INQUIRY INTO HEALTH SERVICES
FOR THE PSYCHIATRICALLY ILL AND
DEVELOPMENTALLY DISABLED

PART 2

SERVICES FOR THE
DEVELOPMENTALLY DISABLED

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MARCH 1983
INQUIRY INTO HEALTH SERVICES
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1. INTRODUCTION

Part 2 of the Report of the Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled examines services for the developmentally disabled, and sets out to:-

(i) identify preferred patterns of service delivery in the light of the general values and principles outlined in Part 1, and the special needs of the developmentally disabled

(ii) translate these into specific proposals to meet needs using minimum resource costs

(iii) develop plans to achieve and implement these proposals.
2. RECOMMENDATIONS

The following recommendations arise from Part 2:

That the Minister for Health -

(i) endorse the principle that the provision of services for the developmentally disabled within the health administration should 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; and

(ii) recommend to the government their adoption and application to all areas of government policy relating to the care of the developmentally disabled. (refer to Section 3.2)

3. That the role of health services in the area of developmental disability be endorsed as follows:

(i) Development and implementation of preventive programmes;

(ii) Provision of comprehensive diagnostic/assessment and associated counselling.

(These services should be available to all developmentally disabled children and their families);
(iii) Provision of early intervention programmes (in consultation with the Education Department and the Department of Youth and Community Services to ensure a range of programmes are developed);

(iv) Provision of home support services (in consultation with the Department of Youth and Community Services, the Horne Care Service of N.S.W. and Local Government as appropriate);

(v) Development of small community residential units to rehouse residents from existing institutions;

(vi) Development of small community residential units for the severely disabled, particularly the severely intellectually handicapped, and others with severe physical conditions, both children and adults, who are unable to continue living with their families;

(vii) Provision of respite and shared care arrangements within these units;

(viii) Provision of specialised therapeutic services as required;

(ix) Access to general health services for the "routine" physical and mental health needs of the disabled. (5)

3. That an amount of $200,000 be allocated in 1983/84 from the Hospital Health Promotion Programme for a public education programme on the importance of ante-natal care and the availability of screening and genetic counselling services. (6.1)
4. That from the specific allocation referred to in Part 1 (approximately $9 million per annum for the next three years), an amount of $4 million per annum be allocated to developmental disability services. (6.1, 8.1).

S. That $1.5 million of these funds be allocated per annum to the expansion of diagnostic, assessment and community support services, with priority to the Western Metropolitan, Hunter, South-East and Central West Regions in the first year. (6.1, 8.1)

6. That all public hospitals implement a policy to ensure that parents of all handicapped children identified at or soon after birth are automatically given access to counselling and assessment and early intervention services. (6.1)

7. That the Health Department implement a policy that all admissions to health services residential facilities and participation in programmes be dependent on prior assessment and subject to regular review by community assessment services. (6.1)

8. That each Region establish a Residential Placement Committee (6.1).

9. That Regional and local management review the location of work oriented facilities and initiate their relocation to community-based premises. (6.1)

10. That the Department of Health consult with the Department of Social Security regarding the potential expansion of co-operative arrangements in the provision of activity and work-related programmes. (6.1)
11. That the Health Department adopt a long term policy of providing all health care residential services for the developmentally disabled in small residential units (with varying staffing levels depending on particular clients' levels of disability).

12. That in each Region a network of community residential units which would normally be ordinary houses each accommodating from 5-10 people be established to provide both short (including respite) and long term residential care and social and living skills training for developmentally disabled people. (6.2)

13. That from the specific allocation ($4 million per annum) referred to in Recommendation 4, an amount of $2 million be allocated to Regions to assist in the development (either directly or through non-government organisations) of community residential units to re-house adults currently resident in institutions and those at home urgently in need of placement. (6.2)

14. That priority for the funding of such units in the first year should go to the Hunter, Western Metropolitan, Southern Metropolitan and Northern Metropolitan Regions. (6.2).

15. That initially these services be funded from the total hospital budget; and that from 1984/85 resources for this purpose be augmented from savings to be achieved through proposed reductions in the size and number of existing institutions. (6.2)

16. That from the specific allocation ($4 million per annum) referred to in Recommendation 4, an amount of $500,000 be earmarked for the support of innovative programmes such as supportive accommodation for developmentally disabled women with children ("Women in Limbo" proposal). (6.2)
17. That the Minister for Health, in consultation with the Minister for Youth and Community Services, negotiate with the Minister for Social Security to improve co-ordination of planning and service delivery and to develop proposals for joint Commonwealth/State funding of these services. (6.2)

18. That the Minister for Health negotiate an arrangement with the Minister for Housing whereby a proportion of welfare housing stock in existing and proposed developments is specifically made available as community residential units for developmentally disabled people. (6.2)

19. That within existing hospitals emphasis in client care be based on the implementation of independent living training programmes. Direct care staff to be responsible to the programme staff for programme maintenance and achievement. (6.2)

20. That as resident numbers decrease the ratio of direct care staff per resident at Stockton Hospital be gradually increased. (6.2)

21. That Regional Directors negotiate formal contractual arrangements between hospitals and Regions to provide social work, psychology and occupational therapy services, where recruitment difficulties are experienced. (6.2)

22. That a new category of direct care staff be established -to be titled "Residential Care Assistant". This category to be used in the expansion of community residential units and eventually as direct care staff in hospitals. (7.1)

23. That the Department of Health negotiate with the Department of Technical and Further Education for the development of an appropriate "apprenticeship-type" educational programme for this category of staff. (7.1)
24. That the employment of "Programme Officers" be expanded as a major staff category in community developmental disability teams, and in specialised hospitals. (7.1)

25. That the Department of Health negotiate with the appropriate education authorities for the development of a suitable undergraduate or postgraduate programme at College of Advanced Education level for this category of staff. (7.1)

26. That at the appropriate level (Regional or supra-Regional) a community based Board of Directors be established with the responsibility for the management of all services within the health administration for the developmentally disabled, both residential and non-residential. Appropriate advisory mechanisms should be established to ensure input from parent and voluntary groups and from local government and the Departments of Youth and Community Services, Education and Social Security. (7.2)

27. That these services be managed by a Chief Executive Officer responsible to the above Board. (7.2)

That care of the developmentally disabled in specialised hospital settings should be separated from the care of the psychiatrically ill by the establishment of a distinct management organisation, responsible to the above Boards, and by the degazettal and physical separation of services. (7.2)

That the role of the Senior Specialist for Developmental Disability Services in the Central Administration of the Health Department be strengthened by involving him or her to a greater extent in budget decisions affecting provisions of services. (7.2)
That the Minister for Health consult with the Attorney-General regarding the development of appropriate guardianship legislation for these clients. (7.4)

31. That the following targets be adopted for the expansion of community residential services recommended above and the reduction of existing institutional services for the developmentally disabled by 1986. (The following targets should be viewed as interim pending the further expansion of community services). (8.2)

<table>
<thead>
<tr>
<th>Region</th>
<th>FIFTH SCHEDULE HOSPITALS</th>
<th>Community Residential Target</th>
<th>Target 1986</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Current Reductions</td>
<td>Current Reductions</td>
<td>Target 1986</td>
</tr>
<tr>
<td>Western</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southern Metropolitan</td>
<td>276</td>
<td>244</td>
<td>32</td>
</tr>
<tr>
<td>Northern Metropolitan</td>
<td>316</td>
<td>174</td>
<td>142</td>
</tr>
<tr>
<td>Hunter</td>
<td>1052</td>
<td>382</td>
<td>670</td>
</tr>
<tr>
<td>South-East</td>
<td>200</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Central West</td>
<td>198</td>
<td>100</td>
<td>98</td>
</tr>
<tr>
<td>Illawarra</td>
<td></td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>North Coast</td>
<td></td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Orana &amp; Far West</td>
<td></td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>South-West</td>
<td></td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>New England</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2913</strong></td>
<td><strong>1301</strong></td>
<td><strong>1612</strong></td>
</tr>
</tbody>
</table>
3. HOW ARE CLIENTS' NEEDS BEST SERVED?

3.1 What are Clients' needs?

Aside from advice from health and welfare professionals, the Inquiry's views of clients' needs in this area have been formulated largely on the basis of submissions received from non-government service provision and advocacy groups, and the limited amount of Australian and overseas research which is available. These non-government groups are in the main composed of parents of disabled people, with some interested professional involvement, and represent by far the strongest and most articulate advocacy for the needs of disabled children and adults and their families. Their perspective which comes from such a deep and close involvement in the problem is invaluable, however their capacity to fully represent the views or needs of disabled persons themselves can be constrained by this very closeness which may lead to an over-protective approach. This limitation only highlights the need for a broader base of advocacy for the disabled and the need to develop mechanisms which actively enable them as far as possible to speak for themselves.

The term "developmental disability" means a severe chronic disability which -

(a) is attributable to an intellectual or physical impairment or combination of intellectual and physical impairments:

(b) is manifested before the person attains age 18:

(c) is likely to continue indefinitely:

(d) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency: and
(e) reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and co-ordinated.

For practical purposes this includes persons with intellectual handicap, severe epilepsy, cerebral palsy, brain damage acquired in childhood, and those with other neurological disorders needing similar provision.

This term was adopted by the (then) Health Commission to:

(i) replace the stigmatised expression of "mental retardation" and "intellectual handicap"

(ii) emphasise the developmental or educational/learning nature of the disability and the services required to assist clients.

(iii) encourage increased access to comprehensive multi-disciplinary diagnostic and assessment services to enable assistance to be provided as early as possible.

(iv) minimise partial or inappropriate diagnosis and therefore labelling especially of children with a range of physical and other disabilities prior to comprehensive diagnosis and assessment.

(v) recognise that a proportion of the handicapped have both intellectual and physical disabilities.

(vi) encourage paediatricians and others associated with early childhood health services to refer clients for more effective assessment.
In 1982 the (then) Health Commission published a draft policy document entitled Health Services for the Developmentally Disabled which outlined policies and proposals for services and sought public comment. This document together with comments on it was referred by the Minister for Health to the Inquiry for consideration in its deliberations.

The use of the term has raised the anxiety of several groups (who would in principle support the widening of access), for example:

"The use of the term "developmentally disabled" without clear direction as to the implications of this is causing some confusion to parents and others. The change of name would seem to imply more than simply re-naming "intellectual handicap", or "mental retardation". Using the definition of "developmentally disabled" incorporated in the recent draft Health policy it would appear that the Health Commission is now responsible for services to a much wider range of people, e.g. cerebral palsied people, and those with physical handicaps. By contrast, most of the individuals and groups presently relating to the term "developmentally disabled" are those concerned with intellectual handicap."

"Services provided presently to those people with intellectual handicap are understaffed, inadequate and unevenly distributed throughout the State. Because of the expansion of the role of the Health Commission, even more resources are now required to meet the needs of the additional clientele. In addition, community nurses within Health Commission teams are not trained in developmental disability. Rather, it is the Action Group's understanding that the nurses are "mental retardation" nurses."

"It is the Group's opinion that parents of children with disabilities other than intellectual, but who now fall within the definition "developmentally disabled", and disabled people themselves, do not realise"
"that the Health Commission has a responsibility to provide services for them."

(Extract from Submission 5.313, Action for Handicapped Citizens, a Northside Group.)

One of the underlying concerns as expressed in this and other submissions is that the broadening of eligibility will result in reduction of resources to the already inadequately resourced area of care of the intellectually disabled.

The Inquiry is also concerned that the unforeseen effect may be to generalise stigma on to those people with purely physical handicaps.

The Inquiry endorses the intent of the change of name, to broaden access of disabled people to comprehensive assessment services and to reduce the stigma of intellectual handicap. These desired changes may also be achieved in other ways. For example, comprehensive assessment services will be more accessible if linked to the paediatric services of general hospitals. The stigma associated with the term "intellectual handicap" will only be reduced as community perceptions change through more positive contact with handicapped people.

On balance, it is considered that the term "developmental disability" covers the broader range of needs and the complexity of the inter-relationship between physical and intellectual disabilities more adequately than other alternative terms and should continue to be used.

It should be recognised that the largest group within this category are those whose primary disability is intellectual, and services are largely directed to this group.

It has been stressed consistently to the Inquiry that developmental disability (in all its forms) is not primarily a medical problem but an educational and developmental problem. This was expressed most coherently by the N.s.w. Council for the Mentally Handicapped, in their submission in response to the (then) Health Commission draft Policy Document:
"Council's Philosophy & Policy Document defines a person who is intellectually impaired as one who has one or more impairments which limit that person's rate and extent of learning so that he or she cannot achieve competence for living or working as an adult without assistance related to the areas of the person's limitations."

"IN OTHER WORDS ••• intellectual handicap of itself is a learning condition and does not require medical treatment in the sense that there is a sickness to be managed or treated."

"PRIMARY NEEDS OF AN INTELLECTUALLY HANDICAPPED PERSON

The result of an intellectual handicap is that - if uncorrected - the person affected may exhibit behaviour below the standards of personal independence and social responsibility expected of non-handicapped persons of the same age and cultural group.

This behaviour can be improved and remedied by developmental and educational programmes which will differ according to the age of the individual concerned."

<table>
<thead>
<tr>
<th>AGE GROUP</th>
<th>POSSIBLE DELAYED BEHAVIOUR IN</th>
<th>SERVICE REQUIRED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infancy/early childhood</td>
<td>Sensory skills, Motor skills development, Communication skills, Self help skills, Socialisation</td>
<td>Early assessment, Early intervention, Appropriate pre-school</td>
</tr>
<tr>
<td>Childhood and Early adolescence</td>
<td>Application of basic academic skills in daily living, Application of appropriate reasoning and judgement in mastery of the environment, Social skills</td>
<td>Specialised education, Independent living, Socialisation</td>
</tr>
</tbody>
</table>
Late adolescence Vocational and social responsibilities and performance Job training
Adult life Sheltered employment accommodation Personal advocate

"All services listed above are educational/welfare in orientation and are designed to promote independence and integration into the community."

"SECONDARY NEEDS OF AN INTELLECTUALLY HANDICAPPED PERSON"

"Intellectual handicap may have associated with it physical conditions that require remedial non-medical therapies such as physiotherapy, speech therapy and occupational therapy."

"Such services are educational/welfare in orientation since the r purpose is to develop the capacity of an intellectually handicapped person for independence and integration into the community."

"TERTIARY NEEDS OF AN INTELLECTUALLY HANDICAPPED PERSON"

Like the rest of the community, the intellectually handicapped person may contract an illness, develop a condition or have an accident that requires treatment from general community health services and hospitals."

As the Council went on to emphasise, the interrelationships between these needs clearly indicate the necessity for co-ordinated inter-departmental and interagency planning, involving both government and non-government services.

"Council's Board does not consider that all the needs described (above) should be met by the Health Commission. Many could be more appropriately met by other Departments and/or voluntary organisations, and vice versa. Many services are not being provided in a meaningful way by ANY organisation.

In addition, the Board believes that there has to be a radical re-organisation of the services currently provided by the Health Commission, with a shift from institutional care to community based care."
The consensus from submissions, the Inquiry's forum with community groups and general discussion further emphasised the importance of a developmental and educational approach, the need for continuity of care through a highly integrated network of services, and for emphasis on normalisation, through services provided in the home or settings which as closely as possible reflect a home environment.

3.2 Principles of Service Delivery

The following extracts from the N.S.W. Anti-Discrimination Board Report on Discrimination and Intellectual Handicap (1981) provide some basic principles underlying the provision of services and these are endorsed by the Inquiry:

"... in general the services for people with intellectual handicaps need to be transformed to promote the maximum development of each individual, to pursue the objectives of normalisation and integration and to promote the rights of people with handicaps. This transformation is required in many areas of health services at present being delivered to people with intellectual handicaps."

"... intellectual handicap does not by itself call for medical treatment."

"... intellectual handicap itself calls for developmental and educational programs and non-medical health therapies such as physiotherapy and speech therapy."

"The health services have a proper and important role in preventing conditions that can result in intellectual handicap in diagnosis, in medical treatment where it is required and in providing non-medical health services ..."

"The dominance of the medical model has unfortunate consequences for some health services ... these include services for people with disabilities and chronic conditions ... (who) are often poorly served at present because services provided do not match needs and the methods of delivery are ineffective and expensive."
"the delivery of community health services should in many instances depart from the medical model and serve the developmental model..."

"The first principle underlying our examination of accommodation for people with intellectual handicaps is the right of access to a residence that is appropriate to the capacities and desires of each person, located in reasonable proximity to family and friends. Further principles are normalisation, the right to developmental programs, and the right to live in the least restrictive situation that can be provided."

"Only a very small proportion of people with intellectual handicaps are actually physically ill; the major need is for programs to develop skills and social competence."

These principles have been accepted and adopted internationally, and incorporated in significant planning documents in other States of Australia, most recently in the South Australian Report - "A new pattern of services for intellectually handicapped people in South Australia" (1981).

The Inquiry from its investigations believes that there is acceptance in all service systems in New South Wales that the predominant form of service delivery should emphasise effective multi disciplinary assessment of clients and on-going services in an educational/developmental mode with "medical" health input varying to meet the needs of particular individuals or groups.

A developmental approach is already in operation in many parts of the health system and can be improved with appropriate management, staffing and service delivery arrangements. Such an approach should be formally adopted as policy in this area of health services and in other government services for these clients.
The Inquiry proposes that the Minister for Health endorse the principle that the provision of services for the developmentally disabled within the health administration should 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.

Adoption of these principles will reinforce the directions already developing within health services:

"It is important that the system of health care be based on principles of normalisation and integration of disabled people in the community."

(Extract from S254: Social Workers for the Developmentally Disabled)

"It is now realised that a community orientation is the most appropriate if the person with developmental disability is to achieve 'behaviours and characteristics which are as culturally normative as possible' (Wolfensberger, 1972)"

(Extract from S226: Occupational Therapy Study Group in Developmental Disability).
4. CO-ORDINATION OF GOVERNMENT SERVICES

Some advocates have argued to the Inquiry that the services currently provided within the Health Department should be transferred to another administration such as the Department of Youth and Community Services.

All departments are constrained by their existing practices and approaches and although a sound theoretical argument may be developed to move services away from Health, the Inquiry is not convinced that this will really make much difference to the quality and range of services available to these clients. A real concern is that they could decline.

The Inquiry has seen some very effective services provided from within the health administration and the emphasis needs to be placed on improving these services along with a reduction in large scale institutional care. A change of administrative auspice will not, at this stage, facilitate this process particularly when most of the available and potential resources are located within the health system.

The Inquiry believes a focus for all service providers can be provided by improving co-ordination and advocacy for these services and allowing the respective service departments to continue to develop better services in accordance with the philosophies outlined in this and other recent reports.

It is a truism that the care of the developmentally disabled requires a highly co-ordinated interdepartmental approach, yet it has not been possible for the relevant departments in New South Wales to achieve a joint co-operative policy on the care of this group.
For example a long-standing arrangement in this area has been the 1964 agreement between the Health Department and the Department of Youth and Community Services that the welfare department would care for the mildly and moderately retarded, and that the Health Department would primarily care for the severely and profoundly retarded and also for the less retarded with specific physical health problems. Such an arrangement has of course never been fully implemented because the bulk of the government's resources in this area have been located in the large hospitals which have by default continued to provide long-term placement for the whole range of intellectually disabled people, in the absence of other services. In 1979, the (then) Health Commission again endorsed this agreement and clarified its role in the provision of preventive and assessment services.

From the client's point of view, the critical issue is that service is provided on the basis of their total functioning capacity rather than one aspect of their problem.

Assessment services must be accessible to the whole population and are appropriately provided by the health system. Once assessment takes place, the issue of continuing intervention by the appropriate service can only really be resolved at the point of service, in the light of the client's total functioning and needs. Some clients depending on the services available could be equally well assisted in either the health system or the welfare system.

The gradual expansion of Education Department services in recent years, based on a policy of universal access to education and integration within schools, and the more recent entry of the Department of Technical and Further Education (providing programmes to develop independent living and employment skills) and the Housing Commission into this area of service delivery has added further weight to the arguments of the non-government sector for improved co-ordination.
The Commonwealth government is also active in this field, primarily through the Department of Social Security and the Department of Health, and more recently through Schools Commission funding of early intervention programmes. Effective planning of services must involve these organisations.

The need for improved co-ordination has been argued by the non-government organisations for some time, and was a theme of submissions to the Inquiry. The issues relating to this matter have not changed since 1981 when the Anti-Discrimination Board ("Discrimination and Intellectual Handicap") concluded:

"Many submissions to the Board described shortcomings in services which can largely be attributed to a failure of diverse service-providing agencies to integrate and co-ordinate their activities within an overall plan. Well documented problems include difficulty in obtaining appropriate referrals from one agency to another, overlap and duplication of services in some localities and gaps in others, and the needs to consolidate staff training programs, career structures and industrial agreements. The Board has given careful consideration to various strategies that have been proposed to overcome these difficulties. The proposals range from reactivating the Inter-Departmental Standing Committee on the Intellectually Handicapped, to establishing a new statutory authority to provide a wide range of special services for people with handicaps."

"The Board rejects the option of attempting to reactivate the Standing Committee. This decision is based partly on the apparent failure of the committee to provide effective leadership and co-ordination in the past, but more importantly because the Board perceives a need for an authority with overall policy responsibilities, separate from departments with responsibility for providing services. The Board believes that the agency would, among other functions, act as an advocate for people"
"with intellectual handicaps by monitoring and evaluating services and pressing for improvements. The agency should also be prepared to act as an advocate for individuals who complain about aspects of service provision. This advocacy could create a conflict of interests if the agency itself is involved in service-delivery."

"The major role envisaged for the authority is the co-ordination and rationalisation of delivery of services required by people with intellectual handicaps. Experience has shown that a co-ordinating body cannot succeed in its tasks if it is within or attached to one of the service departments."

On the basis of its investigations and the history of inter-departmental relationships in this area in New South Wales, the Inquiry endorses the need for a co-ordinating mechanism. In the Inquiry's view, ideally such a mechanism should be attached to a Department which is independent of the main service providers, and should not itself take on a role in service provision.

Co-ordination involves the following functions:

advising the various responsible Ministers on matters relating to services for developmentally disabled persons:

co-ordinating policy development and planning of the various State government departments in consultation with the Commonwealth and the non-government sector:

considering submissions from parent groups and service providers relating to the ongoing development of service provision:
recommending priorities for the expansion of existing services and the establishment of new services;

advising on the allocation of funds for service between departments and for the provision of funding to non-government bodies;

recommending the development of appropriate performance and provision standards;

recommending guidelines to be followed in considering applications for funding from non-government organisations;

performing an overall liaison role;

recommending on evaluation and research programmes, and the development of necessary data bases.
5. **THE ROLE OF HEALTH SERVICES**

The Health Commission's Draft Policy Document, *..Health Services for the Developmentally Disabled...*, released during 1982 summarised "the purpose... of health services for persons with developmental disabilities as:-

1.1 Early identification and treatment followed by early intervention.

1.2 The provision of normal patterns of life within the community as far as is conceivably possible.

1.3 Individually tailored programmes designed to maximise their potential and their quality of life.

1.4 Ready access to aid and support both for themselves and their families throughout their lifetime...

It also argued that there are only a minority who cannot live either at home or in small units within the community, that developmental disability services should be divorced from psychiatric services and identified two main problems in present health services:-

"The main problem for the Health Commission of New South Wales is to devise ways of moving away from the past provision of services in large isolated institutions to a community-based integrated service for the majority of its clients at a time of severe financial constraints. There is evidence to suggest that initially there will be additional costs but in the longer term the cost of such care will be cheaper. At present our largest institution has 800 beds and our smallest 5."

"Not only is there the problem of the large institution, but also a geographic maldistribution of the available beds with a very significant shortfall of adult beds and services as most of the
developments since regionalisation have been provided for children."

The draft policy document identified the role of health services as follows:-

"The Departments of Education and Youth and Community Services have major roles to play in the provision of services, and, indeed, together with voluntary and church organisations, provide for the vast majority of persons with developmental disabilities. The Commission accepts ongoing responsibility for the care of the severely and profoundly affected and for those less intellectually handicapped who have additional problems of a neurological, behavioural, physical or sensory nature which require a high health input."

The components of the health service role were identified in the draft Policy Document as:

Prevention

(including community education re antenatal hazards, genetic counselling and screening).

Identification and Intervention

(including specialised diagnostic and assessment services, support and counselling services and early intervention programmes).

Accommodation

(including community-based residential services "for those needing care in a health setting", and specialised hospital facilities).

Long-term Support Services Co-ordination

(including co-ordination committees and identification of a responsible person for each client.

Responses to this draft policy document from a number of organisations and groups reflected major concerns.
Firstly, that the draft policy represents the intention of the health service to retract resources by limiting eligibility to residential care to the more profoundly disabled and those with physical health needs. The Inquiry understands that the policy is a restatement of the earlier agreement with the Department of Youth and Community Services, however the agencies have a legitimate concern about the availability of resources to other Departments, particularly Youth and Community Services and their ability to develop the necessary services for the less disabled.

As expressed by Action for Handicapped Citizens:

"Action for Handicapped Citizens recognises that the Health Commission sees itself as catering for those people who do not fit this description but who nevertheless live in the Health Commission Schedule V hospitals. However, the long-term implications are unclear, and many parents may fear that their sons and daughters will be dumped. It has already been stated in our region that no new client will be accepted into the Health Services who is considered outside the role of the Commission. Whether this is happening in practice is difficult to ascertain.

"The group considers that, while this is a correct decision, the problems faced by families and developmentally disabled people themselves who are not offered any alternate service by other government agencies will have to be recognised and met as a matter of urgency."

"The Group faces a dilemma in addressing itself to a submission regarding "health services" for people with developmental disabilities when it considers that the principal needs of this group of people are social and educational, and that there are particular health needs occurring at any time in the life of a developmentally-disabled person or the family, which should be met by the Health services."

"The group itself faces the same dilemma in its activities at "grass roots" level in trying to gain better services."
"The historical fact that the Health Commission of N.S.W. has, by default, provided residential services for children and adults is recognised. In addition, it is recognised that clients presently in institutions are there because, at the time, it was considered an appropriate form of care. The group considers that, should history repeat itself, the Commission would provide different forms of services for developmentally disabled people and their families.''

"In addition the difficulties faced by the Commission in relation to the training and education of people who have been institutionalised for many years are recognised."

"It is the view of the Action Group that the present situation is compounded by the recognition of the fact that not only should mildly or moderately handicapped people be given community-based options, but that those with severe and profound handicaps who, until very recently were considered unable to benefit from this form of service, should also have this option."

"The Health Commission therefore faces the added dilemma of having to plan different options for a great majority of its present institutional clients, and must now consider the future of the large institutions. They will certainly not be appropriate for the very small percentage of people who are assessed as requiring total medical supervision and care."

"Consideration has to be given to increasing the budget of another Government Department to enable a range of residential needs to be met while, at the same time, maintaining the Health Commission budget in its transition period from institutionally-based services to community-based services and to provide adequately for those people assessed as requiring total medical care."

(Extracts from 5313: Action for Handicapped Citizens a Northside Group)
The second and related concern is that the policy document does not go far enough in the direction of "normalisation", and continues to place undue and inappropriate emphasis on medical/nursing care and hospital services for example, another group, Action for Intellectually Handicapped Citizens, in their response to the document, stated:

"We represent a group of parents and concerned citizens in the eastern and southern suburbs and many of the proposals of your draft policy strike a very sympathetic chord with people in our group, particularly in the aims of the services to be provided and in the recommendation for expanded residential facilities.

At a committee meeting to discuss the draft policy a number of points were raised which we would like to submit for your consideration before the final policy document is proposed:

A major concern of the committee was the suggested size of the specialized hospitals intended to accommodate those who cannot be cared for adequately in the community residential units. It is difficult to see how the stated aim of the greatest degree of normalization possible could be achieved in a hospital of even 100 beds and we would question whether there would be any advantage in these specialised hospitals being larger than a community unit of a recommended maximum of 30 beds.

The design and staffing specifications of the community units also caused some concern. As represented in the diagram it does not conform to the expressed aims of normalization which is the theme of the policy. In particular we believe that the community team and the assessment and therapy staff should be geographically separate from the residence. The inclusion of a day care unit and therapy centre in the design of the community units also seemed a contradiction of this aim."
It has also been argued, as indicated above, that the "medical" or "illness" perspective so strongly permeates the health services that they cannot perform a broad educational/developmental role and therefore the role of the health services should be strictly defined to a narrow medical service.

Such a view of the role of health services for these groups has been presented by The New South Wales Advisory Council on the Handicapped which proposed redefinition of the "health" role within the context of the proposal to establish a Statutory Authority to be known as the Handicapped Persons Authority (which would perform multiple roles including advocacy, policy formulation and service delivery - see previous section) as follows:-

"(1) Community Services

Prevention - including immunisation, genetic counselling, etc.

Assessment - including medical and behavioural aspects as part of joint assessment processes.

Regional specialist medical teams. (NOTE: Council proposes that non-medical staff of existing Health Developmental Disabilities teams would be absorbed in and form the basis of the Authority's new community service teams.)

"(2) Residential Services

- Health to be responsible for centres for people who require 24 hours, full-time nursing care."

". Authority to be responsible for all other residential services and contract with Health for specialised medical services for any resident who needs them."
"Council envisages that the new Authority would base its new community service systems on a new category of staff - "social trainers". Many displaced Health workers would be able to be retrained (in short courses) for this role. This could be interpreted positively to Unions."

(Extract from document presented by the New South Wales Advisory Council on the Handicapped.)

The Council made the following general points to the Inquiry about future directions for these services generally:--

"(a) **Future Residential Services.** That future residential services should be community-based thus ceasing the placement of developmentally disabled children and adults in large institutions.

Council is totally opposed to the concepts outlined in the draft policy document entitled "Health Services for the Developmentally Disabled".

"(b) **Deinstitutionalisation.** Council is most disturbed that the vital issue of deinstitutionalisation is not being pursued with sufficient vigor because present Government policy only allows for the disposal of assets provided the funds are returned to consolidated revenue. Unless this policy is changed the mistakes of the past cannot be rectified. Present residents will be confined to an institionalised existence and, in addition, future generations of developmentally disabled people will be placed in institutions simply because they exist."

"It is therefore recommended that the Government move immediately to adopt a policy of deinstitutionalisation by the sale of present institutions. Implicit in such policy is that when"
"Government land or buildings are sold, the total sale price be used for the purchase of some suitable premises and appropriate support services for those previously resident in large institutions."

"(c) Staff Redeployment. Council, while recognising that many people are employed in institution settings nevertheless is of the opinion that there would be no reduction in employment caused by the shift of emphasis to community setting. The Council sees the need for the implementation of retraining and upgrading of the qualifications of some staff from which the community as a whole would benefit in the long term."

"(d) Shifts of Emphasis between Government Departments. In view of the principles Council is advocating that the Government should adopt a major implication would be a shift from Health Commission controlled services to allow the Department of Youth and Community Services, Education and Housing to increase their level of activity in direct service delivery to developmentally disabled people.

The transition from Health Commission to greater involvement of other relevant Departments needs a planned and orderly approach and in addition a commitment by the Government to provide a positive, co-ordinated plan of action."

"(e) Need for an Independent Statutory Authority.

Council is of the opinion that the only way to achieve positive co-ordinated services for the developmentally disabled is for the Government to establish an independent Statutory Authority."

(Extract from document presented by the N.S.W. Advisory Council on the Handicapped.)
The Inquiry does not support the argument that health services should have little or no role in the care of the developmentally disabled other than those who are physically or psychiatrically ill. This argument tends to deny the shift in health services towards a broader social perspective which is increasingly reflected in the provision of health services. Any movement towards a more narrow definition of health care would be, in the Inquiry’s view, a backward step.

On the basis of its investigations, the Inquiry believes that the role of health services in this area should be defined as follows:

(i) Development and implementation of preventive programmes:

(ii) Provision of comprehensive diagnostic/assessment and associated counselling:

(These services should be available to all developmentally disabled children and their families):

(iii) Provision of early intervention programmes (in consultation with the Education Department and the Department of Youth and Community Services to ensure a range of programmes are developed):

(iv) Provision of home support services (in consultation with the Department of Youth and Community Services. The Home-Care Service of N.S.W. and Local Government as appropriate):

(v) Development of small community residential units to rehouse residents from existing institutions:
(vi) Development of small community residential units for the severely disabled, particularly the severely intellectually handicapped, and others with severe physical conditions, both children and adults, who are unable to continue living with their families.

(vii) Provision of respite and shared care arrangements within these units.

(viii) Provision of specialised therapeutic services as required.

(ix) Access to general health services for the "routine" physical and mental health needs of the disabled.

This presupposes a strong commitment to progressively reduce the size and number of the existing institutions by decentralising, in the above manner, the services they provide. This process will be gradual and the institutions will continue to provide residential services, particularly for those who are unable to be maintained in the community with the present level of support services.

While there is evidence that increasing numbers of the less handicapped can be maintained in their own homes, if comprehensive assessment and adequate supports are available, the need for additional small community residential units for the adult disabled whose parents die or are physically frail is a growing problem.

Many of these people do not require the intensive staffing of a health-based service. This issue requires improved consultation between the relevant Departments, the Commonwealth and the non-government sector, to co-ordinate planning and funding for these services.
6. HOW ARE SERVICES BEST PROVIDED AND STRUCTURED TO MEET NEEDS?

6.1 Components of Service Delivery

There appear to be a series of critical stages in the life cycles of families of the developmentally disabled where critical service delivery issues emerge. These have been defined by McIntyre (1981) as:

(a) at the time of the child's birth or when it is identified as being disabled:

(b) at the time when the child is due to go to school for the first time:

(c) at the time when the adolescent completes his education:

(d) and finally, if the adult is still living at home, when the parent has to make a choice about his/her capacity to continue to care for the adult at home.

Increased advocacy for these clients through parent-based groups is placing greater emphasis on anticipating or planning for these stages rather than awaiting their occurrence. This is placing greater demands on government for the earlier provision of services to meet their need.

(i) Prevention

One outstanding achievement of modern technological health care is the development of procedures and knowledge which can assist in the ante-natal prevention and identification of some forms of severe disabling conditions. The availability of accessible high quality ante-natal care, genetic counselling and techniques such as amniocentesis are of major significance in
the lowering of risk and prevention of conditions which have permanent and life long impact on the individual and the family. It is important to make people more aware of these services and it is proposed that an amount of $200,000 be allocated in 1983/84 from the Hospitals Health Promotion Programme for a public education programme on the importance of ante-natal care and the availability of screening and genetic counselling services.

(ii) Diagnostic, Assessment and Community Support Services

The Inquiry has been impressed by the degree of consensus on the importance of comprehensive assessment, early intervention and home based care in the care of the developmentally disabled. It has also been impressed by the quality and comprehensiveness of services that can be provided by an adequately staffed assessment service particularly when linked with other service providers such as general practitioners.

The Inquiry considers that high priority in the provision of developmental disability services should be the expansion or provision of adequately staffed assessment teams in each Region, and that these services should be expanded first in the Western Metropolitan, Hunter and Central West Regions.

Access to these services is of paramount importance. The Inquiry is concerned that many families may not receive appropriate support and advice following the birth of a handicapped child.

Accordingly, the Inquiry proposes that the Health Department develop a policy to be implemented in all public hospitals to ensure that parents of all handicapped children identified at or soon after birth are automatically given access to counselling and assessment and early intervention services.
The evidence clearly indicates that with early support and counselling families can be supported to accept the handicap, to deal with their own guilt and grief, and to continue to care for their child with the availability of appropriate back-up support and respite care. The evidence available on the positive benefit for both child and family of this approach and the negative effects of early institutional care on the child's subsequent development clearly point to the need for formal and comprehensive assessment as early as possible and certainly prior to admission to residential care.

The Inquiry therefore considers that as soon as community teams are adequately established in every Region, admission to all Health Department residential services and ultimately all government services be filtered through such an assessment service. Funding and where appropriate licensing of non-government residential care facilities and nursing homes specialising in the care of the developmentally disabled should be conditional on their acceptance of a pre-admission assessment process.

In order to ensure that most effective use is made of available residential care, each Region should establish a Residential Placement Committee, involving service providers, to determine priorities for community residential places.

(iii) Early Intervention and Early Childhood Services

The importance of these services and the problems currently associated with their delivery were best summarised to the Inquiry in the Submission from the Catholic Archdiocese Advisory Committee on Handicapped Persons:
"Recent research evidence has shown that early intervention programmes can greatly reduce the developmental and learning deficits of high risk and disabled children. In Australia, the results of the Downs' Syndrome Programme carried out at Macquarie University have demonstrated that precise techniques and their early application raise previous expectations for Downs' children.

A significant point is that early intervention programmes give parents an opportunity to develop skills and confidence and allow them to receive support and hope. It is seen that the success of a programme is not measured only by the number of skills the child achieves but on the strengthening of the family unit.

In N.S.W. the Department of Health (Health Commission), the Education Department and the Department of Youth and Community Services have broad powers which enable them to provide services to young children with disabilities, but none has specific responsibility for an early intervention service. Historically the Health Commission through its Developmentally Disabled Team has the closest links with early intervention services for the developmentally disabled. However, its services - diagnosis, evaluation, treatment and support are unevenly distributed throughout the State - non-existent in some regions and adequate in none. Even where assessment is available, treatment services may be minimal."

"The demand for early intervention service far exceeds present provisions. In the Department of Health (Health Commission), present case loads for community nurses and therapists are heavy. Department of Youth and Community Services are unequally distributed. The Department of Education's provisions are insufficient- e.g. there is only one Special Education Consultant (pre school) to provide a special advisory service on a State wide basis, also, children can only enter Department of Education's regular pre-"
"school classes when they reach the chronological age of three years nine months by this time important needs could have been overlooked."

(Extracts from S 296: Catholic Archdiocese Advisory Committee on Handicapped Persons)

Similar problems exist in the provision of services for children of school age. As the above submission continued:

"Between the ages of four and five years when a child starts to attend school regularly, there is a need for continuing input from allied health professionals - occupational therapy, physiotherapy, speech therapy and nursing. As the Report Strategies and Initiatives for Special Education in N.S.W. states:

"It is claimed that only one-third of the children requiring therapy services are currently receiving it. This lack of services is said to be even worse in country regions. As an objective and accurate measure of the need for therapists is not available at this stage, it is felt that while there is certainly a considerable need for therapists in special schools and classes, an exact quantification of this need is not possible." (p. 165)

Several consequences follow from the lack of provision by the Health Commission of adequate therapy services:

- It means that some children are only at school part-time and are therefore denied full access to education.

- It may also mean that some children's mobility, independent living skills and communication skills are not being developed to their full potential."

(Extract from S296: Catholic Archdiocese Advisory Committee on Handicapped Persons).

The Commonwealth Government has also initiated some funding of these services, through a pilot project funded by the Department of Social Security, and the programme of special education for dis-advantaged children, funded through the Schools Commission.
The development of a co-ordinated programme for the phased expansion of these services has been beyond the scope of this Inquiry. The Inquiry considers that greater co-ordination of existing services and resources is required as a pre-requisite to the development of a specific coated plan. This issue should be addressed with some urgency by the co-ordinating mechanism discussed above.

In addition, the Inquiry anticipates that the decentralisation of residential care services and associated changes in staffing patterns will release some resources for the expansion of these services.

(iv) Residential Care Services

A primary focus of this Inquiry has been the appropriate and desirable mode of provision of residential care services for the developmentally disabled. On the basis of its investigations, and the submissions received, the Inquiry considers that there is widespread support for a movement towards care based in small, domestic-scale community residential units (housing between 5 and 10 people, usually in an ordinary house).

It is important to emphasise the other components of service delivery such as assessment and early intervention. However, much of the good work performed in these other areas will be nullified unless residential care services are improved and the emphasis changed from large-scale to small-scale accommodation, so that the most likely residential environment is no longer the large institution or the poor quality non-supportive private accommodation.

On the one hand, small-scale residential care has to be provided, on the other, as existing institutions are reduced in size and number, services within them have to be improved.
These issues are discussed in more detail below (see 6.2).

'(v) Activity and Work-Related Programmes

It has been strongly argued to the Inquiry that the Department of Health should upgrade and expand provisions for these services associated with the provision of community residential units. The main purposes of these facilities is defined by the Department of Social Security in its Activity Therapy Centre Handbook as "to develop the individual to the maximum of his potential, and in so doing assist in his greater independence and adjustment to living in the community."

Although the Health Department has provided various types of training and activity centres largely within Fifth Schedule hospitals the Inquiry as reservations about the continued provision of these services based on hospitals particularly as the focus of services changes to emphasis on community based provision of facilities. Further, the Department of Social Security through provision of funding to non government agencies and the administration of the Commonwealth Rehabilitation Service also has an important role to perform. There are a number of examples in Victoria and to a lesser extent New South Wales of joint Health and Social Security co-operation in this area and this should be more actively developed.

The normalisation process not only involves providing clients with community based residential services and supportive health and welfare back up but also access to day to day activities which enhance the individual's social skills by providing worthwhile activities from which personal satisfaction can be derived.
The Inquiry consider that there are a number of problems in the current arrangements:

There is insufficient diversity in the models available.

The traditional sheltered workshop is forced to be too product-oriented, rather than skill-development oriented:

There is insufficient liaison and co-ordination with the Department of Social Security on the co-operative development of these services and wider access to Commonwealth Rehabilitation Services.

It is inappropriate that work activities be located on the campus of hospitals - they should be community-based and accessible.

It is suggested that Regional and local management review the location of work oriented facilities and initiate their relocation to community-based premises; and further that the Department of Health consult with the Department of Social Security regarding the potential expansion of co-operative arrangements in this area.

6.2 Changing the Nature and Focus of Residential Care Services

(i) Community Residential Units

(a) Style of Provision

By their very nature, large hospitals are inappropriate venues for the care of this group. Even where the staff are actively seeking to implement an educational approach to care, the nature of the institution with its tendency to routine, and use of staff resources for daily living requirements such as
cooking and feeding, defeats them, and reinforces dependency. Although the Inquiry has been impressed at the level of staff commitment to a different approach, and the initiatives which several hospitals have taken to develop more "normal" living units within and outside the hospital campus, the Inquiry considers that the alternative model will only be realised through an active programme, resourced explicitly by government, and with active consultation with parents and staff.

Living in normal houses (community residential units) within the community facilitates the developmental/educational approach to the care of clients, in three ways. Firstly the environment of a small house is itself a learning experience in that the residents are exposed to a more "normal" living environment. Secondly residents learn from involvement in the everyday routine of home life with all its associated risks and benefits, and opportunities to interact both positively and negatively with people in their own group and with other children and adults in the surrounding neighbourhood and to participate in the activities of daily living of washing, dressing, cleaning, etc. Thirdly, structured programmes for living skills can more readily be based on particular individual needs.

The conventional wisdom in this area has been that only those with less severe functional limitations could be successfully accommodated in small community-based settings in terms of both their ability to care for themselves and their acceptance by the community. However the experience of re-housing programmes in Nebraska, Queensland and Victoria, and in New South Wales, at Marsden, Peat Island, and Hornsby-Kuring-gai has demonstrated that provided adequate staff support is available (and in some cases this may be 24-hour staffing - as intensive as hospital care) many of the severely and profoundly handicapped can be supported in this style of unit. More
importantly, in the experience of these agencies, the functional ability of these very handicapped people improves (in some cases dramatically) in the more normal environment.

Another aspect of conventional thinking has been to develop a series of graded living places within the institution through which residents move as they are trained.

It is now recognised as preferable that the residents should move to the place in which they will live for some time and that the staff levels should be adjusted to their needs as these needs change. The result is that the residents learn in the environment where they will use the knowledge, and the slow process of developing neighbourhood contacts and support is not disrupted. The key elements in this process were described by Dr. Michael Connolly, Medical Superintendent of Peat Island Hospital, in a Newsletter to the Parents Association, as

1. Careful selection on a range of criteria.
2. As much preparation as possible before the event.
3. Selection of a suitable site—taking into account things like closeness of transport, shops, work and recreation places.
4. Compatible grouping of residents — as much as possible by their own choice.
5. Adequate staff supervision.
6. Establishment of support systems, especially medical and social.
7. The greatest degree of flexibility in all the above, and with the clear understanding that should the system fail or should any individual be unhappy or uncomfortable in it (beyond solution) that the central support service will provide a back up (accommodation) where the whole project may be reconsidered.

Both parents and staff have real fears about this trend. The primary concern is that residents will fail in community-based settings because of lack of appropriate levels of support. This reinforces the view that the residents themselves are unable to cope in the community and should be in institutions,
rather than an acknowledgement that the system itself has failed its clients and the community.

The Inquiry is also conscious that there are some clients whose additional physical handicaps may require intensive and specialised care. However the Inquiry is of the view that the care of these groups would be enhanced in small decentralised units, although more intensive staffing and more specialised support may be required.

As a matter of principle, therefore, the Inquiry considers that in the long-term all care of the developmentally disabled should be based in small decentralised units preferably in the form of individual houses (with varying levels of staffing depending on the level of disability).

In each Region a network of community residential units each accommodating 5-10 people should be established to provide both short (including respite) and long term residential care and social and living skills training for developmentally disabled people.

(b) Catering for Varying Levels of Disability

The need to provide an adequate supply of residential care units has two dimensions. Firstly, the Health Department must accept responsibility to make appropriate arrangements for the continuing care of those who inappropriately and because of lack of other alternatives have been placed in health care institutions.

Secondly, there are a number of developmentally disabled children and adults currently living in their own homes who need either short-term or long-term placement. The age distribution of these clients also indicates the growing problem of the older handicapped person whose family have managed to maintain them and are now unable to continue due
to their own ageing. It seems likely that this pattern will continue and increase as increasing levels of support enable longer periods of home and family care.

The differing levels of need of clients within community residential services has been described by the Mental Retardation Division of the Health Commission of Victoria as follows:

"Children requiring maximum assistance.

Residents will be children up to the age of 16 years who are severely profoundly intellectually handicapped and/or severely physically disabled. Some of these children may also suffer from sensory impairments such as blindness or deafness. Most of these children will be non ambulant, although a few may be frail ambulant. These children will require total assistance from staff to identify and meet their needs. They will require extensive physical care and direct assistance with all activities of daily living. They will require intensive stimulation and assistance with their general development, with particular regard to motor, self help, social and emotional development. These children will attend day programmes that provide specialist services for multiply handicapped children."

"Children requiring moderate assistance.

Residents will be children up to the age of 16 years who are intellectually handicapped, but who do not suffer from severe physical or sensory disabilities. These children will require direction and assistance in all activities of daily living and they will be dependent upon staff to identify their individual learning needs and provide experiences which will enable each child to develop his physical, intellectual and social capabilities. These children will attend Day Centres or Special Developmental Schools and they will participate in all
domestic and family activities within their home. Participation will be dependent on staff skills as the children will generally have a low level of self-motivated activity. Some children may have behavioural disturbances requiring a high level of staff supervision."

"Children requiring minimal assistance.

Residents will be children up to the age of 16 years who are intellectually handicapped. The children will require direction and supervision in daily living activities. Generally, the children will be able to initiate play and participate in the household with supervision from staff rather than direct assistance. The children will be attending an educational facility during the day. Behavioural problems may require a high level of staff supervision."

"Adults requiring maximum assistance.

Residents will be adults who are severely or profoundly intellectually handicapped and who may be severely physically disabled. These residents will usually be non ambulant, although a few may have limited movement using some form of assistance. Standard and individually designed wheelchairs will be required for mobility, however some residents will be unable to sit and will require a trolley for movement between bedroom and bathroom. These adults will require total assistance from staff to identify and meet their needs. They will require extensive physical care with particular regard to maintenance of muscle tone and motor ability. They will require direct assistance with all activities of daily living and opportunities to develop social and emotional maturity and enjoy a personally satisfying life. These adults will attend day programmes that provide specialist services for multiply handicapped adults."
"Adults requiring moderate assistance.

Residents will be adults who are mildly or moderately intellectually handicapped and who may be physically disabled. These people will usually be able to move independently with the use of wheelchairs or other aids, however, a few may rely on staff for assistance. These residents will be independent or semi-independent in most self help skills. They will participate in domestic activities with assistance or direction with certain tasks. These adults will require some assistance with physical care, particularly with regard to maintenance of muscle tone and motor ability. They will attend adult activity programmes, with support from specialist services for physically disabled persons. Behaviourally disturbed residents will require a high level of staff supervision."

"Adults requiring minimal assistance.

Residents will be adults who are not physically handicapped: however, the degree of their intellectual disability limits their potential for independent living."

"These adults will be semi-independent in most self help skills. They will participate in all domestic activities, although direction and assistance may be required with certain tasks. They will be dependent upon staff to provide experiences that will enable each resident to develop skills in all aspects of daily living and to live a personally satisfying life. These people will attend adult activity programmes, with support from other services."

"Adults requiring minimal assistance.

Residents will be adults who are not physically handicapped: however, the degree of their intellectual disability limits their potential for independent living. These adults will be semi-
independent in most self help skills. They will participate in all domestic activities, although direction and assistance may be required with certain tasks. They will be dependent upon staff to provide experiences that will enable each resident to develop skills in all aspects of daily living and to live a personally satisfying life. These people will attend adult activity programmes, with support from other services."

"Adults requiring limited assistance.

Residents will be adults who have potential for living independently in the community, or with minimal assistance.

These adults will be competent or nearing competence in most routine aspects of daily living. However, they may require support or opportunities to further develop their skills in the most complex areas of daily life, such as, human relations, decision making and legal matters. These adults may work in sheltered or open employment or they may be unemployed."

(Extract from "Staffing Patterns for Community Residential Units", Health Commission of Victoria 1982).

It should be emphasised that community residential units are one model of community care.

The Inquiry considers that every effort should be made to develop a range of models of community residential services, for example, fostering and permanent part-time arrangements.

In addition, the Inquiry is aware that special residential arrangements will be needed to cater for clients with additional or special needs, for example, those with severe behavioural disturbance or specialised physical needs. One area of special need drawn to the Inquiry's attention is that of developmentally disabled women who have young children and require particular support to provide a stable and nurturing environment for themselves and their
children. The needs of this group were the subject of a submission from the "Women in Limbo" Group, which includes representatives of the Women's Refuges, and were reinforced by staff in community services.

In order to encourage development of innovative models of residential care and/or special services for groups with special needs, the Inquiry proposes that a fund be established for this purpose.

(c) Auspice and Funding

Community residential services for the developmentally disabled are currently provided by both government and non-government agencies. The Inquiry saw good examples of both, and considers that auspice in itself is irrelevant, provided that there is adequate accountability for standards, that there is effective involvement of residents and families in management, and that the residential care service is adequately linked to a network of other services.

Resources for the provision of residential services are currently provided by Commonwealth funding of non-government organisations and by State funding through hospital budgets. A major issue in this area is the appropriate role and coordination of Commonwealth and State funding.

The Department of Social Security provides subsidies to non-government organisations for capital ($4 for $1) and operating costs (50%) associated with residential facilities under the Handicapped Persons' Assistance Programmes. The capacity also exists for capital funding under the Aged and Disabled Persons' Homes Act (although funding under this programme has primarily been directed to the care of the aged).
The requirement to raise one-fifth of the capital and one-half of the operating costs places great pressure on the non-government organisations working in this field which tend to be small and less able than large charities to raise funds or carry costs (although operating costs are to some extent met by fees and the Handicapped Children’s Benefit). In addition, the fact that the majority of the voluntary organisations are primarily composed of parents not only places an additional and many would argue unjust, financial burden on those who are already handicapped, but can also lead to restrictive and isolationist eligibility policies on the part of these agencies.

Several of the parent-based organisations commented to the Inquiry that they no longer saw it as socially appropriate for them to provide direct services. At the same time, there is some evidence that other (i.e. not parent-based) voluntary organisations are interested in expanding their work in this field, provided that a more adequate funding arrangement can be developed.

An example is the work of the Association for the Assistance of Intellectually and Socially Handicapped Persons. The Association is a charitable organisation operating in the western suburbs whose objectives are to provide community based accommodation for developmentally disabled adults. Over the last six years the Association has provided accommodation for 100 handicapped people, the majority of whom have moved on to totally independent living. This arrangement has primarily provided for the mildly handicapped clients who had been resident in Rydalmere Hospital and who could be accommodated without live-in supervision and with the provision of "drop in" support from the staff at Rydalmere. Towards the end of 1981 the Association in co-operation with the community services staff at Rydalmere started to develop a programme to provide
accommodation with more support which could cater for the moderately and severely handicapped adults. The Inquiry considers that this type of approach should be further facilitated.

In Victoria a programme has been established whereby the accommodation services are managed by community management committees under the "Community Residential Unit Programme" in which they are fully funded by the State Government for the capital and operating costs of providing community residential services for the developmentally disabled. The Victorian Government has established approximately 35 houses in this way.

Related to this arrangement, it is understood that the Department of Social Security in Victoria primarily directs funding under the Handicapped Persons’ Assistance Programme to the provision of activity therapy centres and work programmes.

The Inquiry proposes that the Department of Health establish a fund for the provision of community residential services. These funds should be allocated to the high priority Regions as discussed below. The funds may be used for direct provision by the Department or in contract with an appropriate non-government agency.

The State government should also negotiate with the Commonwealth government regarding future arrangements for co-operative funding of these services.

Accordingly it is proposed to recommend:-

That from 1983/84, specific purpose funds (up to $2 million) be allocated to Regions to assist in the development of community residential units to house residents currently resident in institutions and those at home urgently in need of placement.
Priority for the funding of such units should go to the Hunter, Western Metropolitan, Southern Metropolitan, and Northern Metropolitan Regions.

That initially these services be funded from the total hospital budget: and that from 1984/85 resources for this purpose be augmented from savings to be achieved through reductions in the size and number of existing institutions, as specified in Section 8.

Further, it is suggested that the Minister for Health, in consultation with the Minister for Youth and Community Services, negotiate with the Minister for Social Security to establish a mechanism to improve co-ordination of planning and service delivery and to develop proposals for joint Commonwealth/State funding of these services.

Another source of accommodation is the New South Wales Housing Commission which has in recent years amended and broadened its policies in relation to the housing of disabled people and has indicated that it now recognises that it is appropriate to provide some accommodation for this client group within new and existing housing estates. The Housing Commission has indicated that it would be prepared to provide accommodation for clients under certain conditions and this arrangement could be developed either directly between the two departments or with the co-operation of non-government community groups.

It is proposed that the Minister for Health negotiate an arrangement with the Minister for Housing whereby a proportion of welfare housing stock in existing and proposed developments is specifically made available as community residential units for developmentally disabled people.
(ii) Existing Institutions

It must be appreciated that the transition towards a fully decentralised community-based model of residential care will take some years to implement, and that initial expenditure will be required to develop some of the alternatives in order to reduce the size of the institutions and achieve savings which will enable further expansion of the alternatives. During this transition period, a proportion of those in need of residential care will continue to be placed in specialised hospitals.

The Inquiry considers that a number of management and service changes are essential to improve the quality of care in these facilities. The management changes are discussed below and include the separation of services for the developmentally disabled from the services for the psychiatrically ill.

The Inquiry is concerned that owing to staffing levels, the range of skills involved and the line management arrangements, the educational focus is not sufficiently strong within these facilities. As one submission from an individual staff member asked rhetorically:

"The category of "Programme Officers" was introduced to these hospitals to instil a programming and training emphasis for the clients.

"The Programme Officer position is one of responsibility for "programmes" but no authority for implementation.

1. Why pay someone $21,000 p.a. if they cannot improve the quality of life for the client?

2. Why run a special Health Commission course of 8 months duration, when the Programme Officer has to come and convince a 1st Year Nurse to accept a programme for a resident?

3. Why run activities when the clients don't have the opportunity to attend because staff are not made accountable for the quality of care they provide."

(Extract from Submission S.91: Nurse)
The Inquiry considers that direct-care ward or unit-based staff should be made responsible to the programme personnel (Programme Officers, Psychologists etc.) for the implementation of educational programmes within the ward. It therefore proposes that within existing hospitals emphasis in client care be placed on implementation of independent living training programmes. These programmes should be developed and monitored by programme staff to whom staff in individual wards would be responsible for programme maintenance and achievement.

The Inquiry recognises that mental retardation nurses have a strong behavioural/educational component in their training, and that many of them are enthusiastic about this aspect of their work. However, as a result of perceived inadequacies in staffing levels, the day-to-day physical care of residents becomes paramount. As discussed below, the Inquiry recommends that the staff category of Mental Retardation Nurse be gradually replaced by a mixture of Residential Care Assistants (a new category of direct care worker) and Programme Officers (to provide the educational/programme component). The Inquiry also considers that the ratio of direct care staff in the care of severely handicapped and multiply handicapped residents at Stockton Hospital should be gradually increased as resident numbers decrease.

The Inquiry has also been concerned that some hospitals (particularly Stockton, Morisset, Kenmore and Bloomfield) are inadequately staffed with social workers, psychologists and occupational therapists. Not only are these perspectives essential in a comprehensive assessment process, but they are also vital to the implementation of a developmental, family-oriented programme approach with these residents. The Inquiry appreciates the recruitment difficulties of these hospitals, but considers that the Department could facilitate access to these skills through a formal contractual arrangement between hospitals and between Regions. The development of such arrangements should be expedited as a matter of urgency.
7. HOW ARE RESOURCES BEST STRUCTURED TO PROVIDE SERVICES

7.1 Staffing

As indicated above there is widespread agreement that the care of the developmentally disabled should be based on an educational and developmental approach which aims to maximise the independent living skills of the client. Health services have been and continue to be criticised for an approach which is seen to emphasise care and maintenance rather than education.

It is clear that the staff who are involved in the provision of services for children and adults who are developmentally disabled need to have a strong skill-development orientation - they need to see the clients as people who can learn and change and be prepared to structure their own behaviour to take every opportunity to teach the client the skill rather than to do things for the client. It has been argued that nurses are less likely to be able to take this approach because their orientation has traditionally been towards support, care and protection rather than education and risk taking.

On the other hand, the syllabus for mental retardation nursing does provide some opportunity for nurses to learn these skills and it can be argued that it is the environment of the institutions which limits and conditions the ability of staff to operate in this way because they are working with so many highly dependent individuals and do not have time or adequate staff support to adopt a different approach.

The Inquiry considers that, while the training of mental retardation nurses may have an educational/behavioural perspective, it is inappropriate per se, for the developmentally disabled, particularly those living in community residential units, to be cared for by a staff category identified as "nurses". The concept of nursing held
by the general community will continue (and appropriately so) to emphasise care, treatment and support rather than the desired developmental function.

The Inquiry considers that care of the developmentally disabled requires two distinct but related sets of skills.

The direct care both in community residential units and in hospital settings requires a high level of consistency and continuity with staff who have skills in:-

- providing a physically and emotionally secure environment and promoting physical, emotional, social and intellectual development.

- sharing the responsibility for life decisions with natural families and/or the adult resident.

- assessing, with assistance, the need for skill development and maximizing naturally occurring opportunities in the home to develop these skills.

- caring for the residents' normal health needs, providing basic first aid treatment in emergencies and providing home care in the case of influenza and such illnesses.

- working in conjunction with other direct care staff and the multi-disciplinary regional team to assist in the planning, development and implementation of individual programme plans designed to develop the residents' skills in daily living.

As well as implementing specific skill programmes, the direct care staff will have a general "household management" function, which will require them to demonstrate and undertake normal household tasks in conjunction with the residents. These would not normally be classified as "nursing duties."
The Inquiry proposes that a new category of staff be developed for this purpose; an appropriate title would be "Residential Care Assistant". The advantages of such a position would be the ability to provide continuity of unit and ward-based staff, with an appropriate mix of nurturing and developmental functions.

To meet the different levels of care required by clients two shift patterns would be necessary within the category of Residential Care Assistant - a 24 hour shift (similar to the existing Houseparent category) and an 8 hour shift (similar to Child Care Workers or Enrolled Aides).

The Inquiry considers that there are many currently unqualified staff in the existing hospitals who have the capacity to develop these skills with appropriate training.

The training of the Residential Care Assistant should be structured as an apprentice-type programme, with day release for course attendance. The training would be appropriately located in the Department of Technical and Further Education. The skills required have some elements in common with the existing Child Care Certificate course in T.A.F.E. and some elements of this programme could be incorporated, while recognising that the Residential Care Assistant will be expected to care for either children or adults.

Entry to this programme should be on the basis of either school certificate or mature-age entry. Mature age entry should be encouraged to attract staff in existing institutions who may not have educational prerequisites but have the desired personal skills and empathy.

The second level of skills required are in some aspects similar to those of current Programme Officers/Training Officers within the existing institutions. Within the current arrangements, these people are nurses who complete an in-service training programme.
The functions required to be performed at this more senior level are:

development of appropriate educational programmes for residents in consultation with direct care staff, and psychologists and occupational therapists on the regional team.

monitoring and evaluation of their implementation:

participation in multi-disciplinary assessment of new clients and their families, and the development of appropriate management programmes:

provision of supervision and support for direct care workers in community units and existing hospitals.

The Inquiry proposes that the employment of Programme Officers be expanded, as a major staff category in community developmental disability teams and in specialised hospitals. The salary should be the equivalent of the range for Charge, er Senior Charge Nurse. It will be necessary to incorporate this classification into the Public Hospital awards.

However, the education of Programme Officers should be upgraded to increase the theoretical content and level of skill commensurate with the broad range of functions required.

This programme would appropriately be developed at C.A.E. level, either as an undergraduate or post-graduate programme, open to people from a range of disciplines. It is essential that the programme be structured in such a way to ensure access to the course for current mental retardation nurses, who will provide the major work-force in this area, and already have a grounding in these skills.
Within the existing hospitals, these classifications of Residential Care Assistant and Programme Officers should be used in re-staffing hospitals during the transfer of nursing education to the education sector.

In the longer-term where nursing care is required for the developmentally disabled this should be provided by the comprehensively-trained single register nurse, whose training should include a strong behavioural/social perspective, a theoretical understanding of normal and delayed development, and an appreciation of the importance of an educational/developmental perspective in the care of the developmentally disabled.

7.2 Organisation and Management

The major organisational issue raised in submissions to the Inquiry was the need for increased co-ordination and advocacy at State government level, in the form of a central co-ordination mechanism. This has been discussed previously.

The Inquiry also considers that a number of parallel changes are required in the organisation and management of health-based resources for the developmentally disabled, to improve the advocacy for this group within the health services and to more effectively reflect the principles enunciated above.

The first and over-riding change proposed is the movement of services currently provided within State-run specialised hospitals and community health services away from direct management by the Department of Health to a decentralised form of management through community-based Boards of Directors. The rationale for this proposal is discussed in detail in Part 1 of the Report, but can be summarised here as:
The negative social and psychological effects on clients and staff of a separate, isolated, stigmatised, system of care:

The lack of community-based advocacy for these clients:

The inappropriateness of centralised constraints on this area of human services:

Problems in continuity of care in a fragmented system:

Inadequacies of staff training in an isolated system.

The objectives of such a proposal are to integrate services and increase management's ability to use resources flexibly between different service components, and to improve the opportunity for continuity of care and training opportunities.

In addition, the resources available for these services are very limited and will continue to be for some time. Consequently regional management is appropriate to ensure that resources are co-ordinated and effectively utilised. As services develop it may be appropriate to decentralise management to the local level through local hospitals boards.

The Inquiry does not consider that it is appropriate to establish separate Boards for the existing developmental disability hospitals, as this may create a climate which tends to reinforce the status quo, rather than actively seeks to redistribute the staff and resources into alternative community-based services.
The care of the developmentally disabled (unlike mental health services) is distinctly different from mainstream acute health services, in that the focus is life-long and educational. This distinction and the need for close collaboration with other agencies and departments can best be reflected in a distinct management structure with broad representation from the various interest groups.

It is therefore proposed that at the appropriate level (Regional or supra-Regional), a Board of Directors be established with the responsibility for the management of all services within the health administration for the developmentally disabled, both residential and non-residential. The Board would be community-based, including representatives of parent and voluntary groups, and should establish advisory mechanisms to include representatives of the other relevant government departments. These services would be managed by a Chief Executive Officer responsible to the Board.

The Inquiry is aware that in some areas of the State, the provision of developmental disability services has already been linked to existing general public hospital Boards. This has happened in Hornsby-Kuring-gai (where the Board has an area responsibility), Wollongong, Kogarah, Albury and Armidale. The Inquiry visited the Hornsby-Kuring-gai, Kogarah and Wollongong services and was impressed by them. Clearly, management arrangements need to be flexible to suit local needs and capabilities, and it may well be appropriate to expand such local arrangements, particularly as Area Boards are developed.

Priority should be given to the development of Regional Management Boards in the Regions serviced by existing institutions, that is, Southern Metropolitan, Western Metropolitan, Northern Metropolitan, Hunter, Central West and South-East Regions. It may also be appropriate to link some Regions together for this purpose.
Appropriate contractual arrangements will need to be negotiated between the Regional Board and general hospital boards providing these services within that Region, or Area Boards as they develop. Each Regional Board must be given detailed responsibilities and specific timetabled goals to be achieved. These would include:

- Development and implementation of a detailed programme for the re-housing of residents of the institutions.
- Development of staff training programmes.
- Liaison with other government Departments and agencies for additional community support services.
- Development of feasible proposals for the alternate use of institutional land and buildings.
- Full consultation with parents and staff on all these matters.

As new services are developed, and the existing institutions rationalised, priority must be given to the removal of residential developmental disability services from the campus of psychiatric hospitals. Throughout the Inquiry concern was expressed at the inappropriateness of this juxtaposition of services, and the negative effects of this for residents and their families, particularly through the association of the two conditions in the eyes of the general public.

In this transition period, which will clearly be of some years duration, steps should be taken to separate the services as much as possible, through the establishment of a separate management structure in hospitals, to be responsible to the Regional Chief Executive Officer and Board (discussed above) and by the physical separation of facilities as far as
possible. The developmental disability services in these hospitals should be degazetted in the terms of the Mental Health Act, when the new Act is introduced, and this should be clearly promulgated.

Accordingly, it is proposed that care of the developmentally disabled in specialised hospital settings should be separated from the care of the psychiatrically ill by the establishment of distinct management organisations, responsible to the Regional Boards and by the degazettal and physical separation of services.

The appointment of Regional Boards should provide a strong basis for improved advocacy at Regional level and an appropriate professional officer should act in an advisory capacity to the Board.

Within the Central Administration of the Department it is essential that some well-defined mechanism exists to represent the needs of this client group. The area in which current arrangements in the Central Administration is most deficient, in the view of the Inquiry, is the active involvement of client advocates in the budgetary process, both capital and operating.

It is suggested that the role of the Senior Specialist (Developmental Disability Services) in the Central Administration of the Health Department should be strengthened by involving him or her to a greater extent in budget decisions affecting provision of services.

7.3 Funding Priorities

The Inquiry's assessment of resources required in this area of service delivery has had regard to the following factors:
(a) review of current expenditure (primarily in the Fifth Schedule Hospitals):

(b) assessment of the size and nature of the demand for services:

(c) assessment of the costs involved in providing an appropriate range of services:

(d) determination of priorities:

(e) assessment of the capacity for and potential pace of redistribution:

(f) consideration of additional or alternative funding methods.

The principles on which the Inquiry believes services should be based, as discussed above, are:

that as far as possible all care should be provided in small units of 5-10 places, even for the severely and profoundly handicapped:

that as far as possible residents should not be moved from unit to unit as their needs change: staffing levels should be adjusted appropriately.

The development of proposals for funding has been based on the following assumptions:

(a) that services should be developed as a network, with strong organisational links between the various service components, rather than isolated units:
(b) that Regional and sub-regional community developmental disability teams will have responsibilities for the assessment of new clients, family support and for programmes and activities for clients living at home and in residential care.

(c) that staffing levels in residential units will range from minimal supervision to intensive 24-hour staffing:

(d) that as far as possible school and day programmes should be separated from accommodation, in the interests of normalisation.

The Inquiry has argued that the two prime operational principles should be:

(i) fund and/or provide services which maintain clients in their normal living environment: and

(ii) progressively reduce the size and number of existing Fifth Schedule Hospitals by decentralising the services they provide.

The competing priorities in the care of the developmentally disabled would appear to be:

- the improvement of the level of care within the existing hospitals, by increasing the ratio of direct care staff and programme staff to residents and upgrading physical facilities.

- establishment of community teams and residential units:

- the re-housing of existing residents:

- the housing of clients on waiting lists.
In the current economic climate, with government's seeking to reduce expenditure in all areas, any new initiatives or programmes must be funded within existing resources, that is, by a re-organisation of priorities and redistribution from other service areas.

Within the framework of current health expenditure on the developmentally disabled there is clearly capacity for redistribution of existing resources, given the level of consensus that both residents and staff in Fifth Schedule Hospitals for the developmentally disabled would be more appropriately located in small decentralised community units. In some hospitals, a gradual programme of relocation of services into community settings is already underway.

The capacity for redistribution both within and between Regions is constrained however by the prior need to develop the alternatives which will make it possible to reduce the size of the institutions with minimal disruption to residents, families and staff. Genuine efforts to deinstitutionalise services must be preceded by the planning and development of community services and adequate links must exist not only within health services but also to other welfare services. The initial investment required for this development must be specifically allocated for this purpose and the Inquiry has recommended in Part 1 that an amount be drawn from the hospital system as a whole, including acute general hospitals and the Fifth Schedule Hospitals, for the "seeding" of these new services over the next three years.

The initial investment should be clearly targeted to services and facilities which will explicitly facilitate the reduction in the size of the existing institutions. Resources thus freed would provide the impetus for the on-going expansion of community-based services.
This will also mean that some priority must be given to the re-housing of residents currently in institutions, over the needs for placement of those on waiting lists, or newly-identified clients. Balance must be achieved between the two objectives. The provision of a proportion of respite care places within the residential units will assist to ease the burden on families. These decisions should be made on a local consultative basis by a Regional Placement Committee, as recommended.

The Inquiry's clear preference is for overall priority to be given to the development of alternative community-based services. Within this objective, priority should be given to the development of services which can directly facilitate the reduction in the size of the institutions. In the short-term this will mean initial investment in the metropolitan and Hunter Regions. The urgently needed services in the country Regions must be financed out of savings achieved as the institutions are reduced.

The choices however are not always clear and the pace at which, for example, the process of re-housing can occur will be dependent on both the resources to establish the alternative services and the level of preparation of residents within the institutions. Therefore while it may be necessary to improve the level of programme staff (both programme officers and psychologists) in the existing hospitals, these staff should preferably be attached to a community service, to ensure that the clear orientation of their activities is toward the goal of deinstitutionalisation.
7.4 Legislation

The former Mental Health Act provided for protection and guardianship arrangements for developmentally disabled people who were unable to handle their own affairs and were without parents or guardians. It was rightly considered inappropriate for such people to be required to be declared "mentally ill" to receive this protection, and consequently this arrangement has been removed from the new Mental Health Bill.

A legal arrangement is now needed to provide for the protection and guardianship of such people, without stigma or institutional admission being required.

The Inquiry recommends that the Minister for Health consult with the Attorney-General regarding appropriate legislation for this purpose.
8. IMPLEMENTATION TIMETABLE

8.1 Development of Community Services

(a) Community Developmental Disability Team

The major priority component to be funded is the provision of community based multi disciplinary teams which will prevent unnecessary future admission to institutions by providing effective assessment and early intervention to facilitate the process of rehousing from the institutions by providing support services to the community residential units.

Incentive funding totalling $1.5m per annum over the next three years is necessary to commence to stimulate provision of these teams (or to supplement existing teams). This will focus on regions with institutions with some provision for other regions with little or no existing services of this kind. In those regions with institutions, funding for additional services would be provided on a tapered grant basis with full funding in the first year and reduced funding in second and subsequent years as staff resources are transferred from the existing hospitals. After the third year services would be fully funded from savings from institutions.

Those regions without institutions would be funded during the first three years after which funding would come either from savings from institutional reductions in other regions or from savings in other services within the "non institutional" regions.

These multi-disciplinary teams operate at two levels. At Regional or sub-regional level (200,000 - 250,000 population). The team has the functions of:
comprehensive assessment of all new clients.

provision of early intervention programmes

development of educational programmes for clients in residential care

responsibility for admission to all residential care and programmes

liaison with other Departments and non-government organisations.

To undertake this diversity of functions the following professional categories should either be included in or available to these teams:

- Psychologist
- Social Worker
- Programme Officer
- Medical Practitioner
- Occupational Therapist
- Physiotherapist
- Speech Pathologist

It may be efficient and appropriate to obtain the medical and physiotherapy skills on a sessional basis from hospitals or the private sector. When costed on the basis of equivalent full-time position (7 professional staff plus support staff) the estimated cost is $220,000 per annum.

At local or area level (60,000-80,000 population), the Inquiry supports the concept of two-person teams, located in community health centres, to provide individual client and family support, supervision and support of the residential care programme in that area, and liaison with other departments, and agencies. Appropriate composition would be a Programme Officer and a Social Worker.

The estimate cost of such a team is $50,000 per annum.
Incentive Funding Priorities for the Resourcing of "Regional" and "Local" Community Developmental Disability Teams

<table>
<thead>
<tr>
<th>1983/84 Regions</th>
<th>Target Allocation Staff Numbers</th>
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<tbody>
<tr>
<td></td>
<td>Western Metropolitan Region</td>
</tr>
<tr>
<td></td>
<td>6 local teams</td>
</tr>
<tr>
<td></td>
<td>1 sub-regional team</td>
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<tr>
<td></td>
<td>Hunter</td>
</tr>
<tr>
<td></td>
<td>6 local teams</td>
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<tr>
<td></td>
<td>1 sub-regional team</td>
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<tr>
<td></td>
<td>South-East</td>
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<tr>
<td></td>
<td>1 regional team</td>
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<tr>
<td></td>
<td>Central West</td>
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<tr>
<td></td>
<td>1 regional team</td>
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<tr>
<th>1984/85 Recurrent expenditure</th>
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</thead>
<tbody>
<tr>
<td>Western Metropolitan</td>
</tr>
<tr>
<td>1 sub-regional team</td>
</tr>
<tr>
<td>Hunter</td>
</tr>
<tr>
<td>1 sub-regional team</td>
</tr>
<tr>
<td>South-East</td>
</tr>
<tr>
<td>1 regional team</td>
</tr>
<tr>
<td>Central West</td>
</tr>
<tr>
<td>1 regional team</td>
</tr>
</tbody>
</table>
1984/85 New Expenditure

South-West
Target 9.5
Allocation $220,000

Orana & Far West
Target 9.5
Allocation $220,000

Total

1985/86 Recurrent Expenditure

Western Metropolitan
1 sub-regional team
Target 9.5
Allocation $220,000

Hunter
1 sub-regional team
Target 9.5
Allocation $220,000

South-West
Target 9.5
Allocation $220,000

Orana & Far West
Target 9.5
Allocation $220,000

New Expenditure

North Coast Region
Target 9.5
Allocation $220,000

New England Region
Target 9.5
Allocation $220,000

Total

$1,320,000
(b) Residential Services

In order to obtain some indicative levels of costs the Inquiry has examined the components of service in a range of models operating in Victoria, South Australia and New South Wales providing residential services. The key variation in cost is the staffing factor which depends on the ultimate capacity of residents to live with varying degrees of resident supervision.

The broad range of levels of supervision and the associated costs of the model preferred by the Inquiry are listed on the next page. These are based on the Victorian Health Commission guidelines.

The costs only reflect expenses incurred in managing the community residential units and do not include the costs of support and programme staff which are provided for in the "local" community developmental disability teams. As the teams will undertake a variety of roles including assessment, family support it is not possible to apportion the costs of services to community residential units from the total costs of these teams.

The Inquiry considers that to stimulate the provision of community based services and to reduce the number of beds within the large institutions a feasible target would be to create around 500 "community placements" per annum (i.e. 100 community residential units each with 5 or 6 residents). This can be achieved by funding the equivalent cost of actually establishing and running these units (i.e. rental of houses, power, light, food etc.) with costs of staffing being largely met by transfer of staff of staff resources from the institutions. It is estimated that the cost of this programme to achieve 500 places per annum would be approximately $2m per annum.
Indicative Gross operating costs Per Community Residential unit (per annum)

(To House 5 to 6 residents)

<table>
<thead>
<tr>
<th>Independent Living</th>
<th>Minimum Live In Supervision</th>
<th>Medium Live In Supervision</th>
<th>Maximum Live In Supervision</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3.6 staff F.T.E.</td>
<td>4.8 staff F.T.E.</td>
<td>6.8 staff F.T.E.</td>
</tr>
</tbody>
</table>

1. Staff Costs
   - $57,400
   - $76,000
   - $106,900
   - $00,100

2. Other Operating Costs
   - $14,400
   - $19,000
   - $26,700
   - $X>,000

3. Total Gross Operating Costs
   - $71,800
   - $95,000
   - $133,600
   - $100,000

* Gross operating costs will be reduced marginally by client contributions for "hotel" services.

Note: Additional staffing of 0.33 F.T.E. per house is required as "contingency" for intensive care of behaviourally disturbed residents.
As indicated elsewhere, to facilitate the process of releasing staff resources from the institutions it will be necessary to give priority to those regions in which institutional services exist. Further as also already pointed out the full extent of savings from reductions in these institutions cannot be realised unless "whole units" are closed (for example proposed closure of Peat Island by 1984 and Gladesville - north side by 1986- see below). The desired approach therefore, is to achieve this end and proposals have been structured accordingly, while still attempting to meet needs in some of those regions where services are most deficient.

The proposals tabulated below provide for incentive funding of these services on the basis of achieving the target of around 500 new placements per annum.

The mechanism proposed is that for example, in the first year, in Western Metropolitan Region $460,000 for equivalent non-salary operating costs would be allocated to establish 115 placements, with staff resources necessary to support these facilities being transferred from the institutions along with the clients so placed. In the second year the equivalent operating costs for the initial 115 placements would be met from savings in operating costs within the institutions and not from a special allocation. At the same time a further special earmarked allocation for an additional 125 placements would be made on the same basis as in the first year. A similar arrangement would occur in the third year. After the third year all services would be fully funded from savings achieved from reductions in institutional care.

In those Regions without institutions recurrent funding equivalent to both non-staff and staff operating costs will be necessary as they have no local potential to extract resources. It is envisaged that the regions with institutions will be expected to achieve additional savings to provide for growth
in demand in their own region and for services in other regions, commencing in 1984/85 when realised savings from the complete closure of Peat Island Hospital would contribute towards services in Illawarra, Orana and Far West and North Coast regions. The opportunity to apply savings across regions resulting from reductions in institutional care needs to be monitored as the process continues so that as savings are realised they can be translated immediately into alternative services in the regions where they are most needed.

It is estimated that the savings from the closure of Peat Island, after relocation of staff resources and operating costs necessary to rehouse existing residents, will be of the order of $500,000 - $900,000 per annum. This will be used in subsequent years to partially fund the development of community residential units in other Regions.

On the basis of the current staff: resident ratios in the specialised "mental retardation" hospitals, and average staff costs in these hospitals, in comparison with the proposed ratios in community residential units, and the reduced staff costs associated with the new category of staff, the Inquiry estimates that the transfer to community residential units will release additional resources for the expansion of community teams, as recommended below. This process will clearly require careful management to ensure that services within the hospitals are organised to maximise transfer of resources.
### DEVELOPMENTAL DISABILITY INCENTIVE FUNDING PRIORITIES FOR 
**ESTABLISHMENT OF COMMUNITY RESIDENTIAL UNITS**

<table>
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<tr>
<th>1983/84</th>
<th>Region</th>
<th>Target</th>
<th>Allocation</th>
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<tbody>
<tr>
<td>1</td>
<td>Western Metropolitan Region</td>
<td>115 places</td>
<td>$460,000</td>
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<tr>
<td></td>
<td>(non-salary costs equivalent)</td>
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<tr>
<td>2</td>
<td>Hunter Region</td>
<td>115 places</td>
<td>$460,000</td>
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<tr>
<td></td>
<td>(non-salary costs equivalent)</td>
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<tr>
<td>3</td>
<td>Northern Metropolitan Region</td>
<td>150 places</td>
<td>$600,000</td>
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<td>(non-salary costs equivalent)</td>
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<td>Hospital)</td>
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<tr>
<td>4</td>
<td>Southern Metropolitan Region</td>
<td>SO places</td>
<td>$200,000</td>
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<tr>
<td></td>
<td>(non-salary costs equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>South-East Region</td>
<td>12 places</td>
<td>$40,000</td>
</tr>
<tr>
<td></td>
<td>(non-salary costs equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Central West Region</td>
<td>12 places</td>
<td>$40,000</td>
</tr>
<tr>
<td></td>
<td>(non-salary costs equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>North Coast Region</td>
<td>12 places</td>
<td>$200,000</td>
</tr>
<tr>
<td></td>
<td>(full operating costs)</td>
<td></td>
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</tr>
</tbody>
</table>

466 places $2,000,000
### 1984/85 New Expenditure Target Allocation

<table>
<thead>
<tr>
<th>Region</th>
<th>Target Places</th>
<th>Allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Metropolitan</td>
<td>125 places</td>
<td>$500,000</td>
</tr>
<tr>
<td>Region (non-salary costs equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hunter Region</td>
<td>125 places</td>
<td>$500,000</td>
</tr>
<tr>
<td>(non-salary costs equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southern Metropolitan</td>
<td>150 places</td>
<td>$600,000</td>
</tr>
<tr>
<td>Region (non salary costs equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orana and Far West</td>
<td>12 places*</td>
<td>$200,000</td>
</tr>
<tr>
<td>Region (full operating costs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illawarra Region</td>
<td>12 places*</td>
<td>$200,000</td>
</tr>
<tr>
<td>(full operating costs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South-West Region</td>
<td>12 places*</td>
<td>$200,000</td>
</tr>
<tr>
<td>(full operating costs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>436 places</td>
<td>$2,200,000</td>
</tr>
</tbody>
</table>

### Recurrent Expenditure Target Allocation

<table>
<thead>
<tr>
<th>Region</th>
<th>Target Places</th>
<th>Allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Coast Region</td>
<td>12 places</td>
<td>$200,000</td>
</tr>
</tbody>
</table>

*To be funded from savings from Peat Island closure, estimate $600,000 per annum*
<table>
<thead>
<tr>
<th></th>
<th>New Expenditure</th>
<th>Target</th>
<th>Allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Western Metropolitan Region (non-salary costs</td>
<td>150 places</td>
<td>$600,000</td>
</tr>
<tr>
<td></td>
<td>equivalent)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Hunter Region (non-salary costs equivalent)</td>
<td>150 places</td>
<td>$600,000</td>
</tr>
<tr>
<td>3</td>
<td>Southern Metropolitan Region (non-salary costs</td>
<td>100 places</td>
<td>$400,000</td>
</tr>
<tr>
<td></td>
<td>equivalent)</td>
<td>(and closure of</td>
<td>services at</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Gladesville)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>400 places</td>
<td>$1,600,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Recurrent Expenditure</th>
<th>Target</th>
<th>Allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Orana and Far West Region (full operating costs)</td>
<td>12 places*</td>
<td>$200,000</td>
</tr>
<tr>
<td>2</td>
<td>Illawarra Region (full operating costs)</td>
<td>12 places*</td>
<td>$200,000</td>
</tr>
<tr>
<td>3</td>
<td>North Coast Region (full operating costs)</td>
<td>12 places*</td>
<td>$200,000</td>
</tr>
<tr>
<td>4</td>
<td>South West Region (full operating costs)</td>
<td>12 places</td>
<td>$200,000</td>
</tr>
</tbody>
</table>

* Funded from savings Peat Island Hospital.

It is envisaged that by 1986/87, the metropolitan and Hunter Regions will have achieved adequate savings to fund their own services and to augment funds for other Regions. In Central West and South-East Regions, an additional 88 places in each region will be funded from within existing regional resources.
8.2 Rationalisation of Existing Institutions

Subject to the provision of alternative community services targets can be set for the reduction of existing institutional services including the complete closure of Peat Island Hospital and the north side of Gladesville and substantial reduction of the size of some other hospitals such as Stockton. The targets listed below represent the Inquiry's evaluation of reductions that can be achieved through the provision of alternative community services and as argued repeatedly the critical factor is the provision of adequate funds for this purpose.

In setting targets regard has also been had to factors such as the standard of physical stock, isolation of facilities, potential to close "whole units", potential for eventual alternative use of sites and the need to remove developmental disability services from psychiatric hospitals (other than those clients with clearly defined psychiatric illnesses).

Western Metropolitan Region (Currently 871 Developmental disability hospital places)

To achieve the desired objective of separation of psychiatric and developmental disability services, and to maximise potential savings by the closure by "whole services" (as recommended by the Parliamentary Accounts Committee) it is proposed that by 1985-86 Rydalmere Hospital operate solely as a developmental disability service by removing existing psychiatric services from the southern side of the hospital (see Part 3 for proposals concerning the psychiatric services).

With the planned provision of community services over the next three years, it will be possible to close residential services at Marsden Rehabilitation Centre, by relocation of residents either to community units or to Rydalmere. The total number of places in hospitals will be reduced by 150 approximately in this process.
In addition Rydalmere and Marsden will be reduced to approximately 570 beds with progressive further reductions as community services develop.

Subject to the "heritage" considerations associated with the Marsden Rehabilitation Centre site alternative uses should be examined including possible disposal. Ultimately the rehabilitation facilities (workshop etc.) may have to be relocated.

Southern Metropolitan Region (Currently 276 developmental disability hospital places)

The rationalisation of Gladesville and Rozelle Hospitals as a specialised psychiatric service is proposed in Part 3. At the same time the opportunity exists to completely decentralise by 1986-87 developmental disability services from Rozelle and Gladesville (currently 190 places) into the community in view of the planned provision of community services previously outlined for this region.

This would completely separate these services from psychiatric services and provide an excellent model for a totally community based service in a region formerly dependent on care in a large institution. Scope would then exist to consider the north side of Gladesville Hospital for possible disposal and the planned closure would achieve the important objective of closing a "whole service" which would ensure resources can be fully transferred to community based services.

Grosvenor Hospital currently provides both residential and community services (including assessment) and it is proposed to reduce the number of residential places from 86 to 32 by 1986-87. This will provide an appropriate scale of residential care more in keeping with the physical capacity of the hospital.
At the same time the Inquiry is aware that regional management has proposed the relocation of the Grosvenor assessment service and this is endorsed as a way of providing more locally accessible services for the region by linking assessment services with general hospitals.

Northern Metropolitan Region (Currently 316 developmental disability hospital places)

The main hospital facility is Peat Island Hospital (174 places) which is an extremely isolated facility largely consisting of old barrack style buildings reflecting its original purpose as an isolation facility.

Physically the hospital is an anachronism and typifies the isolationist and segregationist philosophies which underpinned the provision of these "services" in the past. The facility has no place in a modern service but fortunately due to progressive management the hospital is well advanced in the process of placing clients in a planned way in the community. Therefore, the opportunity exists to facilitate this process by adequate funding of community services and to close the hospital by 1984 and utilise the savings achieved to fund services not only in this Region but as indicated before in others. The other facilities in the region are Collaroy (54 places) and Macquarie Hospital (88 places). It is not proposed to reduce places at Collaroy and the facilities at Macquarie (a specialist psychiatric hospital) are largely used by disturbed developmentally disabled clients and this arrangement should continue for the present.
Hunter Region (Currently 1052 developmental disability hospital places)

Morisset Hospital is an isolated facility which currently provides 208 places for the developmentally disabled as well as 481 for psychiatric services. In accordance with the Inquiry's principles of service delivery all developmental disability places should be moved from Morisset by 1985 to either Stockton Hospital or to community residential units.

Stockton Hospital has some locational disadvantages but its major difficulty is its scale (844 places) which must be reduced to enable the progressive policies pursued by the hospital administration to become fully effective.

The ability to reduce the size of Stockton is also constrained by the need to move the above places from Morisset and accordingly a target of 670 places by 1986 has been set which accords with the provision of community services outlined above.

South East Region

Currently 200 places are provided at Kenmore Hospital and with the provision of community services over the next two years it is proposed to reduce this number to 100. Although it would not be feasible to physically separate these facilities totally from psychiatric services the management arrangements proposed in this Report will create a separate identity for these services until the services are completely relocated in the community.

Central West Region

Bloomfield Hospital currently contains 198 places and on a similar basis to Kenmore a target of 98 places by 1985-86 has been set. Once again total physical separation from psychiatric is not possible, however, separate management arrangements are proposed by the Region and this Report.