CRU's') that I visited was physically excellent. The staff were obviously clear about the human value of the 3 women who lived there, and had a good relationship with the support staff from the

Community Health Team. The women who lived in the house were obviously 'at home' and it was clear that they themselves had developed a variety of capabilities since moving there. An interesting index of their 'ownership' of their home was the confidence with which I was shown the house, and the polite but firm way in which one of the women refused me permission to take her photograph.

There is a general staffing ratio of 7 staff to 5 people, (which yields 4-5 for groups of 3-4). While the H.Q. resource planning model is based on CRUs of 5 residents, there is some scope for flexibility, as witnessed by the house just described. However, in general it seems that groups of 5 will be set up, partly because of the system-wide assumption that CRUs are 5 person houses, and partly because of the drive to resettle large numbers quickly. While the three women I met all had their own bedrooms, this is not necessarily the norm in NSW CRUs (or CRUs elsewhere in Australia): few houses have 5 bedrooms.

The resettlement process is as follows. As part of the strategy of making resource distribution equitable in terms of resident population across the state, people are nominated to the Region and thence to the Area. Staff from the Community Health Teams meet with institution staff and rough judgements are made with regard to groupings. Groupings are made on the basis of age and disability in that order, and there can apparently be wide disability mixes in some houses, which would have some benefits but also significant disadvantages (see Wolfensberger and Thomas, 1982). People are involved in the process of choosing furniture, and given some familiarisation with the house prior to making the move. Few demands are made of the person during the first 8 weeks, and after this time an individual service plan is drawn up. This includes both 'training goals' and 'environmental goals', although unfortunately the video-based training package on individual service planning focusses almost exclusively on training goals. Community Health Team members in the Eastern Area believed that the pressure of the move is often underestimated by planners and staff.

There was also a general feeling that day services were insufficient. The NGOs had traditionally been the main providers, but now the Department of Health was setting up additional day services. However in addition to the institutional day centre model there was some use of (relatively) more ordinary facilities, for example one elderly woman went to a centre used by non-handicapped old people. Furthermore, **the development of vocational services in Australia is advanced well beyond that in Britain:** there is a variety of true supported employment

programmes for very disabled people, and there is a greater availability of both on the job training and post placement support than we have here. The reasons for this appear to be a). there is a higher 'disregard' on benefit payments (A\$30 = £12) giving rather more space for the development of more competitive work, and b). the 'readiness model', exemplified in MENCAP's Pathway Scheme, for example, holds less sway in Australia, perhaps because of a greater sophistication about behaviourally based training methods.

The dominance of the '5 place Community Residential Unit' was striking. Some influential people saw no great problem with this, but by and large there was an awareness that the CRU was not the last word in community-based service provision. One informant described the Richmond Programme as 'four bedroom, brick veneer-oriented', rather than as orientated towards the ordinary life experiences of the service user. However, he did point out that the CRU was an efficient tool for closing down an institution. In other words, the CRU is adequate to the narrow definition of resettlement, but perhaps not to the wider definition developed by Towell and in the introduction to this report.

Agency set up

The agency responsibilities are described at the beginning of this chapter on NSW. In terms of the relations between agencies, my own view is that NSW has the worst possible arrangement, with demarcation between the Department of Health and YACS on the basis of degree of disability and historical ownership of services, rather than on that of agency capabilities (e.g. skills of staff, linkage with communities and generic resources/services, capacity to manage large scale system change, etc). While there was obvious respect between key people in senior positions in both agencies, local collaboration was minimal. While not wanting to wish the British system of joint planning on anyone, it does seem that the situation in NSW represents a stage in service system development reminiscent of Britain several years ago when agencies were 'doing their own thing' in isolation (this still happens of course) while the DHSS view was of a similar and unworkable demarcation on the basis of level of disability (still unfortunately the position in some English Regions).

Within the Department of Health, planning is highly centralised, and this must lead to a degree of insensitivity to local needs and the interests of consumers, unless as seems to be the case (by default or by intention?), H.Q. staff are drawn from the Regions and do not stay at H.Q. for long. While there is clearly some local discretion, the basic

model (and the finance) is prescribed at State level, rather than giving local staff clear guidelines and a budget to work to. The long range consequence could be to hamper experimentation and model development, leading to a service system based upon a limited range of models and options.

Financially, the system seems cumbersome (as is the case in most welfare bureaucracies). There is a developmental disability budget at State level, but the money for developing the new services are routed through the Second Schedule (public general) Hospital administration. One problem seems to be that there is little understanding or ownership of the aims of intellectual disability services among these administrators (leading to difficulties in, for example, staff training). There was a vagueness about finance, particularly with regard to the mechanism for release of funds from the institutions, but also evidenced by H.Q. staff working from the ministerial press statement. This may reflect what is a strong tradition of centralised line budgeting in Australian public administration, which is gradually being supplanted by programme budgeting, but as yet with little obvious decentralisation of budgetary information or control (Regional Co-ordinators have budgets, and Area co-ordinators will eventually too). Apparently a 'dowry' system has been tried for transfers of people from the institutions, but this was based on only 45% of unit hospital costs. A variety of arrangements have been tried, including direct negotiations between Regions and the institutions. While there is not a bridging fund as such, the new resources announced by the Minister in 1987 are likely to serve the same function.

Legislation

At the time of my visit it appears that removing people with intellectual disabilities from mental health legislation had led to gaps in the legislative framework, so for example, a person with an intellectual disability could not be confined if s/he were a danger or in need of treatment outside the mental health legislation. Assuming (as I do) that there are occasions where, with strong safeguards, it is appropriate to prioritise a person's rights, this led to genuine problems in providing a service to some people in need. However, as mentioned above, State Cabinet had agreed to a Guardianship Act that would provide an alternative means for dealing with these issues (see section on Victoria). NSW is unusual in Australia in not having enacted specific legislation relating to services for people with intellectual disabilities.

Ideology

In my account of the history of change in NSW (above) I stressed the

building of an alliance around an ideology. One Informant used the term 'philosophical shift' to describe this process. My description of that ideology was purposefully general there, because here I want to 'unpack' or 'diagnose' the dominant (or hegemonic) ideology in NSW. This task is difficult because it is necessary to be sensitive to the commonalities as well as the discrepancies in the ideologies expressed in people's actions and words, while gauging as well the relative influence of these different strands. Again, I must state the usual caution given the brevity of my visit, although this was an area to which I devoted much attention.

O'Brien and Lyle (1987) redefine normalisation in terms of '5 accomplishments' for services to attain for their users. The following scheme is based on this account, but makes some changes in terminology and also in the basic definitions of the accomplishments (see North Western Regional Health Authority, 1988, for more detail):-

1. **Presence in the Community** — sharing places and activities with ordinary community members.
2. **Relationships** — having a variety of relationships, of various types, with other people, including some who are socially valued, i.e. not solely family, staff or other clients.
3. **Autonomy** — having real control over what happens to you; including protection of rights.
4. **Respect** — being seen and treated as a valued human being; having a positive identity and self image.
5. **Capability** — having the resources to get things done that are important to you. Includes a variety of possible means of which one is through becoming personally competent, but others include having the means to get assistance. Includes maintenance of bodily and mental integrity.

In NSW, the hegemonic ideology stresses certain of these areas, namely **competence** (part of capability, above), and **rights** (chiefly subsumed under autonomy, above). In addition there is some emphasis on **presence** but perhaps the most striking aspect was a failure to have thought through the implications of social integration (**relationships**, and the non physical aspects of **presence**) for service delivery. To illustrate this, I found a great deal of emphasis on the use of 'generic services'. There are sound reasons for using generic services where these are available and where they can deliver an effective service (see Wolfensberger and Glenn, 1975), but I was not

convinced that in NSW these services had been actually itemised or explored, but rather this seemed like an inchoate striving for ordinariness from within the mind set of 'service consciousness'. In other words the goal of an ordinary life with other citizens in the places that characterise typical patterns of everyday life, could only be expressed in terms of an image of people using generic **services**. In a context of a shrinking or threatened resource base for human services, this is a dangerous emphasis, since there is little evidence that generic human services are in any way extensive enough or effective in performing the fairly specialised task of enabling people with significant disability to use ordinary human places, activities and resources in common with the rest of the general population. (NSW was not unique in this apparently naïve emphasis).

The above summary is an attempt to capture the key themes in the dominant ideology, throughout the social movement of those committed to progressive change in the pattern of services. It ignores the great insight of many people, especially many in leadership positions, that goes beyond the simplified *rights + competence + generic services + ordinary buildings = normalisation* formula that dominates. What does not seem to have happened sufficiently is the wider dissemination and ownership of a practical, thoroughgoing, but developing articulation of normalisation. One explanation for this is perhaps the relative lack of normalisation — based training (e.g. through PASS).

Political Context

As a visitor to NSW arriving in November 1987, I was quickly struck by the high media profile of mental health services, as well as to some extent by a concern with people with intellectual disabilities. In my first day in Sydney there were the following news items on ABC radio;

- The 'pack rape' of a young man with an intellectual disability in prison.
- The loss of a licence and hence grant aid by a sheltered workshop following allegations of cruelty and a series of accidents. The Liberal Member of the (State) Legislative Assembly was involved through financial interests.
- An interview with the Chief Executive of Gladesville/Rozelle psychiatric Hospitals following the discharge (outside the Richmond Programme) of a man no longer diagnosed as mentally ill, who later died apparently as a result of neglecting to carry out self administration with insulin.

In the following weeks there were numerous news items on the broadcast media as well as major articles and editorials in Murdoch's papers the *Sydney Morning Herald* and *The Australian*. The deinstitutionalisation programme, was a major news item, and the opposition of psychiatric nursing staff to poorly managed and under resourced discharges was given prominence. The media tended to make two errors in their coverage, *a)* often, although not always failing to distinguish between people with mental illness and people with intellectual disabilities, and *b)* within the Richmond Programme with ordinary discharges from psychiatric hospital in the context of a shrinking hospital capacity (and perhaps redefinition of eligibility criteria). However, whatever the reasons, this was bad publicity for the move towards community in general, and it could rebound on people with intellectual disabilities.

Moreover, there was considerable evidence that the Liberal (urban conservative) opposition was beginning to make political capital from the issue. This of course, is despite the implementation of similar policies (less generously resourced) by the right wing administration in Queensland, by the Thatcher Government in Britain, as well as in the USA. With the ALP ten years in power in NSW, an uncharismatic premier, persistent talk about corruption, and a general election in mid 1988, there is a real danger that the resettlement programme could become a political pawn. What happens depends on whether it becomes an election issue, and to what extent and in what way it is reported, and on whether the ALP or the Liberals win power.

The obvious concern of many parents of institution residents, the Nurses Union, and the self interest of people in towns where institutions are a major industry, are factors that also impinge on the strategy, and the skill with which the programme is steered through this minefield will be crucial to its survival.

Necessary hegemony and hegemonic strain

In the above account of the history of change in NSW, I described how a progressive social bloc was formed that drew together a variety of interests, cemented by a common ideological commitment. That bloc was able to initiate and sustain change between the late 1970s and 1987. I raised the question, however, of whether it was likely to be able to maintain its ideological hegemony — the basis for its action for change — as success led to a quickening of change, and therefore to the entry of other interest groups into the picture. My assumption here is that as the scope of reform increases the 'necessary hegemony' — the amount of ideological hegemony necessary to hold the alliance

together and marginalise competing ideologies — will increase. If the hegemonic social bloc fails to maintain necessary hegemony, a phenomenon of 'hegemonic strain' will develop, allowing other social interests and their ideologies to enter the stage from the margins, and change the terms on which the debate and hence decision making, is based.

Whether that scenario will take place, or whether hegemony will be maintained is likely to depend on

1. The robustness of its hegemonic ideology.
2. The extent to which the dominant ideology can be reproduced and disseminated.
3. The scope for assimilating further interest groups into the social bloc.
and
4. The degree and nature of outside turbulence, i.e. the changes in the social system within which the development disability system is located.

1. and 2. We have seen that the hegemonic ideology is far from inclusive. It could be deepened throughout the service system, but this would depend on those with a sufficient grasp of the complexities of normalisation grasping this nettle. There is a staff development and training resource for the Developmental Disability Division of the Department of Health, and this comprises a competent and confident group of staff. However, the strategies required probably go beyond what can be achieved through staff development.

3. To assimilate other interest groups would require at the very least taking on nurses' professional sensibilities, if this could be done without significantly compromising the programme. It would also involve building support among the parents of people currently in the institutions, and in the wider community. The latter issue is important given the widespread confusion with mental illness. A stronger emphasis on social integration, which might, for example involve the development of a non buildings-based cadre of non professional staff might help here.

4. The issue of the unpredictability of the wider political environment has been discussed. However, there are likely to be allies in the political centre and right.

Conclusions

Services in New South Wales have progressed greatly during the 1980s. This is due to the principled alliance of parents, professionals, public servants and politicians who have come to understand the interests of people with intellectual disabilities in terms different from those that dominated in the previous decade. As a result new money is still being found for services for people with intellectual disabilities, there are some better services in existence, and there is a major programme of reform under way.

There are, however some weaknesses that could seriously compromise the goals of the reform movement. These can be listed as follows:

1. A highly bureaucratic service system, over centralised, and weak in the localities where people with intellectual disabilities will need effective and creative leadership for the services that they use. Moreover this service system is fragmented between two major agencies on largely meaningless lines, resulting in a weakness in the capacity of both organisations to respond effectively.
2. A failure to take key interest groups along with the reform. This includes some nursing staff, many parents of people in the institutions, local interests in the country towns, opposition politicians, and the mass media.
3. An ideological weakness, particularly with regard to the importance of social integration, and a failure to build such understanding in the staff who run the service. This is complemented with a common failure in service systems to systematically learn from good practice.
4. An over-reliance on one service model, the so called community residential unit.
5. An excessive haste in trying to create what are truly massive changes in service systems, in the lives of people with an intellectual disability, and in the lives of those who care for or about them and those who might want to share part of their lives with them. Such haste is likely to intensify the opposition the plan will receive, severely straining the ideological hegemony that until now has cemented a formidable alliance for reform. Moreover it is likely to increase the number of mistakes, the stress experienced by users and everyone else involved, and therefore to threaten either the quality of the new service system, or even its very realisation.

6. Limited sophistication about the nature of both social integration and community.

It will not be long before the situation becomes clearer. The dangers of a collapse in NSW for reform programmes elsewhere in Australia could be significant.

VICTORIA

Background

Victoria lies to the south of New South Wales, occupying the southeastern corner of the continent. The population is smaller than that of NSW, just over 4 million. The largest population centre is Melbourne (pronounced 'Melbun'), which like Sydney is a vast sprawling metropolis. While the country areas are sparsely populated, Victoria is considerably more compact than is NSW.

The present ruling party in the State Legislative Assembly is again the Australian Labor Party (ALP) which has held office since 1982.

Service to people with intellectual disabilities are provided as follows:

Community Services Victoria (CSV), through its Office of Intellectual Disability Services (OIDS), is the State Government agency with overall responsibility for co-ordination of services to people with intellectual disabilities. It covers all degrees of intellectual disability, and all age groups. Its direct services comprise:-

The 8 hospital-type institutions, known as State Training Centres, where 2,700 people live (this excludes 3 institutions jointly run with the Office of Psychiatric Services and largely staffed by this division of the Department of Health).

Field services provided by 18 Regional Teams, which together have about 600 staff, are responsible for those activities that in Britain would be taken on by Community Mental Handicap Teams or their equivalents.

23 Community Residential Units (CRUs), again 5 person staffed houses, are run directly by OIDS. These were established on the closure of St. Nicholas Hospital and house its former residents, most of whom are profoundly disabled physically and/or intellectually.

OIDS also subsidises a variety of services run by —

Non Government Organisations (NGOs). Day Training Centres offer day and vocational services, as well as some family support services. They provide for approximately 2,700 people.

126 Community Residential Units are operated by NGOs. Running costs are met by the State Government, Commonwealth Government, and partly through their own fundraising. The Capital costs are met by OIDS which also runs a payroll service, and provides a manager per 4 houses.

Advocacy and related functions

Advocacy for people with intellectual disabilities is available from several sources.

Citizen Advocacy. There are 7 citizen advocacy programmes in Victoria, 6 of which have been established in the last two years with a 50/50 combination of funding from OIDS and the Commonwealth.

Corporate Advocacy. This is no body corresponding to the NSW Council for Intellectual Disability. This gap is being addressed by a number of interested people. There is a pressure group somewhat analogous to the Campaign for People with Mental Handicaps in the UK, but this seems somewhat marginal at the present time.

Self Advocacy is most notably expressed by REINFORCE, the Union of Intellectually Disadvantaged Citizens. This body was most impressive in its links with the OIDS bureaucracy, its ability to produce policy statements, videos, interventions, and other ways of expressing the interests of people with intellectual disabilities. The obvious abilities of many of its leading members belies the fact that many of them are ex-residents of institutions for people with mental disabilities. REINFORCE has an office base and some limited government financial support.

Public Advocacy is another recent development in Victoria in the form of the Office of The Public Advocate, which covers a number of functions (further discussed below). The legislative basis for this impressive development will be discussed later. The Office is administratively located within the State Attorney General's department, which gives a degree of distance from the departments concerned with service provision, but which could at times raise the possibility of conflicts of interest.

The History of Change

As in the case of NSW it is not easy to piece together the Victorian history of changes in ideology, provision, and consumer experiences. I have been fortunate in there being an historical account of the development of services in the Interim Report of the 10 Year OIDS Plan (1987), which provides a chronology of the milestones. To provide a history that recognises the role of interest groups, ideology, and politics, I have also drawn on other documentation, interviews, and discussion with outside observers. Again my limited time has meant that I was not able to pursue all the details, but as in NSW the broad picture should be a generally accurate portrayal.

The oldest Victorian institutions housing people with intellectual disabilities date from the 1860s; they are situated in the Melbourne area, and near the country towns of the gold industry in the western and north-central areas of the state. A further phase of institutional building occurred as part of a public works programme during the depression of the 1890s. These institutions were, as in NSW, established to serve both people with intellectual disabilities and those with mental illness. Between 1913 and 1937, a small number of special schools were established by the Education Department, and two of these, established in association with existing institutions, became the largest and third largest of the present OIDS institutions, Kew Cottages and Janefield.

As in Britain, children with intellectual disabilities defined in terms of an I.Q. below 50 were denied the right to education until the 1970s. This led to a substantial development of Day Training Centres by parent-based organisations, which from 1959 could be funded by the State. There is now a large Non Government sector which has its roots in this period, but today runs a variety of residential services (including CRUs), and day services. The sector is complex and fragmented, but understandably tends to be highly localised.

The late 1960s and early 1970s saw an increase in demand for services, and a growth in the estimation of the potential of people with intellectual disabilities. A focus was provided in 1974 by 'The Age' newspaper in a series of articles that exposed conditions in the institutions and the need for improved provision to intellectually disabled people and their families. There was also a fund raising campaign at this time.

In response to this activity the State premier established a committee to investigate intellectual disability services in Victoria and to report on service needs. This body, 'The Victorian Committee on Mental Retardation' reported in 1977. The report established normalisation as the guiding principle for service provision, although its definition of normalisation was limited to an emphasis on the promotion of growth and development through making life conditions as normal as possible, together with some mention of the desirability of integration but some ambivalence with regard to how far this should go. The Committee also made 137 recommendations, few of which were implemented.

In 1980 the Committee's recommendation to establish a separate division within the Department of Health was implemented. The first

director of the new Mental Retardation Division (MRD) was appointed in early 1981. He was Errol Cocks, an educational psychologist from Western Australia. Cocks had a very clear vision of what people with intellectual disabilities should be able to expect from life, and of how services might enable those patterns to happen. It is clear that he had a key role in establishing a strong value base for the Division, and he moved very quickly to generate change, both organisationally and ideologically.

At around this time there was growing interest in normalisation training through PASS (Wolfensberger and Glenn, 1975) and (subsequently predominantly) PASSING (Wolfensberger and Thomas, 1983). This grew into a substantial emphasis within the organisation and outside: there was considerable enthusiasm for these approaches, especially 1983-5 (with perhaps some decline latterly), and a PASSING workshop is now an established part of nursing training.

Those who were involved in MRD from 1981-1983 describe a state of high energy and excitement, together with a clear vision of a desirable future, at the centre of the organisation as the following developments were initiated:-

The establishment of Regional Teams. There had been two Regional Teams prior to Cocks' arrival, which themselves had their origins in a very limited State-wide outreach service which operated from St. Nicholas' Hospital. It was seen as important to develop a non-institutional base for service provision and within two years 13 Regional Teams had been established, although with minimal staffing as well as recruitment difficulties. MRD was divided into two divisions, Regional and Institutional services. There was some feeling that those at the head of the division were hostile to those involved in institutional provision, and whether or not this was actually so, it is only relatively recently that community-based nursing staff have been incorporated into the Regional Teams.

The St. Nicholas' Resettlement Programme. St. Nicholas' was originally the site of the Victoria Childrens Hospital which closed in 1960. In 1966 it re-opened as an intellectual disability institution. In the late 1970s there was a controversy, centred around a resident called Ann MacDonald who it transpired did not have an intellectual disability, but whose abilities had been masked by physical disability. She was educated by Roslie Crossley who published a book (Annie's Coming Out) describing the events leading to Ann MacDonald's eventual release from the institution. This episode had been handled

poorly by the Health Department bureaucracy which reacted with hostility. St. Nicholas' was also a fire danger and housed mainly children, so it was perhaps relatively easy to seize the opportunity of launching a programme to replace it. The first CRU was opened in 1983 and the institution closed in 1985. There was apparently good communication throughout the process, which enabled both the Trade Unions' and the parents' interests to be accommodated while successfully replacing St. Nicholas' and establishing what Cocks at the time regarded as the high cost component of the community based service system that would be developed over time. The 30 CRUs that replaced St. Nicholas' are operated directly by OIDS, and one price of the development has been rather rigid staff rosters, and hence relatively high costs.

Other service development. During the 1981-3 period, the number of CRUs for people in the community needing alternative accommodation increased from 10 to 80. There was also some growth in early intervention programmes based on home visiting. In addition, there was some upgrading in institutional facilities, including some development of domestic-type environments within the institutions.

Self Advocacy. Cocks also gave encouragement to the developing self advocacy group REINFORCE, helping them to be heard and bestowing legitimacy on their voice.

Legislative Reform. Even before the arrival of Errol Cocks there had been a ministerial directive to consider the legislative base for services to people with intellectual disabilities. Accordingly two committees were established:

1. A Committee on Protection of the Rights of Intellectually Disabled Persons, chaired by Cocks. This Committee reported in 1982 and, after public consultation, its recommendations formed the basis for the Guardianship and Administration Board Act, 1986, which is discussed below.
2. A Committee on a Legislative Framework for Services to Intellectually Disabled Persons. This committee was chaired by John Rimmer, then a lecturer at the Department of Social Studies, University of Melbourne (now Director of Psychiatric Services in the Victorian Department of Health). This Committee reported in 1984 and its recommendations resulted in first a White Paper and subsequently the passage of the Intellectually Disabled Persons' Services Act, 1986. Again this legislation is discussed below.

In 1982 the ALP won power in Victoria, with a commitment to

increasing social justice, an emphasis that is seen as consistent with the philosophy of normalisation.

It appears that while highly successful in setting in motion some major and progressive developments, and in creating a clear sense of direction for services to people with intellectual disabilities, Cocks' leadership raised expectations to a level that the bureaucracy was unable or unwilling to meet. Subsequent leadership has probably been less ideological and more pragmatic, although still working within the broad vision established between 1981 and 1983, when Cocks left.

The Rimmer Report (1984) was a very thorough and impressive review of the issues on which legislation for people with intellectual disabilities should be based. Its main recommendations were as follows:

- That a new Act be created, to be known as the Intellectually Disabled Persons' Services Act. It put forward a set of principles for inclusion in the Act, upon which service delivery should be based. These were a well balanced paraphrase of the principle of normalisation.
- The Act would also define eligibility for services, require services to prepare both General Service Plans and Individual Programme Plans for service users, arrange for the registration of services operated by NGOs and restrict and regulate admissions to institutions.
- The Act would contain provision for offenders with intellectual disabilities.
- The Act would contain some specific mechanisms for the protection of rights of people with intellectual disabilities, particularly vis a vis restraint, seclusion and monies of clients of residential services.
- There was detailed discussion of the issue of what body should have overall responsibility for service provision to this population. The recommendation was that this should be an Office of Intellectual Disability Services within the Ministry of Health.
- That a Consultative Council on Intellectual Disability be set up to advise the responsible Minister, comprising experts in the field, community representatives, and voluntary organisations providing services.

A Ministerial White Paper followed later in June 1984 which reiterated

the State Government's commitment to the philosophy of normalisation, and to the developments already in progress. It sketched out the priorities for development in the near future, in terms of both key tasks and a rapid expansion of funding. It also called for the preparation of a 10 year plan with a focus on deinstitutionalisation.

The White Paper also quoted ALP policy on services for people with intellectual disabilities. Again this was phrased in terms compatible with, and almost certainly derived from, the principle of normalisation. It is clear that there had been good informal communications between those in the forefront of service planning and provision and ALP politicians. Furthermore there were good relations with the main Trade Union, the Hospital Employees Federation (HEF) which was represented on the Rimmer Committee and on the Consultative Council set up at this time. Rimmer himself apparently acted as a 'conduit' between those thinking in detail about how to redevelop services (within and outside MRD) and ALP politicians. It seems that there were also good contacts between some of those at the forefront of the 'normalisation movement' and ministerial circles.

In June 1985, the Premier announced a reorganisation of the government bureaucracy. Responsibility for services to people with intellectual disabilities was transferred from the Health Commission to the new Department of Community Services (CSV). While appropriate in that this population generally has a greater need for social services than health services proper, it led to major industrial action as staff were concerned about the implications of the move, e.g. for their conditions and security of employment, professional recognition, etc. As a result it was conceded that MRD would retain its separate identity, as OIDS, for at least the first twelve months after the move.

In January 1986, the Minister for Community Services, Caroline Hogg, commissioned the production of a 10 Year Plan for Service Redevelopment. This was carried out by a team of consultants led by Lindsay Neilson, a management consultant, in conjunction with an OIDS project team. Overseas experts were also brought in for a 1 month period, during its preparation. An interim report was published in June 1987, as a document for wide public consultation. The proposals were wide ranging, and were backed by detailed work in areas such as demography/epidemiology, survey of the conditions in the Institutions, social impact studies of the likely effects of institutional closure, surveys of the services available, studies of the organisation, workforce, and finance of OIDS, together with some work on models of service. The report's proposals were as follows:-

The *Broad Strategy* would be to provide intellectually disabled people with the support necessary to enable them to live in the community. However, the report goes beyond this broad aim by discussing what living in the community might mean.

'It is our view that the focus of services redevelopment should not be only on the means by which intellectually disabled people are accommodated but also on the daily lives of intellectually disabled people. Some of the most important and fundamental reforms. . . lie. . . in the area of ensuring that opportunities are created for intellectually disabled people to develop and lead interesting, fruitful and fulfilling lives in the same manner as non-disabled people do.

*State-delivered services to intellectually disabled people are insufficient in themselves to create and provide these opportunities. What is also necessary are processes which we describe as processes of "**Opening up the Community**" to intellectually disabled people. This is a different concept from that of "community-based services" or from many interpretations of "normalisation" or "deinstitutionalisation". It is akin in many ways to the "**Breaking down the barriers**" theme which was promoted during the International Year of the Disabled (sic).'*

'Opening up the Community' means three things in strategic terms;

- 1) Opening up opportunities in neighbourhoods, schools, workplaces and daily activities for people with intellectual disabilities.
- 2) Stimulating and fostering the development of community resources in support of intellectually disabled people. This refers both to accommodation and supports for people with intellectual disabilities and their carers:

'We cannot envisage a successful long-term system of accommodation, services and care for intellectually disabled people which is entirely State-provided and entirely State-run.'

Quotations from Part One of Interim Report, p.49

- 3) Providing avenues by which people with intellectual disabilities can lead lives which are as independent and self-determined as possible, i.e. a variety of means whereby people are assisted to manage their own lives.

These emphases in turn imply that the community's participation in service planning and development should be maximised. State involvement is seen as a necessary but insufficient condition for effective community based services. The report therefore suggests that the State's role should be that of stimulating, supporting and maintaining community involvement, and also to provide a safety net.

Given this general definition of the task, the following key elements are proposed:

1. Develop an effective public health and community support programme which minimises the potential incidence of intellectual disability.
2. Develop support services for families which assist them to care for their intellectually disabled children at home.
3. Further develop the education system to support intellectually disabled children.
4. Replace institutional and congregate care placement for intellectually disabled children separated from their natural families with a system of home-based care and training.
5. Develop a major programme of housing opportunities for intellectually disabled adults currently in institutions or in the community but needing accommodation.
6. Develop more flexible systems for service delivery within the community.
7. Develop a major programme of affirmative action in support of employment for intellectually disabled people.
8. Provide institutional managers and staff with the responsibility for, and resources to support, relocation of Training Centre residents to homes of their own or to other appropriate community-based accommodation.
9. Strengthen Regional Teams to support a more dispersed service system and to improve case planning and management arrangements.
10. Develop a programme of community education.
11. Expand access to generic services and provide specialist support to those in greatest need.

The above headings were each followed by a substantial discussion of the issues surrounding each proposal.

The plan also sketched the likely course of the full resettlement programme. Over a 9 year period, 100 placements would be provided for people already in the community (mostly with their families) who need alternative accommodation (900 places). 2,765 places would be provided for Training Centre residents — this was equal to the population living in Training Centres — as in NSW there seems to have been no attempt to take death rates into account. This would amount to an ambitious 360 people resettled per year (building up from a slightly lower figure in the first two years). Of the 3,665 community placements envisaged, 740 would be in 'specialist home based care and training' (if adult fostering), 1,280 would be in clients' own housing, and 1,645 would be in serviced homes.

I have outlined the interim report in detail to illustrate the present stage in thinking about service provision in Victoria. When I visited, the consultation on the interim report was in its final stages.

The account in the previous few pages described the major events in the history of change in Victorian intellectual disability provision. While nearly 3,000 people still live in traditional, hospital-type institutions, there has been an impressive growth in alternative provision, and also in the organisational commitment for further improvements, and in the ideological basis to guide them. To try to go beyond the phenomena themselves and describe the process of change is not easy, but again, as for NSW I will pick out some themes in the change history that seem to have been important:-

1) A changing understanding of people with intellectual disabilities.

In Victoria this seems to have been the result of a number of factors, at least including:

- longer range impact of social movements stemming from the 1960s (see NSW discussion);

- increasing expectations of people with intellectual disabilities following the impact of early intervention programmes, behavioural teaching, etc;

- the mounting critique of institutions in Victoria and beyond;

- the first steps of the self advocacy movement;

- knowledge of developments overseas and in other parts of Australia (Cocks' Western Australian background is probably among the influential factors here);

- normalisation-based training on a large scale;

the impact of successive documents which contained strong statements of principle (Premier's Committee 1977; Cocks Committee 1982; Rimmer Committee 1984; Roper White Paper 1984; Two Acts of Parliament 1986; Interim Report of the 10 Year Plan 1987).

2) Organisational change that altered power relations within the service system.

There has been almost constant bureaucratic reorganisation since 1980 when MRD was initiated. Even before that date there were organisational changes within the Health Ministry. There have been seven directors or acting directors of Mental Deficiency Services/MRD/OIDS in ten years. Such turbulence is generally diversionary of effort that could have been directed at making improvements in the lives of people with intellectual disabilities, and there is plenty of evidence that Victoria is no exception to this generality. However, it was a positive step to set up MRD as a division independent from mental health services; it was important that a non doctor was appointed its first director, and the move to CSV was an important signal about the rightful place and identity of people with intellectual disabilities. Undoubtedly the changes have reduced the influence of the medical profession, demedicalised thinking about people's needs, and enabled the intellectual disability nursing profession to establish an identity that has little connection with the practices of either general or psychiatric nursing, and a great deal to do with promoting human development. This is notwithstanding a period of isolation, when Regional Teams were established with little input from these staff who while trained in inappropriate places generally have a wealth of practical hands on experience with a wide variety of people with intellectual disabilities. As elsewhere in Australia it was striking that much of the leadership in the organisation comes from psychologists, although the remedial professions probably are influential at Regional level.

3) The role of strong ideological leadership.

There is a general agreement among the commentators I have talked with that Errol Cocks' role at the head of the organisation was crucial in producing a quantum leap in the system. He describes his style in those days as somewhat iconoclastic, and it is clear that his principled approach and forthright manner was decisive in taking hold of opportunities such as the possibility of replacing St. Nicholas' and thereby showing what might be possible. It was my impression that the current, more pragmatic leadership of OIDS (in the form of several key

people) is also principled with regard to consumer outcomes, if without the piercing ideological clarity of Cocks.

4) The role of outrage.

The dual scandals of the Age series in 1974, and of Anne MacDonald's struggle later in the same decade were embarrassing to government and meant something had to be seen to be done. Strong moral outrage about the situation of those who rely on shoddy services is a strong motivator for social action as well as being one component in the construction of an integrative ideology that might suggest the way to making improvements.

5) Political patronage and linkage.

As in NSW there has been a degree of political patronage from ALP politicians. There have been personal links between the progressive movement in intellectual disability circles and Ministerial circles, and the social justice emphasis of the Victorian party is ready made for connection with the rights emphasis in the normalisation ideology. These human and ideological links have helped the progressive movement to consolidate its gains, through the allocation of resources to develop the new generation of services as well as through the passing of legislation that probably represents an irreversible reform and reference point.

6) Model development.

From early 1980s onwards, money has been made available for the development of new kinds of service provision. The organisation has been able to learn from its experience, so for example, current thinking is critical of both the CRU and Regional Team models as they stand. Moreover innovative Non-Governmental projects have contributed to thinking with regard to vocational and other services.

7) Consultation and respect.

Significant developments in service provision and legislation have involved respectful consultation with a variety of interest groups. This continues with the 10 year plan report. The St. Nicholas' closure was marked by involvement of both parents and the Unions. This emphasis may not always be so strong; there was a view that the lessons from that time were not being applied with regard to parents of people residing in institutions now.

8) Thoroughness and thoughtfulness.

This is a distinctive quality in developments in Victoria. While the slowness of OIDS to begin its deinstitutionalisation programme was

frequently mentioned in NSW, it could be that time spent in the design phase will prove well spent. The attention to detail in the preparatory work for the legislative reforms was also striking. Such thoroughness is unusual in human service planning and development.

How might the combination of these factors be described? There has clearly been a hegemonic process that has established a new ideology concerning people with intellectual disabilities. That process has some of the characteristics that we noted in NSW. What is significant, however, is that in Victoria it appears to have been far more of a 'within system' (the government and its bureaucracy) process. The hegemonic group has been composed chiefly of key professional, managerial and academic figures. They have been successful in drawing in other groupings, including ALP politicians, and at times trades unionists, parents, people with intellectual disabilities, and other professionals. It seems likely that much of the involvement of these groups is conditional. There has been no great voluntary sector involvement in the alliance and parents of people not living in institutions have not grouped together in anything like the influential New South Wales Council for Intellectual Disability, although this could change in the near to medium term future.

While narrow, the hegemonic group has access to the heart of the bureaucracy. Unfortunately the relative transience of professionals may make the advances vulnerable, except insofar as they are established in law, and are becoming embedded in the wider culture of the intellectual disability service system.

Before examining the prospects for successful wide ranging change in the pattern of opportunities facing Victorians with intellectual disabilities, the next section will review the present situation in the OIDS service system.

The Present Situation

The following overview of the situation in intellectual disability services in Victoria is based on what I was able to see during my visit in late November/early December, 1987. I will not repeat information given above but will attempt to convey my own impressions of the state of development of services, ideology, and their impact on people with intellectual disabilities.

Service Provision

State Training Centres (i.e. Hospital type services)

I visited Janefield Training Centre, the third largest Training Centre

(T.C.) in Victoria, with 435 residents (including 37 under the age of 18, who are targetted for resettlement by December 1989). It is situated within the North Eastern part of the Melbourne metropolitan area in an area where there are other institutions and hospitals: Janefield was originally a T.B. sanitorium. The largest staff group was what are still termed 'mental retardation nurses' — there were 220, resulting in an effective staff: client ratio of 1:15. Of the total 30% were qualified, while others had a lower level qualification of Mental Retardation Aide (based on a 1 year course). The Chief Executive Officer was also from a nursing background, and he clearly provided purposeful and progressive leadership — Janefield was described as the 'best run' T.C. in Victoria, but also as the lowest staffed in Australia.

The 48 bedded units (wards) were striking physically: immense effort has been devoted to the decoration of the lounge areas, with a profusion of greenery and the creation of quiet sitting areas; the dormitories, however, were the most overcrowded that I have seen, with no more than 3 feet between beds in some areas. Staff were typically engaged with the residents when I visited, which cannot be taken for granted in services of this sort.

Janefield had developed its own 'deinstitutionalisation programme', with groups of residents moving into houses in the grounds or just outside, and in the community. 40 people were living in houses in the grounds or nearby, and 12 people were living in rented houses in the local area, and further groups were in the process of moving out. Groups tended to consist of 5 or 6 people. The people concerned seemed relatively able, although some had the 'severely handicapped' label. Their lifestyle was independent or semi-independent. The houses within the grounds were very basic timber dwellings, although they had previously been staff accommodation. The house on the road into the T.C. was an ordinary bungalow. Staff working in this scheme were very enthusiastic, finding the work harder than on the wards but more satisfying. While this development has done a lot to 'sell' the idea of people with intellectual disabilities living in ordinary accommodation with support, there is perhaps a danger that it is still seen as part of a comprehensive system that includes the T.C.

A no admissions policy had been in operation for two years. However, in cases of dire need, a bed can be made available. The new legislation limits all T.C. admissions to 1 year. An increase in demand is anticipated in the next few years, with the ageing of informal carers.

Across Victoria, 8 T.C.s are run by OIDS and there are 3 joint facilities

with the Office of Psychiatric Services (Department of Health) located in country areas. There are 2,800 people living in the eight OIDS T.C.s, the great majority of whom are in the age group 26-40 (a similar age pattern to that in NSW).

The Newer Services

Field Services

I visited the Southern Region which is a metropolitan area to the South East of the city centre. The Regional Team covered a resident population of 500,000 people, but this was to decrease to 372,000 with the setting up of a further CSV region. It was estimated that there may be 5,000 people with intellectual disabilities in the region, 1,092 of whom are registered with OIDS.

The Regional Co-ordinator (a Speech Therapist by background in this case) was responsible to the CSV Regional Director, and there were actually 4 teams within the Regional Team, covering Early Childhood, Child and Family Services, Residential Services, and Adult Vocational Services. [However, in the new inner urban Region, this structure would be rather different with teams covering Early Childhood (as before), Client Services 6 years+ (North), Client Services 6 years+ (South) and Program Development]. Team leaders for the teams in Southern Region included an Occupational Therapist, a Psychologist and a Nurse. The total establishment for the Regional Team, excluding administrators and clerical staff, was 25½ staff (including the Co-ordinator, a half time Medical Officer, and a Staff Development Officer). There was a high proportion of vacant posts. There was no less than 12 administrative, clerical, and finance posts, which seems high in relation to the number of casework staff, even given the responsibilities of the Team for CRUs, voluntary sector services, etc. (All numbers have been expressed as whole time equivalents). By comparison with Britain the establishment is probably fairly average, although considerably lower than the combined NHS and Local Authority complement of comparable workers that we are used to in Manchester and other comparatively well resourced districts.

I will not discuss the services to children here, but interested readers can contact me for further information.

There was a certain amount of overlap between the Adult/Vocational Team and the Residential Services Team. The responsibilities were described as follows,

Residential Services team

- Support to people living independently
- Advice on available residential options
- Consultancy services to existing residential services
- Assistance to Community Groups in planning residential services
- Project CRU Management
- Resource to voluntary sector programmes
- Finding accommodation
- Behavioural programming within houses

The voluntary sector was weak in this part of the State, so it was the Regional Team that played a big part in service development, although those services might be administered by NGOs once set up.

Adult Vocational Services Team

- Advice and referral for vocational, recreational and continuing educational programmes
- Consultancy services to existing employment and vocational programmes
- Assistance to Community Groups in developing programmes
- Maintaining voluntary sector day training services
- Encouraging appropriate work options
- Assisting adults in independence
- Citizens Advocacy (setting up programmes)
- Consumer Participation

The Regional Team works to a set of objectives which are set annually, and this process is replicated for the sub teams. Accountability of team members was to the Regional Co-ordinator via the Team Leader, and this was essentially a form of operational management. There seemed to be little in the way of professional supervision or appraisal, and despite assurances to the contrary I was left with the impression that professionals were left to their own devices with regard to the content of their work. (It should be noted that the situation is not very different in the U.K., although the model of social work supervision, which has been emulated by some community nurse managers, is, at its best, an exception). Staff mentioned the following frameworks as guides for their work:

- Normalisation: the dominant formulation is the Wolfensberger 'social role valorisation' one articulated in and disseminated in

PASSING, although there was some interest in the more accessible and (as I believe) more balanced O'Brien '5 accomplishments' framework. The Victorian Government's Social Justice Strategy was also mentioned.

- Behavioural approaches, especially task analysis, 'systematic instruction' and 'data based training'.
- Other specific frameworks, and tools such as child development assessment scales.

My impression, based on conversations with practitioners, those with whom they come into contact, management, and other observers, is that as in other field services there are some very able, skilled and committed staff working in the regional teams, as well as less imaginative, less motivated and relatively confused staff. There were high expectations of the Teams, and perhaps a lack of model building as these services developed. As a result there has been some vagueness about what they are intended to accomplish, although this may be becoming clearer as they mature. There has been an availability of training but the consultancy needed to help such learning be used (especially in the value-based domain) has been relatively lacking. Inter-professional relationships seemed good, and community nurses have been integrated into the teams successfully, if a little late in the day.

The Regional Teams are in a potentially strong position to have a profound influence on service development in Victoria, but this will not happen without some detailed attention to the model of service underpinning the work, and the development of professional practice in relation to that model, utilising approaches such as supportive supervision, appraisal and collective review.

Residential Services

I also visited one of the OIDS St. Nicholas' CRUs in the Southern region. Four women were living in this staffed house, but there was to be a fifth person, a man. The women share 2 double bedrooms. A sleep-in staff room doubles as an office, and there is a separate staff shower and toilet. The house was an ordinary but well maintained suburban bungalow. It looked indistinguishable from other houses in the street, except for a very large minibus with Government number plates in the drive. This takes 5 wheelchairs.

Staffing was 7 whole time equivalent, one of whom was the house leader. She had been a domestic at St. Nicholas'. Staffing allows 2 staff on duty at a time, and they work 12 hour shifts in accordance with an agreement with the Union: this is wasteful of resources at times since they can be alone with no residents present. Since staff are rostered to the house, rather than to specific residents the staff are not used flexibly at these times. Community nurses from the Regional Teams manage the staff in the houses, having 3 houses each.

The women in this house were very physically disabled, but intellectually able, all of them having been taught to read. They are given, and make choices about many aspects of their daily activity, and also attend a day centre.

The commitment of the staff, especially the house leader, was striking. Her understanding of normalisation was good, yet as elsewhere in Australia I was disconcerted by being shown people's bedrooms in their absence, and I was able to find little evidence of real personal social integration beyond the use of some ordinary community facilities.

The quality of life of these women seemed good in comparative terms: there was purposeful activity and considerable use of available technology to enable them to exert control over aspects of their environment. It was obvious that this was a close group of friends and that there were good relationships with the staff. All of this was far in advance of anything possible in an institutional setting. However, the CRU model is hardly the last word in service provision, and issues of social integration, respect for the householder, as well as the effective use of staff resources need careful examination.

Indeed OIDS headquarters management does not see the CRU as any kind of normalisation nirvana, and there was considerable energy being devoted to alternative models. OIDS includes a section of 'consultants' in particular areas of service provision, one of whom focusses on residential services. A variety of innovative schemes are being piloted, chiefly targetted at relatively able clients. They include a home board scheme (boarding in ordinary households); cluster apartments (for people living independently who may require help at any time); support and counselling, to mildly handicapped adults renting private accommodation, and a fostering scheme for children with intellectual disabilities. There was also work being done on enabling people with intellectual disabilities to stay in their family homes after their parents die. These programmes are all inspired by

the need to contain costs, and to provide less costly alternatives to CRUs. However, for people with severe disabilities, there was a view that the CRU was the only viable model.

The view as expressed in the 10 year plan report (and by those involved in its production) was rather different. Here there was emphasis on devising mechanisms for people with intellectual disabilities to purchase their own accommodation, and for staffing support to be made available there, generally from NGOs, although OIDS would provide CRU — type accommodation for respite care. There was unease (which I share) about the strange verbal trick of referring to ordinary houses in ordinary streets as 'Community Residential Units' or 'CRUs', but also a feeling that the model might be seen as reasonably normative for young adults prior to their making choices about their preferred living arrangements. The 10 year plan section was also doing some interesting work on person-orientated staffing models to overcome the rigidity of the rostering-to-house approach.

Day Services

I did not visit any of the Day Training Centres, although I did visit a vocational service (S.E.R.C.H.) which trained people with intellectual disabilities to mow lawns, and arranged and supported this work for elderly people in the local community. The project had been successful in arranging for real jobs for a number of people from the scheme. The project was a good example of finding a niche in the market for a service that people with intellectual disabilities could provide, arranging the training, logistic, and practical support required, and delivering a useful service as a result. The programme had also been thoroughly evaluated. It had been set up by a parent of a person with an intellectual disability.

Agency set up

The organisational arrangements are more straightforward in Victoria than in NSW or Britain. Furthermore, the responsible agency is the appropriate one (i.e. the social and community welfare agency rather than the Health Department). The existence of a dominant agency seems to have also led to some sensitivity about the undesirability of one agency having total responsibility for all services used by a person: how that issue is to be resolved is not yet clear, although it seems that a variant of welfare pluralism will be tried, albeit one with high levels of State Government funding.

The move from the Health Department has been accomplished

reasonably easily, and perhaps the isolation and organisational integrity of MRD/OIDS has helped. Integration into CSV is more difficult, and the latest wave of re-organisation is designed to facilitate this. There will be significant advantages from greater integration (especially as CSV provides a wider range of services than a British SSD does, including some community health services and nursery education), but there are realistic fears from those in intellectual disability services that it will become easier to 'raid' the intellectual disability budget, particularly if other priorities become 'this month's flavour', and given the declining prospects for State expenditure. (Of course this could happen within the Health Department too).

There appear to be some residual difficulties in accessing some specialist health services, particularly psychiatric services. This may reflect the nature of those services rather than the organisational arrangements that have been adopted.

For historical reasons the Commonwealth Government has not funded services in Victoria to the same extent as elsewhere, and this might mean that OIDS has a higher funding profile in the NGO sector than would be the case in other States.

The general organisational set up should aid effective service co-ordination, but it is probably too early to say whether this is actually the case. For the present there is poor integration of the Regional Teams with the institutional sector, and improvement will be required once resettlement begins in earnest.

Financial management is generally weak. Programme managers only appear to manage some parts of the budget as such. They experience the system as unnecessarily bureaucratic and inflexible, with, for example, little scope for budgetary virement. Financial information is insensitive in both accuracy and in timing.

Legislation

Two Victorian Acts of Parliament were passed in 1986 and proclaimed (implemented) in 1987: The ***Intellectually Disabled Persons' Services Act 1986***, and The ***Guardianship and Administration Board Act 1986***. They stem from the Rimmer and Cocks reports respectively.

The Intellectually Disabled Persons Services Act replaces provisions in the 1959 Mental Health Act, and is thought to be the only piece of legislation anywhere that relates solely to the provision of services to people with intellectual disabilities. Some of its key features are

- A statement of principles. These 14 principles, which are essentially a statement of the principle of normalisation are consistent with the Social Justice Policy, and emphasis equity, access, participation, integration, civil rights and quality of service. They are reproduced as Appendix 8.
- A definition of eligibility for service. This is stated in broad terms, and differs for children of 5 or under who are described in terms of 'development delay', and those over 5. There is some suggestion that the interpretation of this part of the act may increase the amount of psychometric assessment being carried out by psychologists, which would entail a resource cost, particularly since the Victorian definition is very inclusive (essentially, it could include any adult with an IQ below 70).
- Individual Planning is prescribed by the Act and will apply to all people who are OIDS clients. It takes two forms, General Service Planning — 'a comprehensive plan prepared for an eligible person which specifies the areas of major life activity in which support is required and the strategies to be implemented to provide this support'; and Individual Programme Planning which 'specifies activities and methods to achieve goals in areas identified in the general service plan.
- Mechanisms for 3-yearly service planning at a Regional level.
- Limitation of new admissions to residential institutions to a period of 12 months, and definition of criteria for admission.
- Provisions for the funding of NGO services, and for their registration.
- Definition of 'security residents' and of the procedures and safeguards for their admission to institutions.
- Mechanisms for the control, approval, and review of restraint, seclusion and aversive treatments.
- Provisions for the management of residents' monies in institutional services.
- The appointment of Community Visitors for each Region.

There are some potential benefits of the Act. Firstly it establishes the set of principles that govern provision for people with intellectual disabilities, and it also sanctions a normalisation-based attitude to them and the opportunities that should be available to them. Secondly, it provides some important safeguards, for example 'restraint' includes chemical restraint so doctors must be clear about their reasons for

prescribing and drugs must be carefully reviewed. The use of chemical restraint is not ruled out but its use is controlled and open to a wider scrutiny. Thirdly, writing mechanisms for Individual Planning into legislation has some appeal, but it remains to be seen whether the service system really has the capacity to deliver good quality planning for the large number of people concerned. The debasement of Individual Planning can be readily seen in some British service settings, where it sometimes becomes little more than a bureaucratic exercise. However, there may be significant spin offs for at least some clients, and for the service system more generally.

The Guardianship and Administration Board Act covers people with a variety of disabling conditions which make them vulnerable to ill treatment, neglect, or poor service provision. The Act provides for a variety of protective measures, but requires that the least restrictive effective method be chosen. Two entities are created, the Guardianship and Administration Board, and the Public Advocate. The Board was established to hear applications and make determinations in three areas:

1. Guardianship — to take care of a person's personal wellbeing.
2. Administration — to attend to the person's legal and financial affairs.
3. Medical Procedures — with regard to the need for and consent to major medical procedures.

The least restrictive means can, for example, mean taking control of a proportion of a person's financial resources to ensure that rent or heating bills are paid, but leaving the rest of the person's money under their control. This selectivity would seem to provide a way of undercutting the false dilemma between intervention and self determination that is often raised in similar circumstances.

The Public Advocate was established to:-

1. Ensure that complaints made by people with intellectual disabilities are properly investigated and acted upon.
2. Investigate complaints that a person with an intellectual disability is being abused or exploited.
3. To provide emergency or temporary guardians and also a guardianship service of last resort (when no other person is available) as determined by the Board.

4. Develop and administer the Community Visitors Scheme as laid down in the IDPS Act.
5. Provide Community Education and Advice.

I found this legislation most impressive. It appears to offer a person-sensitive means for protecting and prioritising the rights of vulnerable people. I observed a hearing of the Board (they are public hearings but with the option of excluding visitors), and was impressed by the sensitive nature of the hearing, although there might have been rather more exploration of the possible options for solving the problem presented. A mother of an intellectually disabled young woman was applying for Guardianship so that depo-provera could be prescribed to control her menstruation, while the CRU staff did not see the need for this and were concerned about the health risks. The application was turned down. The hearing was conducted by a tribunal with a lawyer in the chair, and it followed an investigative rather than adversary model.

With regard to the Office of the Public Advocate, it is interesting to note that the likely demand was underestimated, so the 4 guardians on his staff are becoming increasingly stretched, having to cover the background investigations for the Board in addition to their other duties. Again it is too early to judge the likely long range effects, and it should be noted that there is some scope for conflicts of interest since this office is also part of the State Government public service. It would be worth our while in Britain watching this development very closely for possible application to the context here — the legislation here is quite inadequate in comparison.

Ideology

I argued above that change in Victoria has been brought about largely through the efforts of an alliance, centred on the bureaucracy and government, that has been united around a shared ideology. In exploring the nature of that ideology it is important to distinguish between a) its statement in the legislation (through the 14 principles of the IDPS Act 1986 — see Appendix 8) and other key documents, and b) its articulation in the practices of OIDS and its staff.

Again using O'Brien's 5 Accomplishments framework as a comprehensive statement of what is implied by the principle of normalisation, we can characterise the ideologies in operation in Victorian intellectual disability services.

The official statements and the legislation emphasise the

accomplishments of presence in the community, autonomy (chiefly in the form of protection of basic rights, and capability chiefly in terms of an emphasis on development and growth). There are also statements that may be interpreted as showing some concern for the areas of relationships and respect, but these are hardly addressed directly. In both the legislation and the interim report on the 10 year plan there is emphasis on participation in the ordinary life of the community (see the quotation from that report in the section on the history of change) that goes well beyond an emphasis on ordinary buildings in ordinary streets.

As so often, practice falls somewhat short of policy, and while there has been dissemination of the 14 principles in the Act as well as a substantial amount of normalisation — based training, it is probably fair to say that for most staff ideology remains rather incoherent and less than comprehensive. The emphasis is probably on capability (mainly in the form of an emphasis on training programmes for people with intellectual disabilities), and I detected rhetoric about rights (autonomy), which seemed to reflect a genuine concern, yet stood strangely with the invasion of privacy noted above. Integration (presence and relationships) did not emerge as a strong theme, despite the emphasis in official pronouncements.

The lack of emphasis on integration surprised me, as it had in NSW. It can perhaps be attributed to two factors:-

a) The Influence of PASSING as definitive of normalisation. PASSING is based on Wolfensberger's most recent formulation of normalisation which stresses two factors in contributing to positive social roles for socially devalued persons (his superordinate goal), i.e. the enhancement of competence and the enhancement of social image. (In my view) it takes a deep reading of PASSING, based on a good understanding of normalisation, to draw out the central importance of social integration.

b) The centralisation of the service, both at headquarters, and also in the Regional Teams which cover a large area and large population. It is difficult to explore and develop integrative opportunities, and support people in them, when the connection of the service to localities is so distant.

I also detected the same emphasis on 'generic services' as in NSW, and the same vagueness about what this really meant in terms of

lifestyles for people with intellectual disabilities. Again it seemed that the imperative of integration was being refracted through a service orientated view of the world. Where people were thinking about more 'ordinary life' models, the thinking had often been led by financial imperatives, e.g. house purchase by clients as a source of alternative funding, or service provision by more than one agency to get around the restrictive practices imposed by the Trade Union in the government service.

Political context

During my visit to Victoria there were media stories about mental health services. These were mostly found in *The Australian*, (Murdoch's attempt at a quality paper, distributed widely throughout Australia). There was some coverage in Victorian papers, and some correspondence concerning the proposed closure of the institutions. Despite the media activity, it did not appear that services for people with intellectual disabilities were particularly identified, or confused with mental health services, and this might reflect the separation between the services that has been achieved. The ALP administration seemed to be in less trouble in Victoria than was that in NSW; at least the Liberals seemed in disarray, and since the reform movement is closely linked to the ALP this is encouraging, at least for the time being.

I visited the office of the Hospital Employees Federation (HEF) which organises 95% of the OIDS workforce. I was impressed by the understanding of the issues expressed by the officials I met. HEF has prepared a substantial and well researched 36 page response to the interim report on the 10 year plan. This response criticises the interim report for making recommendations on the basis of limited information and research, particularly on the characteristics and needs of Training Centre residents. It also reviews the evidence for the existence of such ambitious total deinstitutionalisation programmes elsewhere in the world, and points out that it remains an open question whether such a radical change is workable.

In some of its response, HEF seems to be setting up a rather false dichotomy between community placement (or 'normalisation') and practical help and habilitative care — the dichotomy is assumed but there is no argument that such support cannot be provided in ordinary places. Part of the source for this confusion may be found in the fiscal imperative driving some of the emphases in the 10 year plan report; to reduce costs, less government centred options are suggested. HEF recognises the nature of the crisis in welfare expenditure common to

many Western economies, and is rightly suspicious that normalisation will be used as a cover for reductions in expenditure.

HEF was insistent that it subscribed to the principles in the IDPS Act, and that its concern was to ensure that they could be realised through adequate resourcing and the use of a 'scientific' approach to needs assessment and the development of a variety of service models. The CRU model came under attack, with the assertion that it was not appropriate for people with major physical disabilities or behavioural disturbance. There was also a suggestion that people living in St. Nicholas' CRUs received insufficient inputs such as physiotherapy, and that day and recreational opportunities were limited. This may be true to some degree, but there is considerable evidence that these supports are considerably greater than before the move from St. Nicholas'. There is certainly not an unequivocal agreement by HEF that institutions are inappropriate for all people with intellectual disabilities, a fudging of the issue that is disappointing given their endorsement of the principles in the Act.

However HEF officials suggested that they would be prepared to co-operate with the redevelopment of services if there could be:-

1. A range of services available — especially for those who would need more support than a CRU could give.
2. An agreement on pay awards and conditions.
3. The answering of HEF's concerns about integrated employment and education.
4. No decrease in expenditure.

Overall HEF struck me as refreshingly responsible and comparatively open minded. While I did not agree with everything that was said, their concern about the level of expenditure could act as an important safeguard for quality, and their emphasis on a thorough and reflective process of service development is consistent with the best aspects of the MRD/OIDS history. Obviously a concern for jobs is at the bottom of HEF's response, but to dismiss it in those terms would be to reject a potential source of important if critical support for reform.

A further source of opposition comes from the parents of people living in institutions, particularly the largest, Kew Cottages, which is located in a Melbourne suburb. I did not gather very much material on this interest group. However, it seems that it could be a potent source of opposition, not balanced by a strong movement of reform-minded

parents as in NSW. It was not clear how well OIDS was handling this group, and the point was made several times that the lessons from working with parents during the St. Nicholas' closure were not being applied.

Maintaining hegemony

It is too early to say whether the alliance for change will be able to maintain itself and its influence on thinking and provision for people with intellectual disabilities as the pace of change increases. Given that the rate of change is likely to be reasonable, it should be possible for the momentum of reform to be sustained. However, it will be necessary to draw other interest groups into the progressive social bloc. The prospects may depend on the level of new money that the State Government is able to allocate to the resettlement programme. Finally, it will be important that the productive links with the ALP do not mean that the reform programme will be vulnerable if a Liberal administration came to power; this could be the time to start developing a dialogue with key Liberal politicians.

I was impressed by the sophistication of key figures in OIDS with regard to building and sustaining support. The involvement of institutional staff in some of the planning and service development is a case in point, but this process needs building on so that OIDS headquarters is but one locus of leadership in a broad movement for real change in opportunities for people with intellectual disabilities.

Conclusions

Since 1980 there has been real progress in Victoria in changing the service system so it more appropriately responds to the interests of people with intellectual disabilities. The advances have been particularly strong in the areas of developing community based residential services, in closing an institution that catered for some very disabled people, in developing a common understanding of the interests of people with intellectual disabilities, and in enabling the passage of legislation that enshrines some fundamental principles in law and provides for some sophisticated means for the protection of people's rights. It seems likely that the reform programme will continue, although it remains to be seen how thoroughgoing this will be in respect of replacing the institutions.

Despite this progress there are some weaknesses that, if not addressed are likely to prejudice the success of the move towards community-based services and opportunities. The most significant of these are:

1. Excessive narrowness of the 'movement for change'. There are

few active supports for this outside the State Government and its bureaucracy.

2. An over centralised bureaucracy that leads to services being provided with little sensitivity to and knowledge of the localities where their users will live and spend time. This militates against an emphasis on social integration, which is, after all, a connerstone of the 1986 IDPS Act. Furthermore, the 'ideology-in-practice' of the service system does not emphasise personal social integration as a fundamental requirement if people are to have a good quality of life.
3. Ideology that is present in official documents and in the legislation is not disseminated sufficiently widely, or in sufficient depth to those who have a major influence on the lives of people with intellectual disabilities. It may be that the very enshrining of the philosophy in legislation may paradoxically reduce the impetus for practitioners to constantly struggle with and rediscover these basic principles, in so doing internalising them as a basis for all their practice.
4. A domination of the CRU model, despite a healthy development of alternative models that are being piloted or planned. The 3 or 4 bedroom shared house for 5 people represents a major restriction of individual rights if, other than as a result of their own choice, people have to share bedrooms (as members of REINFORCE were keen to note when we met!).
5. The lack of a clear financial strategy for moving resources out of institutions, as yet.
6. A risk of overemphasising the benefits from a mixed economy of service provision, which could mask real reductions in funding.
7. An overemphasis on the potential contribution of generic services. This seemed to reflect both a preoccupation with costs and a poorly articulated grasping for the importance of integration, while failing to note that integration concerns people's everyday experience rather than the source of the service that supports them in those experiences.
8. These emphases on welfare pluralism (6 above) and service genericism (7 above) seemed to be based on uncharacteristically sketchy research and analysis of the resources and issues involved.

NEW SOUTH WALES and VICTORIA COMPARED

In many ways, NSW and Victoria share similarities in their intellectual disability services. They both suffered years of neglect until the early 1980s. They both have a number of large institutions that are not fit places for people to live in. Both have seen a fairly fast development of more locally based services, and both are embarking on ambitious programmes of reform, with an emphasis on at least some version of the normalisation principle. In both states it has been an ALP administration that has given reform the necessary political patronage, while the success of the reform movement may be attributed to the action of a 'hegemonic alliance'.

Some differences were noted in the Chapter entitled 'The Eastern States', and others have been noted during the lengthy discussion of each state. To summarise the key differences from the perspective of making major changes in the lives of people with intellectual disabilities and in the services that support them, we can point to the following key contrasts between NSW and Victoria.

NEW SOUTH WALES

VICTORIA

1. *The nature of the alliance for change.*

Quite broad, including parent-based organisations as well as professionals and other interest groups. Possibly too narrow now pace of change has quickened.

Relatively narrow and tied closely to the bureaucracy.

2. *Time scale and balance between design and action.*

Very ambitious timescale for closure and replacement of institutions. Emphasis on action: little model development. High risk strategy.

Still consulting, and timescale will be generous. Much emphasis on program design. Moderate risk strategy

3. *Legislation.*

No specific legislation. New Guardianship Act, comparable with Victoria.

Specific legislation for this client group, plus ideologically consistent protective legislation.

4. *Agency set up.*

Dept. of Health is responsible agency, but significant services provided by Community Services. Division is on basis of level of disability.

Dept. of Community Services is responsible agency, with specialist division which is in process of integration within Dept.

5. *Pluralism of model.*

Dominance of CRU model and little evidence of development of alternative service delivery models.

Dominance of CRU model but evidence of effort to develop and test alternative models for supporting people in ordinary housing.

It will be interesting to watch the unfolding of events in these two states, but to draw out lessons for other countries, it will be necessary to carry out a thorough analysis of the interlocking and changing roles of ideology, interest groups, organisational form, and the political, industrial and cultural context, both in Australia and in the country in which the lessons might be applied. There can be no question of simply 'reading off' the surface manifestations of these factors for comparisons made in this way will be truly superficial.

WESTERN AUSTRALIA - A SKETCH

I was able to spend three working days in Western Australia, and this provided a contrast with the Eastern States, that might give an added perspective on how Australian welfare systems respond to the interests of people with intellectual disabilities.

Background

Western Australia (WA) is the largest Australian state in terms of area, occupying nearly half of the mainland, and extending from the tropical north (The Kimberley) to the temperate south (Bunbury/Albany). The State population is 1.4 million, but 97% live in the metropolitan area around Perth and Fremantle. The rest of the territory is extremely sparsely populated; the next largest centre, Bunbury has a population of only 25,000. Perth is 2,718 kilometres from the nearest Australian state capital, Adelaide, a degree of isolation that has some significance for the nature of the West Australian culture as well as the development of services for people with intellectual disabilities.

The State Government is again an Australian Labor Party administration, as it has been since the early 1980s.

Services to people with intellectual disabilities differ from those in the Eastern States. I had heard that there were no institutions in WA. Unfortunately this is not so, but there are now no very large institutions. The largest is Pyrtton, which houses 150 people in three hostels. Otherwise residential provision is mostly in hostel-type accommodation. This is in contrast to the rest of Australia where, perhaps as a result of the late start on community based services, the hostel type mini institution is a step that has been missed.

There was a great deal of development in the 1960s and 1970s, much of it based on the early phase in the development of normalisation theory that stopped short of real integration, the use of ordinary housing, etc., but emphasised the simulation of 'normal environments'. Historically, a large psychiatric hospital, Claremont, provided accommodation for people with intellectual disabilities, and since there had been no development of specialist intellectual disability nursing, the direct care staff in the newer services were established as 'Social Trainers'. Since then that occupational group has itself become professionalised and unionised. Their training consists of one year's work experience with 1 day release per week; Senior Social Trainers have a further year of training.

The last 100 people with intellectual disabilities moved out of Claremont in 1982-84. 77 of them to Pryton, places becoming available there through more able people moving to hostels, or to independent or supported community living. It is therefore true to say that WA now has no hospital type institutions for people with intellectual disabilities.

There is also the familiar Australian pattern of sheltered workshops and day training centres.

Service provision is dominated by two large organisations:-

- The Authority for Intellectually Handicapped Persons. This has its roots in the Irabeena clinic, a community based clinic, originally somewhat akin to a child development centre, but set up by parents. This organisation grew and eventually came under State control. And an Act of Parliament set up the Authority in 1985, as a 'statutory authority' with a board appointed by the Minister of Health and Lands, but otherwise not part of the Health Department: it works across the relevant government departments. (This statutory authority model is a favoured option by many in Australia, including the NSW Council for Intellectual Disability). The Authority (AIH), then is the responsible agency within the State Government, and in addition to running direct services it funds and regulates NGOs, often in collaboration with the Commonwealth Government. Expenditure in 1985/6 was nearly A\$40M.
- SLCG (Inc). An Association for Developmental Disability (WA). The initials originally stood for the Slow Learning Childrens Group, and this explains its origins. SLCG runs residential services, day and vocational services, as well as a family support centre, sitter service, and in-home respite care service. The annual budget is around A\$20M, more than 20% of which comes from AIH.

There are a number of smaller agencies, one of which, Nulsen Haven, specialises in residential provision for people with profound intellectual disabilities and multiple handicaps. This parent based organisation originated as a result of exclusion of these people from other services. It runs a small institution but has recently moved some of its residents into an ordinary house, and encouraged by the obvious benefits of the move is carefully planning further developments.

SLCG has some interesting service developments, including the 'home

care programme', a pilot project that gives practical support to people with intellectual disabilities in their family home; some ordinary housing-based schemes (focussing on moderately disabled people?) organised on a core and cluster basis where the core is an existing hostel; a vocational programme for people with major disabilities; and various forms of family support projects, centred on a drop-in centre, including 'family camps' and a 'father's camp'. Despite this development, SLCG does not appear to have a coherent plan at present. The services that I visited, although traditional (a hostel and a work orientated day centre) would compare very favourably with typical British local authority analogues; they seemed well run, clients were purposefully engaged and the settings were physically of a high standard.

AIH has a very 'bricks and mortar' oriented set of services. In many ways it is a victim of the early start made in Western Australia towards less institutional service models. Nevertheless I detected a great deal of interest and activity directed at redeveloping its services. There are some constraints, including Union agreements (for example unqualified staff cannot be left in charge — major problems for group homes), and financial inflexibility (line budgeting is a strong tradition). AIH has decentralised its services, establishing 5 Regions (4 metropolitan and one country division covering the rest of the state). Despite this, it seems to be a very highly centralised system, and this centralisation affects other agencies too: AIH manages all client placements from headquarters!

I detected some interesting thinking on developing less costly and more individually responsive provision. However, this thinking again seems centralised at AIH head office. Assumptions about resources that could be tapped in the community do not seem to have been tested, and as elsewhere in Australia the lack of sensitivity of the service system to localities was very striking. There was talk of AIH diversing itself of direct service provision, retaining funding, case management, evaluation and training, but those who mentioned this idea could not really see it being feasible.

In terms of ideology, in WA there was a strong emphasis on increasing the competence of people with intellectual disabilities through skills training (not surprising given that direct care staff are 'social trainers'). The emphasis on 'generic services' was again present, but the 'ordinary life model' was poorly developed, a similar contradiction to that noted in the discussions about NSW and Victoria. I did not have the opportunity to explore the sources of that ideology, or the nature

of the alliances that made change and maintenance of ideology possible.

A further notable characteristic of the service system in WA was a commitment to evaluation and quality assurance. A joint approach had been developed by AIH, SLCG and the Commonwealth Government, resulting in a common approach based on a set of standards, and although it seems that these will be superceded by an approach less tied to particular service models, they have been used in other States. AIH and SLCG both have personnel with an evaluation/standards brief.

Conclusion

Western Australia presents a contrast with both NSW and Victoria. An early start on the development of non hospital type services has led to a heavy reliance on buildings, and this may serve as a warning to service planners to avoid constructing services that cannot be easily replaced if they prove less than ideal. Despite the absence of hospital type services, the service system remains very highly centralised, and this together with some weakness in ideology may mean that services remain disjointed from the communities that people with intellectual disabilities could become more authentically a part of.

Nonetheless, there is considerable interest in developing more responsive service models, although the motivation may be as much financial as client orientated.

The establishment of a separate statutory authority may have significant benefits, for example in giving some protection of budgets, and in enabling co-ordination across a variety of governmental and non-governmental agencies. It remains to be seen whether these possible advantages are realised, and whether the authority will be more sensitive to consumer interests than other large welfare bureaucracies.

CONCLUSIONS

My central reason for visiting Australia was to learn from the experience of resettlement programmes there in order to make comparisons with the U.K., and particularly the North West. To do that I hoped to build a means of understanding of how the social change that is resettlement had come about, how it was sustained, and how the organisations charged with the task of managing the change were responding to the challenge. In doing that I hoped to be able to reflect back on the situation in Britain, thereby increasing our understanding of parallel changes here. I also hoped to be able to glean ideas that could be more directly applied here, and the above account has included some of them.

In this concluding section I want to return to a consideration of the four related spheres of activity that I suggested (on page 5) a successful resettlement programme, understood broadly, would rest on, and use those four headings to summarise the situation as I saw it in Australia (that is in the three States I visited). Following that I will draw out a number of lessons and issues that we in Britain might be wise to address.

1. Establishing a vision of what ought to be

Without this step, nothing is likely to change.

In both New South Wales and Victoria, there were active groups and individuals who promoted a vision of what things could be like for people with intellectual disabilities. In both cases this vision drew upon a sense of outrage at the situation these people typically found themselves in. It was also linked with other developments such as educational technology and rising expectations of people with intellectual disabilities, a growing interest in radical and liberal circles in the rights of oppressed groups, and formal normalisation theory imported from abroad. In Western Australia the vision seems to have again been linked to the education technology/expectations theme, as well as to dissatisfaction with the hospital model and to an earlier incarnation of normalisation theory (there seems to be a significant influence of the Scandinavian theorists there).

Key individuals (e.g. David Richmond, Errol Cocks, John Rimmer) have had a role in promoting the new ideology, and less public figures have played, and continue to play, a complementary role, often within local service programmes and non governmental organisations.

At Commonwealth level the New Directions report had a

complementary role in promoting a progressive vision of the proper place and rights of people with intellectual disabilities.

2. Deepening the vision and gaining popular support for it, often through 'prefigurative' experimentation.

Without this step, the vision remains vague and rather incredible. This could be seen clearly in the two Eastern States where what might be termed pilot programmes were established to 'try out' the new ideology in practice (the Richmond CRU Programme and the St. Nicholas closure). This had the effect of giving people in the service system some experience in setting up and running new types of service. It also built support from some sections of parents. The emphasis on consultation in both States seems to have both deepened the vision of what might be possible, as well as building a bloc of support based upon that vision. Despite this, the vision still remains relatively shallow, emphasising service provision in ordinary places rather than the ordinary lives of people with intellectual disabilities supported by services. (Again a similar process may have happened in WA but my information is more limited).

When the momentum of change increases, as the mode of development changes from that of model development to that of system change, both the fragility of the vision, and the limitation of its scope and popular support becomes more apparent. As I suggested in the chapter on NSW, there is 'hegemonic strain' as the level of 'necessary hegemony' increases. This phenomenon is likely to be exacerbated by a too ambitious rate of change, although what constitutes 'too ambitious' will depend on the particular balance of social forces impinging on the particular service system. (In the long run, change might prove more difficult in Australia than in Britain).

3. Developing the capacity of the organisation(s) that will have to deliver the goods.

Without this step the vision remains only partially implemented, or becomes distorted and compromised by the big welfare bureaucracies.

The picture varied here, with NSW failing by and large to tackle this issue, and both Victoria and WA taking some steps to reorganise the structure of the responsible agency in rather different ways. However, these major organisational upheavels do not seem to have addressed the central problems of the unresponsiveness of the service system to the requirements of real people who have real intellectual disabilities and other major barriers to authentic inclusion in the community. Services remain inept at deploying resources where they are needed;

they remain centralised and insensitive to the localities, networks, and social systems that characterise everyday life for ordinary Australians both with and without intellectual disabilities; they retain a lack of clarity — which may be found at all levels — about what they are there to do and how best they might do it; and they remain wasteful, not so much of public money, as of the time and energy of those people, both staff and users, who look to the organisation for guidance and support. Finally they remain intrinsically inadequate to the task of managing the context in which they have to deliver change, yet experiencing buffetting by the waves produced through their own activity. [This is not a diatribe against Australian welfare bureaucracies, the same could be said about those heré, including that in which I work. It is also not meant to be critical of all the people who are struggling with just these kinds of issues].

4. Learning about both means and ends as the system moves towards the vision.

Without this step, the vision remains theoretical, not grounded in the experience of people with intellectual disabilities, nor attuned to the barriers and opportunities that surround its realisation.

The organisations I explored had already gathered considerable experience of managing change, providing services, developing models, training staff, etc., etc. Organisations tend to be hierarchical, with poor flow of information between or across levels. If the development of a better world for people with intellectual disabilities requires complex and linked changes, and if the precise strategies that will help have yet to be identified, then it is imperative that the organisation has an ability to learn from its own practice, particularly its direct practice with its users. Organisations tend to lack the capacity for such transactions, often reifying such functions as cumbersome management information systems rather than developing self reflective practices. The organisations I visited were typical, but did include reflective people, and in some cases (particularly in WA) there seemed to be an interest, initially rooted in evaluation research, in just such processes.

Politics and economics

It is worth noting the wider context in which resettlement programmes are taking place. Australia is in an economic crisis. The high standard of living is now generally considered to be beyond the means of the economy. Public expenditure is an obvious victim, despite ALP governments in Canberra as well as in most of the States. There were debates familiar to a British visitor, on privatisation and deregulation.

The Victorian union, HEF rightly pointed out this context, which means a likelihood of reduced welfare expenditure, and an increased interest in 'welfare pluralism', or a mixed economy of welfare provision, particularly via the use of local government and NGOs to provide more services more cheaply. The pervasive notion of 'generic services' out there ready to be used by people with intellectual disabilities is partly legitimate (access to the resources and services used by the rest of the population has been limited, while it may be possible to gain some resources from different and unlabelled funding sources). But the emphasis is also based on an unresearched optimism about what resources are going to be available, so there develops an uneasy correspondence between normalisation-orientated ideology and an ideology that in Britain would be associated with the New Right. A limit to state expenditure may aid the development of truly integrative options, but only if there is thorough research and development geared towards the use of public sector resources to reap benefits from the informal, private, and non-government sectors, without exploiting other groups such as women and low paid workers.

Unfortunately, the climate is not conducive to the unions taking a less defensive stance, so positive developments tend to be blocked. The reliance of the reform programme on ALP administrations, themselves reliant on union support, is a weakness of the reform programmes, and perhaps a more positive response to the legitimate interest of service workers would help — not likely if cost cutting is a major preoccupation.

Having emphasised financial stringency, it is true that new money is still being found for intellectual disability services, but less clear how long this will last for. Already there have been substantial cuts in the Commonwealth Programme of support for NGOs, putting some leading edge projects at risk.

Australian culture and social integration

In making judgements about the lack of emphasis on integration in Australian intellectual disability services, we should pay some attention to the scope of Australian culture for integrative opportunities.

Perhaps the most striking aspect of the geography of Australian cities is the extensive suburbia. In many of these areas there is a high level of car ownership, as well as a good public transport system, and it would seem that for many people their communities are quite dispersed. The locality is likely to be important for some purposes, but

it may be even less important as a dimension of community than it is now in many parts of Britain.

My impression is that urban Australia has great integrative potential (I am not sufficiently familiar with the country areas to comment). Compared to Britain, Australia culture is characterised by a high degree of openness, directness, and honesty in social interactions. People seem more accessible there, and I notice my own behaviour adjusting into this mode when I am there. This accessibility is likely to increase the possibility of people with intellectual disabilities making contact with ordinary people. The climate is conducive to activity in the open air, and therefore casual contacts with neighbours, or with people engaged in similar activities could be easier than in Britain. There seems to be a high rate of membership of organisations; in NSW, for example, people will often belong to a large multi-purpose social club.

How does Australian culture treat minority groups? The White Australian policy that lasted until the Whitlam years, is of course notorious, and the treatment of aboriginal Australians merits comparison with that of blacks in South Africa. Against this, Australia has been highly successful in welcoming people from Southern Europe, the Middle East, and more recently South East Asia. In the case of the Greeks and Italians, there has been considerable integration, although this has largely been based upon upward mobility and integration into the workforce.

Perhaps because of its convict origins, and the legacy of the colonisation of the bush, there is both a tolerance of difference, and emphasis on fairness and solidarity in Australian culture (so long as you're not an aborigine).

I do not want to overstate the case for integration being easy in the Australian context, but I think it is fairly clear that to work on genuine personal social integration with people who are intellectually disabled will be no more difficult than it is here, and could, in some important respects, be easier.

Lessons and issues of relevance to the British context.

Some of the above issues will be familiar enough to the British reader. What conclusions can we draw from the recent development and current state of intellectual disability services in Australia?

1. *The role of legislation.* Legislation in Britain remains primitive

compared with the best of the Australian legislation. While I am undecided about the usefulness of writing mechanisms such as individual programme planning into legislation, there may well be some usefulness in having legislation specific to this client group. The Commonwealth legislation is impressive in its emphasis on the outcomes that disabled people should experience as a result of service provision, and could form a model for funding agreements with both local authorities and voluntary organisations here. Finally, it would be extremely useful to study the effect of the Victorian protective legislation, of which, since my return, I am repeatedly envious, as a result of my own experience of working in services for people with intellectual disabilities.

2. *Using other resources.* There may be no alternative to making more use of non-governmental services and resources. If this is to be the case, it is imperative that we decide clearly what we can expect of them and what we will try to get for people with intellectual disabilities from these sources. There can be no excuse for woolly thinking on this issue.
3. *The centrality of integration.* The whole process of change, as I have defined it in the introductory section, has to be seen first and foremost as **including** people who have experienced, or risk exclusion, from the ordinary life of the community. Without placing this issue at the top of our agendas it is unlikely that our services will be more than mediocre, since it is difficult to see how people can truly become capable, respected, or have control over their lives when they are, however subtly, shut away from the rest of us.
4. *Broad alliance built around a shared vision.* This has been a major theme of this report. Change comes from the co-ordination of ideology, alliances of interest groups, and joint action. Our welfare organisations and their rational planning mechanisms cannot be trusted to either invent or deliver better futures for vulnerable people. It takes a social movement to energise them and then to watch over them, so the vision is not squandered on some bureaucratic nonsense, but is constantly regenerated, not just as ideas in the imagination, but in reality, in our lives and in the lives of the people who have to rely on the rest of us.
5. *Organisational learning.* Our organisations are no better at this than those in Australia. The widespread failure of most organisations to reflect on their success and failure is no less than

the profligate waste of resources. Every day people delivering services make discoveries about effective and ineffective service delivery. Those discoveries could help the organisation to respond more effectively to its users, but this learning from practice seems generally difficult for these systems, yet managers at all levels can make a commitment to organisational learning, through a variety of informal and more formal methods.

6. *Must central coherence mean a weak periphery?* This seemed a phenomenon in the State-wide organisations I visited. Are there ways of providing leadership based on a clear vision that still allow for local leadership and development of models. Again, this is perhaps unlikely without a dynamic relationship between learning and practice in different parts of the organisation, and the supports needed to nurture such processes.
7. *Just what is the capacity of our organisations to enable and support ordinary lives?* In my introduction I described the task of resettlement as one of ensuring major social change, not just affecting people with disabilities and those who provide services, but everyone. Are our bureaucracies up to this task? As Cocks recently (1987) put it:

... there needs to be an acknowledgement that people with intellectual disabilities are essentially vulnerable to the human service solutions society manufactures for their perceived problems. These solutions, whether in the name of benefit to the person, or more likely, in the name of ideology (or denial of ideology), or cost saving, may create more discontinuity and foster more rejection in their lives. We should recognise this fallibility of our formal service systems rather than treat them as 'ideal' solutions, and comprehend their tendency to decline and deteriorate over time. Even while new and exciting, they contain elements which will contribute to their entropy.

Such an analysis makes our ambitious resettlement programmes look somewhat dubious: a policy of natural decline, associated with a real commitment to developing better futures for the people already in the community might have been more sensible.

POSTSCRIPT August 1988

Since writing this account of the Australian intellectual disability scene there have been some significant developments in New South Wales.

It gives me no pleasure to find that my fears about the vulnerability of developments in NSW were well founded. In March 1988, after 12 years in office, the Australian Labor Party was defeated in the NSW State general election. Several ministers lost seats as the Liberal-Country coalition benefited from a 10 per cent swing against Labor. Among the first actions of the new government were the suspension of the deinstitutionalisation programme, a halt to employing 'unqualified' (i.e. non nursing) staff, and the dismissal of David Richmond.

While the NSW ALP government had been politically to the right of the party, it has been suggested that the result is partly attributable to a backlash against the totality of social reforms that were seen to characterise ALP rule, such as multiculturalism, Aboriginal rights, controls on gun ownership, a 'soft line' on law and order, etc., as well as the corruption rumours and emphasis on downtown prestige projects mentioned above. As one observer who read an earlier version of this piece put it: '... ours was not the only hegemonic social bloc.'

Moreover, the new Health Minister set up a 'Ministerial Implementation Committee' to, among other things, '*... advise on the delivery of services for the developmentally disabled to ensure that an appropriate balance is achieved between institutional care and community placement. . . To advise on whether developmentally disabled people should be placed in recently acquired community residences or whether such residences should be sold. . . [and]. . . To advice on the most suitable sites for the development of residential accommodation on Fifth Schedule Hospital campuses.*

Despite promises from the Minister about keeping the two disabilities of development disability and mental illness separate, the committee was to be a joint one, only one member of which had a background in the field of developmental disability.

Despite all this, the picture is not quite all negative, so for example there are indications that developmental disability services may be transferred from the Department of Health into Family and Community Services (as Youth and Community Services has been ideologically renamed).

New South Wales provides a rather extreme example of the 'hegemonic strain' phenomenon discussed above (pp34-35). At the time of writing there are some indications that a similar phenomenon might be happening in British Health Regions with regard to 'Community Care' for people moving from psychiatric hospitals, with perhaps some spill-over into the intellectual disability area. Again we must seriously ask, how robust and inclusive is our ideology? How broad are our alliances? And have we really looked sufficiently at the implications of our social change experiment for civil society, or have we looked out too narrowly from within the bureaucracies of state and local state?

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METHODOLOGY

In my study of Australian intellectual disability services, my enquiry was inevitably impressionistic in style and scope, but in arriving at my impressions I was guided by a methodological approach. This approach may be described in the following terms:

By way of background, my experience in service evaluation includes a variety of methods from direct observation to the use of interviews with service providers and users. A major influence has been PASS which teaches a discipline for looking at normalisation related features of service provision, and an emphasis on the likely impact of service design and functioning on service users.

I was guided by an 'agenda of enquiry' (Appendix 5) that I referred to during key interviews as well as in planning my questioning and observation: it did not form an interview schedule but instead an agenda that was always in the background and could be referred to to make sure I covered important areas. Having said that, it is fair to say that at times it was difficult to remember to refer to it, particularly, as in the later weeks of my tour, I was beginning to suffer from a certain amount of information overload!

In visiting services I was keen to 'take a vertical slice' of the service system. That is, I was interested in looking at all levels from that of the consumer up to senior management and the political level. Again, it was not always possible to be entirely systematic, but I do feel that I was reasonably successful in this.

My approach to interviewing was generally to ask interviewees to talk freely about a particular area — e.g. the aims of their service, the development of service provision since 1980, current challenges to resettlement, etc. As they spoke I would note follow up questions, and at times I would adopt a more challenging mode of questioning, or come at a topic in another way if I was unsatisfied with the coverage of a topic. Where possible I cross-checked between interviews, and with other sources of information.

Interviews were generally tape-recorded, and written notes taken at the same time. Particularly important interviews were listened to in detail before compiling the report, while other tapes were 'dipped into' as a means of checking or interpreting written notes.

After visits, I would write notes to aid my memory of what I had seen, and I distinguished between my interpretations and impressions and views for which I had hard evidence.

Finally, a massive amount of documentation was collected — enough to fill a large suitcase, and this was a valuable source of further information.

My itinerary is shown in Appendix 4.

Travelling Fellowship to Study Services for People with Mental Handicaps in Australia

I have been awarded a Travelling Fellowship by the British *National Health Service Training Authority* to study Australian programmes for the resettlement of people with mental handicaps/developmental disabilities from hospitals or similar institutions into community settings. I expect to visit Australia between mid November and mid December 1987, for 4-5 weeks, visiting NSW, Victoria, and WA in that order. I am interested in learning from the Australian experience since there are important similarities between the Australian and British human service systems, yet most of the influence on Britain has been from North America. I am also aware of some progress in changing the service system from an institutional one to a community based one in parts of Australia, something that seems still to be eluding us in Britain, despite some impressive localised progress.

This is a request for help with my visit, since it is rather difficult to set up such a study alone from the other side of the world! Firstly, here is some information about me.

I hold a joint appointment as Clinical Psychologist and General Manager of the mental handicap service in North Manchester Health Authority. The North Western Region of the NHS, of which we are a part, has a radical plan to close its mental handicap hospitals over the next 10-15 years, resettling people to ordinary houses (with the appropriate supports) in their home districts. I have responsibility for this process in my own Authority although most of the staff of the new service will actually be employed by the Social Services Department of the City Council. We are in fact still negotiating the financial package with the Region, although we have resettled a number of people to staffed and unstaffed houses over the last few years. I also sit on the Regional Advisory Group for mental handicap services and am completing a document on the monitoring and evaluation of the new pattern of services for the Region. In addition I have interests and particular experience in the following areas:-

- Values-led training for all grades of staff as well as parents.
- Planning on the basis of individual needs — both in general service planning and in the planning of specific provision with consumers and those close to them.

- Action research in the areas of *a)* facilitating relationships between people with a mental handicap and other local people; and *b)* social skills and social knowledge in people labelled mildly and moderately mentally handicapped.
- Developing interdisciplinary and interagency teams with a shared vision of their purpose and tasks.

I would be happy to discuss any of these areas with interested people so that my visit can perhaps be of mutual benefit.

For the purposes of my study, I am interested in meeting policy-makers, managers, and practitioners as well as consumers and if possible their relatives. I would also like to visit at least some actual services but am very aware of the need for such visits to be set up in ways that respect the dignity of those who rely on the service in question.

At this stage it would be very helpful if people could let me know whether they would be able to help with my visit. I will make my own arrangements for accommodation, but it would help if introductions could be arranged, and the visit given some kind of formal recognition by the relevant agencies.

I would also be grateful to receive copies of any key policy documents before my arrival so that I might familiarise myself with the policy context in advance.

Finally, I wonder whether you could pass this on to any other relevant people, and suggest people whom it might be worth contacting, in both this and other states.

My contact address is as follows:-

Community Support Team
Resource Centre
Beech Mount
Harpurhey
Manchester M9 1XU

Tel. 061-205 1364
061-205 4926

Mark Burton
7 June 1987

ITINERARY

NEW SOUTH WALES

- Friday 20 Nov. Developmental Disability Services, NSW Department of Health (Head Office). Ms Joy Woodhouse, and Mr John Dewhurst.
- Monday 23 Nov. Staff Training and Resource Centre, Lidcombe Hospital (Department of Health), Ms Kathy Wilde and Colleagues.
- Tuesday 24 Nov. University of New South Wales, Dr John Taplin, Dr Beryl Hesketh, Professor L.B. Brown.
- Wednesday 25 Nov. Developmental Disability Services, NSW Department of Health, Ms Janet Anderson.
NSW Council for Intellectual Disability, Ms Jeanette Moss and Mr Jim McLoughlin.
NSW Dept. of Youth and Community Services, Mr John La Bretton.
- Thursday 26 Nov. Southern Metropolitan Health Region and Eastern Area, Mr Steve Jitts, Dr Helen Moloney and colleagues, included visit to Community Residential Unit and other services.
- Friday 27 Nov. South Eastern Health Region, Strathallen Centre, Goulbourne, Dr Simon Hasleton and colleagues.

VICTORIA

- Monday 30 Nov. Office of Intellectual Disability Services (Head Office), Mr Alan Hall, Mr Brian Butterworth and colleagues.
Visit to REINFORCE Union of Intellectually Disabled Citizens, Northcote.
- Tuesday 1 Dec. OIDS Consultants, Early Intervention — Ms Pip Wisdom, Residential Services — Mr Tim Tench, Family Support — Ms Meg Gordon, Vocational Services — Mr Chris Glennon.

10 Year Plan, Mr Lindsay Neilson, Mr Geoff Smith, Ms Di Berriman.

Wednesday 2 Dec. Southern Regional Team, Cheltenham, Ms Bronwyn Dredge and colleagues, including visit to SEARCH vocational service — Ms Suzette Gallagher, and to an OIDS CRU.

Thursday 3 Dec. OIDS Head Office: Legislation, Individual Planning, Ms Frankie Gregson.
Janefield Training Centre, Mr Tibor Bakos and colleagues.

Friday 4 Dec. Office of the Public Advocate, Mr Graham Williams, observed sitting of the Guardianship and Administration Board.

Monday 7 Dec. OIDS Head Office, Justice Issues, Ms Jenny Bright.
Hospital Employees Federation, No 2 Branch, Mr Michael Leighton and Ms Melanie Raymond.
OIDS Head Office, Feedback to Alan Hall, Director Client Services.

Tuesday 8 Dec. Ten Year Plan and sharing of experience and frameworks for resettlement, Di Berriman and colleagues.

WESTERN AUSTRALIA

Thursday 10 Dec. Western Australian College of Adult Education, Mr Errol Cocks.

Friday 11 Dec. Commonwealth Department of Community Services and Health, Ms Cheryl Keelock and colleagues.
Nulsen Haven, visit to Nulsen Haven and to group home, Mrs Jill Bennett.

Monday 14 Dec. Authority for Intellectually Handicapped Persons, Mr Haydn Lowe, Mr Charlie Rook, Ms Barbara Bruce, Mr Brian English, Mr B. Frost. Covered AIH, its history, strategy, plans, experience of the closure of Claremont Hospital, Evaluation and Research and Regional Services.

Tuesday 15 Dec.

SLCG (Inc) Ms Vicki Jacobs and colleagues.
Family support, Residential and Vocational
Services.

Agenda of Enquiry: Australian Developmental Disability Services

For all States

A. Ideological Issues

1. Vision/Ideology:
Extent of its articulation — understanding and commitment to AOL/Normalisation-based models.
 - at each level of the service system
2. Impact of Vision/Ideology:
 - on Strategic Plans
 - Short Term Plans
 - Practice
3. Balance in Vision/Ideology
 - e.g. Respect vs Choice
 - Genericism vs Adequate Assistance
 - Independence vs Safeguards/Protection/Adequate Assistance

How are the goals construed? — Service led vs led by users' experience?
4. Dissemination of Ideology and Origins:
 - What are the mechanisms for dissemination? See Qs on leadership
 - e.g. impact and extent of normal training
 - Key sources of ideology
 - e.g. Home grown theory
 - normn theory [which?] if all what proportion?
 - Local Practice
 - Practice elsewhere

B. Basic Facts

1. Numbers of users/potential users
2. Location of users/non users now
3. Agency responsibilities and linkage
4. Strategic and short term plans
5. Finance

6. Service emphasis in plans e.g. resettlement vs build up of community services
 - strategy thus revealed?
7. Service organisational structure.

C. Politics

1. Interest Groups
 - 1.1 What are the interest groups?
 - 1.2 How are they organised?
 - 1.3 What are their interests/ideologies?
 - 1.4 What is their relative power?
 - how is this changing?
2. Motor
 - What is the motor(s) of change
3. Leadership
 - 3.1 Who leads the initiatives?
 - 3.2 What support do they have from others?
 - 3.3 What is leadership based on?
 - hegemony/vacuum/legitimate role/
 - political patronage/consensus/respect/
 - bureaucracy/resources (control of)/
 - threats. . .
4. History of Change
 - 4.1 What were key events?
 - 4.2 How did present impetus get under way?
 - formal events
 - ideological/political/resource changes prior to or surrounding the formal events
 - 4.3 What are the official and unofficial histories?
 - 4.4 Was there a process of radicalisation
 - incrementalism/big bang?
 - 4.5 Poacher/gamekeeper phenomena (dynamics/contradictions)?
 - 4.6 Battles won and lost? role as 'events'?
5. Opportunities and Constraints
 - 5.1 Were there particular opps. for the 'radicals' to seize?
 - and now?
 - 5.2 What constraints were/are there?

5.3 What are the pressures for retrograde actions and decisions

6. Assurance for Strategy

6.1 How do the leaders/'radicals' build up the momentum/safe-guard policies and changes?

- training/sanctions/incentives/recruitment and redundancy/dealing with threats and contradictions taking consumers and other interest groups with them/PR.

D. The New Services

1. What are the new services like?

- numbers and size
- what is covered? housing/employment & daytimes/adult ed./leisure/relationships/community support services
- who gets a service? institution/community residents, degrees of handicap
- locations
- co-ordination of services/management/networking
- case management/IPs etc.
- resourcing
- training
- user involvement/control
- models underpinning
- additional costs over institution
- vanguard areas?

E. The Old Services

1. What is strategy for replacement?

- timescale
- boldness of plan

2. Transfer of funds

- capital/revenue how do budgets work?

3. Resettlement? where can people go?

4. How is movt. of people tied to strategic planning of future service system?

5. Admissions policy during transition?

6. Personnel issues during rundown

7. Management of contraction

8. Future use????

For Comparison Across States:

1. Role/influence of institutions
2. Agency responsibilities and linkage cf. Audit
Commission/Griffiths?
3. Professional and other interests
4. Role of ideology and its influence
5. Differing political set ups
6. Legislation, and political or top managerial patronage
7. Degree of Strategic forethought
8. Fragility/strength of progress
9. Commitment to organisational learning
10. Demographic/geographical issues.



Department of Community Services **Disability Services Program**

Bulletin No. 1

DRAFT STATEMENT OF PRINCIPLES AND OBJECTIVES

Accompanying the Disability Services Act is a statement of the Principles and Objectives which underline the Disability Services Program. They are to be used as broad measures in evaluating the range of services assisted by the Commonwealth.

Principles

1. People with disabilities are individuals who have the inherent right to respect for their human worth and dignity.
2. People with disabilities, whatever the origin, nature, type and degree of disability, have the same fundamental rights as all members of Australian society.
3. Every person with a disability has the same rights as other members of Australian society to realise his or her individual capacity for physical, social, emotional and intellectual development.
4. People with disabilities have the same rights as other members of Australian society to services which will support their attaining an acceptable quality of life.
5. People with disabilities have the same rights as other members of Australian society to participate in the decisions which affect their lives.
6. People with disabilities have the same right as other members of Australian society to the least restrictive alternative in the services they receive.
7. People with disabilities have the same right of pursuit of any grievance as have other members of Australian society in relation to the services which they receive.

These Principles may be translated into objectives for service delivery as follows:

Objectives

1. That the focus of service delivery to people with disabilities should be the achievement of positive outcomes.
2. That services for people with disabilities should ensure that the conditions of the everyday life of people with disabilities are the same as, or as close as possible to, norms and patterns which are valued in the general community.

2.

3. That services for people with disabilities should be provided as part of local co-ordinated service systems and integrated with generic services wherever possible.
4. That people with disabilities should receive services which are tailored to their individual needs and goals.
5. That programs and services should reflect the needs of people with disabilities who experience double disadvantage as a result of their sex, ethnic origin or Aboriginality.
6. That programs and services should promote a competent and positive image of people with disabilities.
7. That programs and services should promote the participation of people with disabilities in the life of the local community through maximum physical and social integration.
8. That no single organisation providing services should exercise control over all or most aspects of the life of an individual with disabilities.
9. That services providing assistance to people with disabilities, be they specific or generic, should be accountable to consumers and their representatives, funding bodies and the public at large.
10. That programs and services should provide opportunities for people with disabilities to reach goals and enjoy lifestyles which are valued by the community at large and are appropriate to their chronological age.
11. That people with disabilities should have access to advocacy support where necessary to ensure adequate participation in decision-making about the services they receive.
12. That services should provide appropriate avenues for people with disabilities to air and resolve any grievances about the services they receive.
13. That people with disabilities should be provided with avenues for participating in the planning and operation of individual services and opportunities for consultation relating to major policy development and program changes.
14. That services for people with disabilities should respect an individual's rights of privacy and confidentiality.

In the above references, individuals with disabilities should be read to include advocates and families of children with disabilities where appropriate.

**DEPARTMENT OF COMMUNITY SERVICES
JANUARY 1987**



NEW SOUTH WALES GOVERNMENT

PUBLIC NOTICE
INQUIRY INTO HEALTH
SERVICES FOR THE
PSYCHIATRICALLY ILL AND
DEVELOPMENTALLY DISABLED

The Minister for Health, Mr Laurie J. Brereton, announced on 27 August 1982, the establishment of an Inquiry into the provision of health services for the psychiatrically ill and the developmentally disabled. The Inquiry will be conducted by Mr David Richmond, a Member of the Public Service Board, who will be assisted by one assessor nominated by the Labor Council and one assessor nominated by the Health Commission of New South Wales.

The Inquiry commenced on 13 September 1982 and will report to the Minister at the end of December 1982.

The terms of reference of the Inquiry are as follows.

1. To determine the appropriate nature, extent and distribution of services for the psychiatrically ill, psycho-geriatrics and the developmentally disabled in New South Wales.
2. To review the appropriateness of the existing range of care and services for these groups and examine alternative methods of care and service delivery.
3. To identify priority areas for the development of new services.
4. To assess resource requirements for the psychiatric system in light of the findings in (1), (2) and (3) above.
5. To review the role of the non-government sector in these areas and to recommend future arrangements for co-operative planning, funding and co-ordination between government agencies.
6. To identify a broad strategy and mechanisms for implementing recommendations arising from the terms of reference.

The Inquiry invites organisations and individuals with an interest in this area to make written submissions by 22 October 1982, and to indicate whether they would be prepared, if required, to make an oral presentation of their views to the Inquiry.

Submissions and enquires should be addressed to:

Ms P. Rutledge, Executive Officer,
Inquiry into Health Services for the
Psychiatrically Ill and Developmentally
Disabled,

PO Box K110 Haymarket 2000
Telephone: 217 6666

Metropolitan and Ethnic Press

- September 1982



Victoria

Acts 1986 No. 53

Intellectually Disabled Persons' Services Act 1986

Statement of principles.

5. It is the intention of Parliament that in the administration of this Act and the provision, management, development and planning of services for intellectually disabled persons the following principles are to be given effect to:

- (a) Intellectually disabled persons have the same right as other members of the community to services which support a reasonable quality of life;
- (b) Every intellectually disabled person has a capacity for physical, social, emotional and intellectual development and a right to individualized educational and developmental opportunities and is entitled to exercise maximum control over every aspect of his or her life;
- (c) The welfare of an intellectually disabled person is the first and paramount consideration;
- (d) The needs of intellectually disabled persons are best met when the conditions of their everyday life are the same as, or as close as possible to, norms and patterns which are valued in the general community;
- (e) Services should promote maximum physical and social integration through the participation of intellectually disabled persons in the life of the community;

- (f) Services generally available to all members of the community should be adapted to ensure access by intellectually disabled persons and specialized supplementary services should be provided to the extent required to meet individual needs;
- (g) Services to intellectually disabled persons should be provided in such a manner that an individual need not move out of his or her local community or travel inordinately long distances to receive the services needed;
- (h) Services to intellectually disabled persons should be sufficiently flexible in structure and organization to meet the varying needs of intellectually disabled persons in developing towards independence and to maximize the choices open to them;
- (i) It is in the best interests of intellectually disabled persons and their families that no single organization providing services to intellectually disabled persons exercise control over all or most aspects of an individual's life;
- (j) It is the responsibility of the State of Victoria to plan, fund, ensure the provision of and evaluate services to intellectually disabled persons according to the principles stated herein;
- (k) It is in the interests of intellectually disabled persons and their families for non-government organizations providing services to intellectually disabled persons to continue to play a significant role in direct service delivery;
- (l) The State of Victoria must ensure that government and non-government organizations providing services to intellectually disabled persons are accountable for the extent to which the rights of intellectually disabled persons are advanced and service quality assured;
- (m) Intellectually disabled persons have a legitimate and major role to play in planning and evaluating services;
- (n) When some restriction on the rights or opportunities of an intellectually disabled person is necessary, the means chosen should be the least restrictive of the available alternatives having regard to all the circumstances.



Changes in British society pose major challenges to public and voluntary agencies with responsibilities for serving people and communities. The King's Fund Building Community Strategies Programme is designed to support members, managers, professional staff and community representatives in devising and implementing the strategies required to meet these challenges. A key priority is to promote large scale change in opportunities and services for people with learning difficulties. Starting from the framework set out in **An Ordinary Life In Practice** (edited by David Towell and published by the King's Fund in 1988) a series of Working Papers is planned to explore issues in the management of strategic change and report local experience.

The first paper in this series **Australian Intellectual Disability Services - Experiments In Social Change** draws lessons for the United Kingdom from recent Australian experience of efforts to establish alliances for social reform and the way government agencies have been pursuing ambitious plans for de-institutionalisation.

The author, Mark Burton, is a clinical psychologist currently responsible for the management of mental handicap services in the Central Manchester Health Authority.

**Building Community Strategies
King's Fund College
2 Palace Court
London W2 4HS
Tel: 01-727 0581**