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(Inq into better support for carers)

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INQUIRY INTO BETTER SUPPORT FOR CARERS

This Association has been concerned for many years about disability services and carer support, especially since the NSW Government implemented the recommendations of the 'Richmond Report' from about 1984 onwards, but has continually failed to arm the community with sufficient resources to successfully implement the process.

I am the father of a 52 year old daughter who is intellectually disabled since birth, who has been through the mill of life in institutions since the age of 13, progressed through Stockton, Morissett and Kenmore hospitals, group homes in Nowra from 1985, independent living and 'sheltered employment' until 2007 and is now resident in a local aged persons' nursing home having been assessed as unable to care for herself or her medication.

Had I not been a member of the permanent defence forces (RAN) until 1977 and in receipt of DFRDB pension after 31 years service, I would not have been able to afford the treatments, medications, services and care which my daughter needed, and I really had to resign earlier than intended from service life after the early death of my wife (her mother) to care for her and my other youngest son aged 12 years then at high school. At this time my daughter was in Morissett, and at my request she was transferred to Kenmore to be closer to 'home' and more convenient to visit regularly.

In responding to the terms of reference I will make the following submissions:

Role & contribution of carers: Obviously this will vary immensely and will be driven by:

the level and needs of the disability,

the age of the family member involved and the carer(s) involved,

the financial and accommodation status of the family,

the number of other family members,

the city, region or country area of residence.

services available within accessible range of the family

recognition that it is usually the mother who provides the care because often the father of disabled children can't handle the issues and leaves availability and entitlement for social security and medical services. and availability of regular and frequent respite services for carers and other family members.

Barriers to participation for carers: Again there will be a variety of barriers experienced by carers to both providing assistance and sustenance to disabled family members, as well as restrictions to gaining employment which takes the carer away from the member in need. These barriers can be:

level of care needed e.g. mild, medium or severe disability; residential area - city/regional/country; transport needs and availability; carer assistance whilst at work; needs of other family members; and financial status.

Practical measures of support: There are many ways in which carers could be supported and these will depend again on those factors outlined above, but priority should be given to:

Functional and available respite facilities on a regular (weekly/monthly) basis;

Reliable, adjacent, and compassionate respite providers & facilities;

Affordable or free respite services dependent on financial status;

Respite availability to other family members also; and

Supported living accommodation for disabled family members assessed as able to leave the family home at an appropriate age;

Strategies to assist carers: The difficulty carers experience is usually in feelings of being either ignored, treated as incompetent, or thought of as not having the knowledge to deal with the disability and up-to-date methods, even though they are the ones with the problems and time constraints. This could be improved by:

Regular personal contact with the carer ensuring they are not being forgotten or ignored once a service is provided.;

Ensuring during personal contact that they are aware of all pertinent services available and that these have been accessed if beneficial; and Ensuring that the maximum social and financial support has been applied for, and assist in overcoming any shortfalls in obtaining benefits.

The answers to all these problems are may and varied, but from a government point of view can only be overcome by:

Provision of more resources to disabled people of all levels

Greater levels of financial support for carers:

Provision of more reliable, close to home and frequent respite services for both carers and disabled people; and

Provision of more social support services to both sides of the equation.

This obviously does not cover all exigencies of services to carers of people with disabilities. The relief can only be provided by both Federal and State Governments working in concert to improve the levels of service and support.

Yours sincerely

George J. Mackenzie OAM JP President

I have felt the need to place on record my personal opinions about the provision of accommodation and other services for intellectually disabled people since the inadequacies which have come to the fore in the NSW Community Services Department during the past year, the problems being uncovered in accommodation standards and treatments being reported widely in the press, and occurrences and inadequacies of facilities in Shoalhaven which have been brought to my attention recently. My options described herein would apply also to disabilities other than intellectual, and would suit most levels and types of disability with or without modification. They might also be worthwhile as a basis for policies which might be introduced on a bipartisan level for the future provision of accommodation and services for the disabled community.

There are many aspects to be considered when looking to provide accommodation options for people with disabilities, not the least of which is the rights and responsibilities of the individual person with a disability, and those of community members, governments and service providers inherent in both the Federal and State Disability Services Acts and Regulations and associated legislation.

I am not aware of any widespread notions made to define the various stages of accommodation which should be made available to people with a disability, but suspect that, since the advent of the Richmond Report in 1983, and the subsequent progressive closing down of institutions in NSW, the provision of services has undergone many changes and the provision of suitable accommodation has developed on an ad hoc basis.

Generally, in the past 40-50 years, medical science has developed methods of dealing with the birth of disabled babies which ensures the survival of babies which previously did not survive, and with the diagnosis and treatment of disabilities which were previously considered untreatable, or which were not diagnosed nor recognised as disabilities.

World-wide there has been recognition that the treatment and accommodation of people with disabilities was not being carried out with any recognition of their ability to cope with life and develop to their potential. In may cases, people with a disability develop more slowly than average, require more teaching and training effort, and take time and effort to regulate their disability with medication, but, with modern methods and treatments, they often progress to become able to live as individual and worthwhile members of the general community.

With the closure of these institutions, and the advent of changed responsibilities for care and control of services, along with the changes to government policies, differing outlooks of a variety of responsible ministers, and the differing emphasis placed by incumbent government parties, there has been an underlying lack of sufficient resources put into the community to properly and adequately provide services for those people previously housed in institutions, let alone the increased numbers of people with disabilities in the community due to advances of medical science.

In my own case, my daughter ,having been born "blue" and revived to survive in 1956, was diagnosed as brain damaged causing epilepsy over the period to age 3, attended primary school with her twin brother to age 8 when the pressures brought on had increased the epileptic seizures to a level where we could not cope with her at home and she was admitted to care at Stockton Hospital at age 9. She stayed there until transferred to Morrisset at age 18, was subsequently transferred to Kenmore Hospital at age 21 after the death of her mother, then discharged to a private institution at Cooranbong at age 28. From there I managed to gain her a place in the first group home opened in Nowra in 1985, and she has since progressed through another group home then on to supported accommodation, both sharing and alone, in her own flat in Nowra, and works 4 days a week at Shoalhaven Advance Industries after 9 years of employment with "The Improvers".

In the early stages of action emanating from the Richmond Report, some functions of treatment for people with disabilities were transferred from the Health Department to the Department of Community Services (then known as Family & Community Services). These services were mainly those dealing with basic family care, evaluation of disabilities to receive services, and basic family health care services. The result of this was to almost immediately create a shortage of all types of therapy services, because the rates of pay under the Health Department were far greater than under Community Services, and the therapists opted for private practices rather than work for Community Services at reduced rates. Therapy services are still in short supply 12 years down the track, and there seems no respite from the shortage.

I would suggest that inappropriate services, presently in Community Services domain which are more appropriately managed by the Health Department, be returned to that department, as a matter of urgency, and that any other services considered similarly misplaced be transferred to an appropriate department to manage. Community Services should be structured for the community to consult for assessment and referral to appropriate service providers, while the newly formed Ageing and Disability Department speed up its work and produce workable plans and programs for the aged and disabled community.

Above all this, it has to be recognised that people with disabilities have the right to decide how they will be housed, where they will be housed, where they will work, and even if they want to work. Their families have the same rights until their family member is of an age to make his/her own decisions, or until relieved of this right by court order or guardianship board.

These options are not the be-all nor end-all of accommodation problems, but they could be embraced as a basis to begin to formalise the process and to allow families with members who are disabled to make considered choices for the care and accommodation of their family members when the time comes. If the notion of paying financial supplementation is embraced, it will probably encourage more parents to care for their children with disabilities longer, which will relieve some pressure on the rest of the system.

The overall system of options I have described in the following pages, needs to be supplemented by a system of respite services which is sufficient to allow families to gain access as soon as needed. The advent of families having to wait weeks or even months is not conducive to the smooth functioning of the family unit, and produces pressures which impact on the health of family members at an increased cost to the community and health services, and exacerbates the underlying problems associated with the disability.

G.J. MACKENZIE PRESIDENT INTELLECTUALLY HANDICAPPED PERSONS OF SHOALHAVEN INC 3RD MAY 1997

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By GEORGE J. MACKENZIE

President, Intellectually Handicapped Persons Of Shoalhaven Inc

FAMILY HOME:

This would be the normal accommodation from birth until diagnosis, categorisation of disability, treatment regime, and assessment of needs.

There would be a continuation of this accommodation for some time unless permanent hospitalisation was necessary, and this may continue, in many cases, up to adolescence, early adulthood, or even longer.

This accommodation is obviously the least expensive option for governments, but in most cases is terribly disruptive to the family routine and engenders problems with siblings, relatives, friends and neighbours, etc. It is invariably an extra drain on parental time, family finances, medical expenses, and budgets in providing the extra necessities to care for the disabled member.

During the time when accommodated in the family home, the mother is generally the prime carer, and usually suffers early burn-out due to the additional time and effort required to attend to the disabled member's needs, medication, assistance, etc. In many cases the mother is also restricted in her ability to take on employment to bolster the family finances, due to the caring role in addition to normal family requirements. Additionally, when there is a young family member diagnosed with a disability, the father often abandons the family unit leaving the mother to cope alone as a single parent with the additional stresses involved in marriage break-up.

The father is not immune from the effects of having a disabled family member either. If he is the prime financial support for the family, his employment can be affected by the needs to take extra time off to attend medical, physical, and psychological appointments with the disabled family member, and is usually restricted in choices for advancement and improvement opportunities in his employment because of the need for stability of the family unit, especially the disabled member.

The social life of the whole family is affected when there is a disabled member, and this is especially detrimental to siblings who tend to feel deprived of parental attention from time to time. On many occasions social activities have to be curtailed or denied because of the needs of the disabled member.

In most cases, under the existing arrangements, families tend to gravitate to community services for care, treatment, accommodation, and case management for the disabled member, and this is extremely costly, usually in short supply, not always accessible, and not always in the best interest of the individual or the family unit.

A less costly, but more effective and acceptable option might be to supplement the family finances, over and above any disability allowances paid by the Department of Social Security, with a substantial amount weekly so as to overcome the additional costs of medical appointments, treatments, aids, special clothing, necessary home alterations, and additional care. If this amount was made unconditional, as well as substantial, but on provision that the disability is properly assessed and categorised, then it would allow not only for those special things attributable to the care of the disabled member, but would allow the family to hire the necessary assistance when needed for that care so that they, and other family members, could have a break and respite from the burden of the extra effort involved. Such assistance would also allow the other family members to have time to themselves and recharge their batteries devoid of the continuous concerns associated with a disabled family member.

If it costs \$30,000 per client per year for government to provide services, respite, accommodation, etc., and the family were paid \$15,000 per year per disabled member to arrange, accommodate, and pay for the same things themselves, then government's costs are halved. Some account would need to be taken of the family's use of HACC services, meals-on-wheels, etc., which could be charged to the family in receipt of such financial supplement. Medical services would be taken care of by Medicare plus private health insurance which would be affordable with the supplement, and could be made conditional to gain the payment.

Such a suggestion might seem costly and unacceptable to government, but would:-

- + reduce the overall costs in the long term;
- + reduce some pressures on the overall system of care for the disabled:
- + encourage families to accept responsibility and care of disabled members for longer than at present;
- + enable families to readily access services where and when needed, without having to await vacancies or meet under-resourced facilities;

The welfare and well-being of the family unit would also be enhanced by the reduced pressures with the opportunity and ability to take control of the care in a way that they need to suit the family and the disabled member.

Financial supplementation provided to the family would continue whilst ever the disable member is accommodated in the family home, irrespective of age.

RENTED ACCOMMODATION:

Rented accommodation, either private or department of housing, is an obvious option for older disabled family members, especially those under the Post-Schools-Options program with the ability to fend for themselves even though their disability, which entitles them to DSS disability allowances, might preclude them from full-time open employment,. In many cases this type of accommodation is also suitable for older disabled people who have been discharged from institutions to live in the community.

Disabled people living in rented accommodation are able to choose to either live alone or to share with others with whom they are compatible. Sharing would be preferable for the mutual support of the occupants, but needs to be flexible to cater for changes in attitude, pressures, etc.

For disabled people living outside the family unit in rented accommodation, some measure of extra attention would be needed from community services, and regular visits and assessments would be needed to ensure that:-

- exploitation is not taking place;
- that the standard of accommodation is not deteriorating;
- * that suitable nutrition is being provided;
- * that medication regimes are being observed;
- * that budgeting is under control; and
- * that the individuals are coping with unsupervised living conditions alone or in company.

Disabled people living under such conditions would still need access to HACC services, meals-on-wheels, etc., similar to those provided for the aged community but not to the detriment of that section such to engender claims of discrimination in provision or access to services. Concessions provided with disability allowances are similar to those that accompany aged pensions or service pensions, and would be provided to disabled people with their disability allowance.

Medical, dental, hospital and pharmaceutical services would be available as for any other recipient of DSS allowances.

Additional financial supplementation might be advantageously provided on an individually assessed basis to cater for special needs, especially for transport in country and remote areas where public transport is lacking or deficient for their needs. Any financial supplementation made to parents for their offsprings to live at home would cease once the member graduated to self-sufficient accommodation in the community, or left the family home to reside in community housing elsewhere.

SUPPORTED ACCOMMODATION:

This would be primary accommodation away from the family home similar to RENTED ACCOMMODATION, but with higher levels of support and supervision necessary to assist disabled people to manage their own disability, when assessed as suitable, with acceptable living skills.

Clients could choose to either live alone or share with another disabled person with whom they should be compatible. Sharing with another supported accommodation client would be advantageous from a service provision viewpoint, for mutual support in handling each client's disability, and the benefits of sharing living expenses and household chores.

Case management would be needed with regular reviews of ability to cope, with hygiene, care of living quarters, effective budgeting, medication regimes, medical and dental check-ups, daily regimes for work and leisure, compatibility with neighbours and those sharing accommodation, etc.

At present this type of service is provided by organisations which are funded by government, to provide it. The quantity of service available is dependent on availability of funds and the capacity of organisations to provide the management. This is also restricted by the availability and willingness of incorporated local associations to undertake provision of service, manage the funds and the service to the required standard, and the locality needing the service. It is also restricted by the availability of suitably trained staff within the locality, and the availability of suitable accommodation for rental. The quality of such service is dependent on the management organisation, the expertise of staff, and the numbers of clients seeking access to the service. The numbers seeking access are usually in excess of the organisation's ability to provide the service, which produces great pressure in some communities, especially in country and remote areas.

Finance for this type of service could be either by:-

- * government funding an organisation to provide the necessary services on a cost-per-client basis, or
- * government supplementing the disabled person's existing income from DSS allowances and allowing the individual to purchase his/her necessary services from this supplementation.

This latter option assumes that the necessary service(s) are readily available locally with the capacity to undertake the client's requirements.

The level of financial supplementation or cost per client basis would need to be assessed on individual needs. Some clients might need support for one day a week while others need more, less, or regular .access to additional services.

GROUP HOME:

A GROUP HOME would be a home in the community capable of taking up to 6 clients assessed as needing supervised living daily, yet able to carry out the majority of living skills under minimum supervision with safety, and able to integrate and live in the community without undue pressures or interference.

These residences could be allocated along recognised "age-related" lines if necessary, so that the residents are usually all progressing along similar career paths. e.g. Residents aged 0-6 could be catered for in a home separate from those of school age; school aged residents could be together up to school leaving age; post school and working residents would reside together and could remain in a group home, even after transfer to aged pension, for continuity, sense of belonging, and to preclude upheaval because of age and change of social security category.

Some overlapping of the basic groups would be acceptable, but not to the extent that older clients are living closely with the very young or vulnerable residents on a permanent basis. Allowances must be made for clients to progress through the system of group homes so that positions are readily available when needed, and continual assessment and forward planning would be needed to assure that inappropriate mixes of residents does not take place, and that the safety and well-being of all residents is paramount.

In each community there should be at least one group home which may be larger, and which should be used as the first experience for clients assessed as suitable for group home living. This group home would be used to assess the client's behaviour and compatibility, conduct some living skills training and assessment, and generally be used to ease the residents into the vagaries of living with others in a group home. In addition such group homes should contain at least one "respite bed", which can be used to provide short term respite for families with disabled members living at home. Beds which become vacant in other group homes could be used as "respite beds" until filled on a permanent basis, as there is usually some delay in filling positions vacated for whatever reason.

Properties for group homes should be rented from either public or private stock, and the residents would be required to jointly meet the bond and rental amounts, and to provide their own furniture such as beds, mattresses, wardrobes, linen, etc. They may even be asked to make a contribution towards the provision of communal furniture, fittings, cooking utensils, crockery etc. The liability for power, gas, telephone and heating would also be a joint resident responsibility, but all costs should be structured so that no more than the recommended percentage of pensions or disability allowances is charged to each resident, and they should be left sufficient to cater for personal needs, clothing, holidays, social activities etc.

When private housing stock is rented for group home use, a long term agreement should be made with the owner to allow for possible alterations to cater for certain disabilities, wheelchair access and bathroom or other modification where necessary. Specific agreement would also be necessary to cater for regular maintenance and repair. Housing needing major alteration to cater for disabled residents would ideally be from public housing stock which is specifically modified, but where owners of private rental accommodation are agreeable, use should be made of it, saving government expenditure on property and making public housing available for other tenants.

Each group home would need to be staffed with appropriate personnel for at least one to be present in the home at all times on rotated shifts, with sufficient numbers to equate with the needs of the residents and to cater for staff holidays, sickness, compassionate and other leave, as well as to allow for the invariable stresses associated with caring for a variety of disabilities and personalities.

Group homes could be managed by either an appropriate government department or community-based incorporated organisations, with the staff under individual employment contracts to the department or organisation. Once established, a group home would need permanent recurrent funding guarantees with allowances for regular review and movement consistent with ongoing costs, wages, and CPI increases. The provision of recurrent funding should be bilaterally agreed by political parties to cater for the uncertainties of State election results from time to time, or changes in ministerial responsibility, and to remove the vagaries associated with government budget deliberations, which usually places managers, staff, and clients under stresses of uncertainty, and which often precludes effective contractual arrangements being drawn up, and adhered to and engenders industrial unrest.

Financial supplementation of the client's allowances would not be made for group home residents, and because of the staff/client ratio needed, this would be a costly option to government. Nevertheless, sufficient funding should be made available for each group home to cater for relief staff for permanent staff holidays, sick leave, etc. Funding allowance should also be made for each group home to either acquire or hire suitable transport to cater for the residents' and staff uses, with running costs attributable to the residents on a pro-rata basis.

Normal household chores, cleanliness, gardening, lawns etc., would be the responsibility of the residents. They could either do it themselves or engage contractors to undertake tasks at the residents' cost and individual pro-rata contribution.

Hospital, medical, dental, pharmaceutical, therapeutical and other health services would be the responsibility of individual residents, and available through Medicare and the disability allowance entitlements of DSS.

PURPOSE-BUILT GROUP HOMES:

Purpose-built facilities are needed for several categories of people with disabilities and medical conditions without resorting to full institutional care.

These clients would be assessed as needing constant care and attention, or would be unsuitable for other group home accommodation due to age, ability or family circumstances. This would be greatly needed for older people with disabilities whose parents are ageing and unable to continue providing care at home.

There are many children in the community and living at home who have a variety of disabilities either singly or in combination , which render them incapable of fending for themselves, unable to communicate, confined to wheelchairs, battling medical conditions not normally met by others, but living, thanks to the advances of medical science of the last 50 years. In very early years the parents spend many days visiting medical specialists and hospitals while seeking accurate diagnosis and prognosis, and learning to cope with the many demands of their baby as he/she grows and develops (or fails to develop). In all cases with such a family member there is disruption to the normal family routine, and the same disadvantages as described earlier for families with a member who is disabled. If anything, the advent of a severely disabled child is a trauma for the whole family which is usually unexpected, and which poses problems for which the parents are invariably unprepared. In addition they have little knowledge of where to turn for help, and spend many hours trying to arrange for care and assistance.

For such children there is need for purpose built facilities to take them under full time care with appropriate staff and facilities, close to hospital and medical facilities, and easily accessible to the family without having to travel inordinate distances to see their family member. Every region of the state would need a number of such facilities, strategically placed to be accessible to communities, and capable of providing both full time care and respite care on a regular basis for families who keep their children with disabilities at home.

There would be a need to provide other purpose built facilities to cater for the above children as they get older, grow in stature, and need their care modified. There should not be cases where adolescents, teenagers, and young adults are accommodated in homes catering for permanent or respite care of young children, yet these older people should not be subjected to possible traumatic moves into accommodation provided for ageing people with disabilities. There should be a gradual progression through the various levels of accommodation consistent with the client's assessed ability to cope with changes in growth and circumstances.

As soon as a child is diagnosed with a disability, a financial supplement should be paid as described earlier, to encourage parents to obtain the best possible outcome for their child, and assist them in meeting the additional associated costs for medical care and assessment of the disability. This would cease on entering full time care.

There is an increasing need for other purpose built accommodation for people with disabilities whose parents are aged and no longer able to care for their disabled family member (who is also ageing), and who seek peace of mind that the welfare of the disabled member will be taken care of when they are gone. In most such cases, generic aged services are often inaccessible or not appropriate for people with disabilities, especially those under 65 year of age.

Purpose built facilities for these cases could take a variety of formats, ranging from individual units with associated quarters for attendant staff and communal lounge, dining and kitchen areas, to dormitory type housing with communal kitchen, lounge and dining facilities, attendant staff and staff quarters, both located close to hospital, medical, pharmaceutical and other necessary services.

Other options could be for small nursing-home style accommodation to be provided for younger (under 65 years) people with disabilities, or for aged persons' retirement-home style units to be available for the family unit and including attendant staff for those with a disability as well as the aged parents, with the unit to be "inherited" when the parents pass on, so that the disabled member does not have to cope with a change in accommodation from his/her home as well as the loss of mother or father or both.

In all cases the residents of purpose built accommodation would be responsible for rent and food plus pro-rata for power, gas and telephone costs, and a contribution for cleaning, gardens, and grounds maintenance, but no financial supplementation would be paid due to the attendant care provision. Food preparation could be by the individual, communal or by employing a cook with concurrence of the residents.

Hospital, medical, dental, pharmaceutical, therapeutical and other health services would be the responsibility of individual residents, and available through Medicare and the disability or age allowances of DSS.

Provision of purpose built accommodation would need to be funded, built, managed and run by government, local government, community services, community incorporated associations or a combination of these, and the initial costs would be heavy, with recurrent funding being guaranteed for provision of staff and services within the accommodation. No financial supplementation would be paid to clients as full services for care are provided.

Some purpose built accommodation for people with disabilities might be provided by commercial interests on a for-profit basis, and these would need to conform to certain standards, be licensed, regularly inspected and have services reviewed on a regular basis. In the interest of government economy, this could be encouraged with benefit to the provision of community services and the community.

NURSING HOME ACCOMMODATION:

Specialised nursing home accommodation for people with severe disabilities is an option which should remain available to families as a choice for placement of family members with a severe disability who are assessed as not suitable for any other type of accommodation, not likely to improve in the short term as they grow older, and not able to be effectively cared for at home. Not all families will avail themselves of this option, preferring to keep their family member either at home or in purpose built group homes, but the option should be available for those requiring it.

In early years, parents are usually reluctant to look at this option, but often come to the realisation that it is a desirable option after doing the rounds of medical specialists and accepting the severity of the disability as not able to be properly catered for satisfactorily within the family unit at home.

In many cases the stability of the family unit and well being of parents and siblings is dependent on placing the severely disabled member in accommodation and care which is specialised to deal with the disability properly. After some years of caring for severely disabled family members at home, the family unit succumbs to the pressures and tend to disintegrate or become dysfunctional, drawing on additional health and family services provided to the community, thereby costing government more and increasing pressures on such services.

Nursing home accommodation, built especially to deal with a range of severely disabled residents, provided with specialised equipment and staff, and catering for larger numbers of residents than smaller purpose built group homes, would be more cost effective, and less expensive than hospitalisation.

Nursing homes would need to be strategically placed to be close to larger specialised medical facilities, readily accessible to families, and close to communities where specialised staff is readily available. These homes could be arranged to cater for clients on an age and disability basis, especially for children aged 0 - 12 years, then for the group embodying teens, adolescents and young adults, and finally for adults of all ages, even past 65 years.

In all cases prior to access to a disability allowance being paid by DSS, an equivalent financial allowance should be paid to the individual client (or family) to pay for accommodation and additional services. Hospital, medical, dental, therapeutic services, etc., would be provided under Medicare, and clients not in receipt of DSS allowances should be awarded pharmaceutical benefit privileges until DSS benefits become available.

Nursing home facilities would be funded by government, and be managed by either an appropriate government department, contracted to community-based incorporated bodies, or purpose built by private enterprise on a for-profit basis. In all cases strict licensing, inspection, standards, and review procedures would be a formal requirement.