Royal Rehabilitation
Centre Sydney

rrcs

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO AGED CARE

Background Information on Royal Rehabilitation Centre Sydney (RRCS)

RRCS is a charitable not-for-profit rehabilitation and disability service with an independent Board of Directors. It operates under the Health Services Act 1997 and NSW Disability Services Act 1993. RRCS is a 124-bed hospital facility with several community-based services providing specialist rehabilitation programs for adults with disabilities, arising from spinal cord injury, occupational injury, orthopaedic injury and illness, traumatic brain injury, neurological loss or other degenerative neurological disorders, age related illness and disease, burns and multi-trauma. RRCS also provides community support and residential services for people with complex support needs living in the community or through the Extended Care Service.

Summary of Issues Relating to Aged Care and in particular Young People in Nursing Homes

Introduction

As the Senate References Committee is aware, aged care services are established specifically for the aged and to provide appropriate service and care. The fact that a high number of young people need to be admitted to an aged nursing facility is a clear indication that the systems and network of support services are failing, particularly for those who require a high level of heath-care and associated support.

It is important to note that many of these issues and concerns noted below are inter-related and have a “ripple effect” that impacts on a continuum of service delivery. The impact on the continuum of service delivery includes acute care settings in a hospitals, rehabilitation centres, community-based services and in the context of the family/primary carer.

This submission will not be discussing the sequelae of acquired or life-long disability resulting from injury (such as brain injury or spinal cord injury), chronic illness or other neurological conditions. However it is important to highlight that the research literature in the area indicate that the impact is long-term on all aspects of daily living for the individual, and puts increasing pressure on the family or primary carer; and impacts also on community resources.

The result of the impact of disability and the issues noted below often lead to the inappropriate placement of a young person in a nursing home or in other inappropriate accommodation, e.g. hostel. Or it may lead to the young person living in his/her home without adequate support services. Or the family or primary carer is left with the unenviable task of caring and supporting the individual without appropriate supports that may in many cases lead to a breakdown of the family unit.

What are the issues?

1. Need for whole-of-government approach in the co-ordination of services and responsibility of services

The current experience of health-care and disability support providers is the lack of a whole-of-government approach in engaging young people with disabilities, their primary carer, and relevant support services in finding a prompt and responsive resolution. Young people with disabilities have a range of service needs – health and medical, housing, personal support, housing, transport, education or vocational, leisure and employment. These needs require a ‘whole-of-government approach’. The whole-of-government approach includes state and federal government services.

The various government departments identified in New South Wales that need to work together with community agencies and the young person with disability and the primary carer includes:

- Department of Ageing, Disability and Home Care (DADHC)
- NSW Health
- Department of Housing
- Planning NSW

- Transport NSW
- Local government councils
- Local community services
- Commonwealth Department of Health and Aged Care
- Commonwealth Department of Family and Community Services
- Relevant statutory agencies

The young person with disability and/or their primary carer are often required to liaise with different and various Government and non-Government organisations and services with its own different eligibility criteria and assessment processes, policies and protocols, funding arrangements and various forms of bureaucracies.

There is also a lack of clarity in terms of the definition in which the various government agencies consider to be their “client group”. Currently in NSW, DADHC is suggesting that some disability groups would not be eligible for services and funding by the department and that these population groups belong to NSW Health. This approach by government departments fails to acknowledge that people with disability do have health-care and medical needs that require continuing care to live in the community. The “compartmentalisation” of services by Government departments contribute to the problem.

Adding to the lack of clarity of government responsibility and ownership of the problem is the lack of state-level co-ordination of services. The lack of co-ordination often lead to the “ripple effect” that often have a deletrious effect on the individual, the primary carer and relevant services that support the individual. The lack of co-ordination of services leads to delays in service delivery and impact on the well-being of the individual. The "ripple effect” is described in the following issues.

2. Need for prompt and timely service delivery, in particular funding and support services (e.g. Home Care or attendant care packages)

The lack of a prompt response and service delivery by state-level government agencies add to the problems and difficulties experienced by the young person with disability and other relevant government or non-government organisations, such as acute-care and rehabilitation services. For example, a young person with acquired disability as a result of brain injury or spinal cord injury might have completed rehabilitation and are ready to be integrated into the community; but the lack of prompt response to funding for support services such as attendant care or other support services often mean the person is unable to be discharged from rehabilitation. Another case might be the lack of appropriate housing for the young person with acquired disability would result in the person remaining in rehabilitation for an extended period of time.

The current experience for RRCS is that there are about 11 persons who cannot be discharged into the community or appropriate accommodation/services who have been in rehabilitation between 5 – 18 months. This results in a blockage of rehabilitation beds for other individuals in hospitals who are being referred for rehabilitation.

3. Blockage of acute-care hospital and rehabilitation beds

As described above, the next ‘ripple effect’ is that the blockage of rehabilitation beds and services lead to further blockages at the acute-care hospital end of services. This means that there are persons in hospitals who are ready to be discharged to rehabilitation services but are unable to do so because of the blockage at the rehabilitation. The impact contributes to the delay in health-care and medical services for the person and it is also costing the hospital services substantially in maintaining the young person within a hospital setting.

The impact is not just the blockage of hospitals and rehabilitation beds and services, and subsequent high costs in maintaining these persons. The impact on the psycho-social well being of the person can in turn lead to a poorer recovery progress as the person is remaining in a service that is no longer appropriate for his or her health-care and medical needs. The person is also remaining in an environment that is no longer appropriate to his or her medical and health-care recovery.

4. Need for appropriate accommodation (housing) requirements, in particular for those with mobility issues

Research in the area indicate that there is a lack of appropriate accommodation (housing) specifically designed to meet the requirements of people who have mobility issues. Many of these individuals require a safe level of home modifications that not only meet their needs but relevant legislation, such as OH & S. The limitation of appropriate housing contributes to the problem, leading to young people with disabilities being placed into inappropriate accommodation such as a nursing home. There is also a lack of appropriate accommodation models to suit young people with disabilities. Often there is an assumption that young people with disabilities could be adequately housed in a traditional “group home” model. Appropriate housing must also be timely and flexible to meet the needs of young people with disabilities. The delay in locating suitable housing as described in the above adds to the dilemma of bed blockages.

5. Urgent need for creative and responsive funding and support models

There is an urgent need for federal and state governments to facilitate creative and responsive funding and support models for the young person with disability, the primary carer and relevant disability and community agencies that support such individuals. There is such an urgent need because:

- There is an increasing trend that young people with disability are living longer and are living in the community. With the appropriate supports such individuals do become part of the community and contribute as citizens in the society. There is a false assumption that many of the young people with complex continuing medical and health-care needs are best served in a nursing home. There is now ample research to indicate the contrary and that a creative and flexible model of service delivery can lead to positive outcomes for the individual, cost savings and for the community.

  Vignette

  - *Female with acquired brain injury with complex support needs (e.g. visual impairment and chronic health issues) and totally dependent for activities of daily living, more than 30 years in an institution – transitioned into the community – 10 years later, living in a 16-hour support model and in 2004, graduated with a Bachelor of Education.*
  - *Female with brain injury and complex support needs, lived for many years in an institution requiring 24-hour care model – transitioned into community living – now lives in a drop-in support model and recently completed TAFE.*

  Other support models for the young person include:

    - Increase in day placement services – mentoring and peer support.
    - Respite for the young person away from the family – camps, holiday schemes etc.
    - Variety of housing options that allow flow-through from 24-hour care to drop-in support models.
    - Improve co-ordination of employment and educational network.
    - Prompt and readily available transportation.
    - Increase accessibility of local community services and public amenities.
    - Create supportive neighbourhoods and participation of local organisations to assist community inclusion.

- Research in disability indicates that many persons with disability are living in their own homes or in the family home. This is an increasing trend both in Australia and internationally. There is also an increasing ageing population in Australia. The research also indicates that the long-term impact of disability can be deletrious on the family unit. The lack of adequate support services for the family can lead to a breakdown of the family unit that in turn leads to the long-term placement of the young person with disability in inappropriate accommodation such as a nursing home. The lack of adequate carer support has also led to a crises in respite accommodation and placement in government care.

  Some of the creative and support services for the primary carer or family include:

    - Urgent need for flexible respite services and level of respite provided.
    - Carer support models that target specific needs and ensure that carer actually use the “free time” for themselves.
    - On-going carer training to care and support the young person with disability.
    - On-call centre to problem-solve health-care or psycho-social concerns.

    - Flexible funding/cash vouchers for purchase of services, equipment and other appropriate needs for the family and the young person. Or financial assistance to ease financial strain on carers.
    - Greater variety of service support options and information.
    - Family case management and support.
    - “One-stop shop” for information and referral services.
    - Appropriate models for rural and remote communities, and those from diverse cultural and linguistic backgrounds.

  Vignette

    - *Young adult with developmental disability with complex health-care support needs, lived in an institution for many years – transferred into nursing home – while in nursing home, flexible funding allowed for community access and life skills development – person will now be transitioned into supported community living.*
    - *Adult with developmental disability, severe cognitive impairment, lived many years in an institution – transitioned into family home of sibling about 5 years ago – flexible funding allowed for community access and skill development, and purchase of equipment needs while in care of sibling, flexible funding also allowed for holiday etc. Flexible funding prevents person from returning into institutional care as family is provided “respite” in daily caring.*

  - Research in housing indicate that tenants with disability who receive adequate support services (such as case management, support services, vocational options) are more likely to sustain long-term tenancy than those who do not have such support needs.

- The current nursing home models are incompatible to the needs of young person with disabilities. Research has also indicated that for a variety of reasons, young people in nursing home deteriorate while in the best care of nursing homes.

6. Disability Specific Services for Young People with Disabilities

While it is important to continue the community inclusion of young people with disabilities accessing generic services, it is equally crucial to recognise that there will be service needs that are specific to particular disability types or for young people. For example, there is an assumption that general practitioners have a comprehensive knowledge of the client-group. However studies have indicated that general practitioners do miss on timely and important diagnosis of disability specific and/or other health-related issues of persons with disabilities. Furthermore, people with disabilities are supported by disability workers who are not necessarily from a health-care trained background. Service providers are required to train these direct care workers without necessarily additional funding from Government agencies. As such, this notion contributes to the myth that young people with disabilities are better off in a nursing home facility where there is presumed better health care.

While there have been several initiatives in co-ordination of services such as the enhanced primary health-care and the general practitioner and aged-care assessment teams; there are still a number of problems at the level of face-face delivery of services. Some of the problems include HACC and community services with generic health services or broader support services. For example, a young person with disability may be discharged following a stay in hospital and may require wound dressing or some other medical intervention. Often there are many cases in which certain community nursing or community health-centres do not provide such a service, e.g. wound dressing. This may result in the young person having to stay longer in the hospital or be referred to a nursing home where there is on-site nursing service, rather than in their own homes, family home or in a disability-specific home.

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