RDNS
Royal District Nursing Service of SA Inc.

Senate Community Affairs References Committee

Inquiry into Planning Options and Services for People Ageing with a Disability

Submission
May 2010

Introduction

RDNS SA welcomes the establishment of the Inquiry into 'planning options and services for people ageing with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of currently available'.

RDNS SA is delighted to be able to provide comment and input to the Inquiry and wish it well as it strives to make a positive difference to the health and care options available to all Australians living with a disability. RDNS would welcome the opportunity to discuss our submission with the Committee.

Attachments

- A: summary of RDNS SA
- B: summary of RDNS SA Disability Service

Preamble

The most glaring issue for people who are ageing with a disability is that they are ageing prematurely compared to the rest of the population. This means that people living with a disability are often too young to receive the services they really need as they do not fit the aged care system and the disability sector is not geared to the needs of aged clients.

The RDNS Disability Service provides services to people with severe and multiple disabilities living in the community. The service is designed to provide health support to address the secondary health needs of these individuals. Many of the people referred to the RDNS Disability Service are from Community Disability Accommodation services or day options programs.

Introduction of issues

Individuals with severe disability who are ageing are likely to be living in a variety of settings. For those living in institutional care might be as a result of the social pressures or medical opinions entrenched in the 1960's and earlier of 'put your child in a home and forget about them.' In some senses, these people are representative of Disabilities 'Stolen Generation'. Indeed some of these individuals are representative of Indigenous Australians with a disability also.
Others may have since moved from institutional care to community based supported accommodation. This may have come about due to personal preference and availability, but more likely due to devolution of institutional care to community based care. Others may be living at home with family. This may be due to personal choice and family and cultural factors, or availability the lack of alternative accommodation that meets their needs.

There are many people with a disability known to our service that are not in supported accommodation, and are living at home with their family, outside of their day option program. It is these individuals, and their families, who are of particular interest when it comes to the issue of Ageing with Disability.

What is known about some of the chronic health issues faced by these individuals include:

- Down's Syndrome – early onset dementia and congestive cardiac failure
- Recurrent Aspiration – leading to chronic airways limitation
- Continence issues secondary to immobility and neuromuscular deficits
- Malnutrition
- Osteoarthritis and vitamin D deficiency.

It might be that these individuals have always had a supportive family or community network, were well off, or just simply consciously rejected the advice so prevalent in the past. Another explanation may be a disability version of the theory of ethnic family values put forward by Storer (1985). Ethnic families migrating to Australia at this time were frozen in time with regard to their cultural values of family and community from their homeland. The idea of giving up a child to the state was not consistent with their culture, and was interpreted as such, rather than a generational value.

In South Australia, we find many case examples of people with sometimes severe disabilities, in their 40's and 50's, still living with their ageing parents, and to be of culturally diverse background. These families will do as much as they can to support their loved one at home. In the same way they would typically support their elders in the family home, much longer than say 'mainstream Australia'. They do even more so for their adult child with a disability.

Indeed some of the issues of ageing that are happening prematurely to the individual are also happening to their ageing carers creating even further pressures for the family unit.

Case Example

S. is a 53 yr old woman who has Cerebral Palsy with spastic Tetraplegia.

She is the daughter of M. (mother) and V. (father) both in their mid 70's.

S. lives in the family home fully supported by her mother and father as she always has been. They have been living in the same house since 1963. S was diagnosed with her disability 2 days after her 2nd birthday. M. was heavily pregnant with S. younger brother at the time.

M. suffered with post natal depression, which meant that V. had to stop work to support the family causing some financial strain at the time. M. has carried guilt about this all through their married life, and as a consequence is very resistant to any outside help choosing to carry as much of the load as she can herself.

<u>S.'s care needs</u>

- Non ambulant but stands with assistance
- Non verbal communication
- Nutrition is met orally but has some swallowing difficulties necessitating vitamised foods and fluid thickeners.
- Prone to constipation
- Neurogenic bladder requiring supra-pubic catheterization.
- Menstruation controlled to manage her epilepsy
- Intranasal midazolam for Tonic Clonic seizures
- Fully dependant for all activities of daily living
- Wakes up frequently through the night calling out
- S. weighs 96 kg despite her eating difficulties.

<u>V.'s health</u>

- 77 yr old semi retired builder
- Osteoarthritis
- Myocardial infarct at age 60 + bypass surgery
- Alcohol – home brewer
- Tobacco – smokes a pipe at the end of the day.

<u>M.'s health</u>

- 75 yr old wife and mother of 2

- Arthritis
- Hypertension
- Type 2 diabetes.

Current supports

- Domiciliary Care 3-5 hrs / week showering and domestic support
- S. attends day options program 5 days a week for 5hrs a day. She is finding this very tiring and would like to cut back to 3 days a week or maybe shorter days. These kinds of day options programs S. attends are directed at people much younger than S.. She receives this service under block funding which prevents her having the option of splitting days, or reducing hours
- S.'s younger brother married with 3 children and lives interstate
- Disability SA service coordinator regularly visits every 2 months as point of referral for occasional Physiotherapy and Occupational Therapy visits
- Has a floor lifter which sits in a spare room covered in dust – V. prefers to lift S. as "She feels not as scared". V. then tells stories of how many sacks of cement render he would shift by hand. "S., no worries!"
- M. and V. have used centre based respite care once. This was for V.'s hospitalization during his heart attack and subsequent surgery
- Although M. has some access to domestic support, she chooses not to burden the support workers from Domiciliary care so that they can give S. their full attention.

Summary of current and future concerns

- S. always looks well and is cared for immaculately. If anything she is sometimes over cared for, as evident in her frequently being over dressed for spring and autumn weather
- Due to the families 1960's ethnic cultural values that they have bought with them from their home country, and the life issues which have emphasized these values, they are reluctant to take advantage of the services that are available
- Quite often both M. and V. will ignore their own health needs till the very last minute, and when one is unwell the other compensates. They have not forgotten the words of the medical specialist upon S.'s diagnosis "A child such as this will become too great a burden for any parent. Better to have them placed in a home!" This makes them very resistant to any care away from the family home as they feel that they will be seduced into giving her up
- Although S. is finding her day options program tiring it is the only funded care hours she is eligible for other than the Domiciliary Care hours for showering in the home. Any decision to drop hours at the day option would result in more hours of support needed to be provided by V. and M.
- Although M. and V show resilience, we see they are becoming tired, and are concerned there is no future planning for S.'s care. Whenever the Disability SA coordinator opens this topic for discussion, they will either stare off into the distance or change the subject. "Not while M.is cooking for us will we die! M. you have biscotti?" V will say
- If M. and V. died today, S. would go to an emergency care respite bed if one was available, but the more likely outcome would be a presentation to the acute sector, waiting sometimes months to a year for placement. This placement may be to a high level aged care facility
- Aged Care is not a good fit for people with a disability as staff knowledge of disability issues is poor and the facility and activities are geared to the aged residents
- There are in South Australia, Government and Non Government aged care facilities purpose built eg: Minda Aged Care Unit as part of disability

institutionalized care. This is as a result of no suitable option for their own aging residents.

What is needed

- Meaningful proactive case management and future planning options.
- Inbuilt progression in community based care from family to shared care to 24/7 supported community accommodation.
- Flexible responsive individualized support packages reflective of the needs of individuals.
- Self managed funding or a National Disabilities Insurance scheme would put the individual and their family at the centre of the decision making process. This would create a 'power shift' and necessitate support provider agencies to create more flexible individualized models of support to win business.
- The disability support industry would need appropriate regulation around support that can be purchased by individuals. This may necessitate the tightening of existing policy and guidelines in the industry, towards the level of licensing, to protect purchasers from service providers operating below safe standards.
- Increased resources / training for medical/ allied health professionals and disability sector workers to specialize in disabilities and understand the premature ageing related issues so that appropriate resources can be implemented.

Current Services from RDNS of SA

The RDNS of SA model of disability service delivery is based on a Delegated Care model commensurate with the Nursing and Midwifery Board of South Australia (nmbsa) Standards for Delegation of care by a Registered Nurse or Midwife to an unlicensed Health worker May 2005.

The method of service delivery has evolved over the last two decades, and uses nursing strategies of Assessment, Planning, Implementation, and Evaluation of Health issues, using values of inclusion and social justice, for people living in the community with a disability.

The model draws on standards of Health, Education, and Disability service delivery in the effective use of the appropriate skill mix for a particular individuals need. It is health support designed around the individual who empowers the individual and their family. It uses only the resources required to safely meet health need for the individual in their chosen environment, while addressing and managing risk to the person and support agency according to the relevant standards of care.

More often than not the skill mix required to meet the need is that of a Care Worker or Community Support Worker. Because of this, it is affordable, flexible and transferable. Being less intrusive due to the presence of a non- professional in the provision of direct support.

The Registered Nurses employed to design and monitor this care, are the health professional resource to the person and their care worker, and also have Certificate 1V TAA in Workplace Training and Assessment, as a base requirement.

Services, such as those offered by RDNS through their Disabilities program, put individuals central to the design of support. Its method of care is changeable, and flexible, and has the capacity to follow an individual throughout the changes

in their life. For individuals such as S, health support, consistent with that provided by RDNS, can monitor, plan and review effectiveness, continuing to meet her needs as she ages.

Conclusion

As people with disabilities are now living longer and with this the associated complexities of ageing, disability agencies have had to change to meet the persons new and emerging needs.

Ageing adds an additional dimension to the support needs of people with a disability that compound the persons support needs. Existing aged care services have difficulties meeting the persons disability support needs and likewise disability services do no not have the skills to recognize and apply appropriate aged care practices.

Self managed funding packages is being trialed across Australia with some early positive results, however, it is not clear how this model would be implemented for people with severe and multiple disabilities.

Although this is a welcomed step in promoting choice for people, the most appropriate services will require a support framework that is flexible and adaptable to individual need.

Meeting the workforce demands is already proving challenging with the changing demographics of the care worker workforce. What is required is a workforce with the right skill mix and competencies to meet the needs of people with disabilities who are ageing to allow 'ageing in place' to occur.

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Attachment A:

Formed in 1894, The **Royal District Nursing Service of SA Inc** ("RDNS") is a not for profit, non government provider of community-based health and care services. RDNS has an operating budget of $45m and more than 25 contracts with all levels of government as well as many corporate clients providing community nursing services to, in excess of, 24,000 people per annum.

RDNS Today

We have great outcomes:

- 71% of RDNS clients have met their goal of care when discharged (above the national DVA benchmark of 66%).
- ICCOP clients: 51% reduction in unplanned Emergency Department presentations and hospital admissions and a 37% reduction in total bed days for older people with complex chronic conditions.

Each month:

- 6,300 active clients.
- 1,500 new referrals.
- Intake from the acute sector: 850 clients (650 public hospitals; 200 private hospitals).
- An average of 44,000 visits.

Each year:

- Over 530,000 visits and consultations.
- 10,000 referrals from public and private hospitals.
- Call Centre receives 582,000 calls.

Services

- Community acute, post acute and sub-acute health care.
- Chronic disease management models that integrate with primary healthcare
- Specialist services – continence, dementia/mental health, palliative care, wound management, gerontology, diabetes, disabilities, Infection Prevention and Control, HIV/AIDS, homeless, immunization.
- Multi-disciplinary care provision (including Nursing, Podiatry, Physiotherapy and Occupational Therapy).
- Personal Care and Domestic Services.
- In-home respite services.
- A 24 hour, 7 day a week customer service call centre staffed by nurses to ensure communication with clients and providers at all times. Evidence based health advice is available.
- Secure, web based eHealth Record which can be activated as a part of our service delivery method.
- Automated quality, patient care and risk management systems (RiskMan and ComCare).
- RDNS Mobility solution enables service delivery staff to communicate in real time, including accessing and scheduling referrals, ordering medical consumables and equipment, updating client data, entering service data, managing appointments and accessing all RDNS policies and procedures.
- A pool of 450 service delivery staff who deliver client care.
- RDNS SA has an Education Unit that holds National RTO status, offering nationally accredited courses such as Certificate III in Aged Care, Diploma of Nursing for Enrolled Nurses.
- An internationally renowned RDNS Research Unit is regularly sought after as author and editor of seminal publications, evaluation consultancies across Australia and overseas.

Attachment B:

RDNS SA Disability Service Model

The RDNS model of service delivery is based on a Delegated Care model commensurate with the nmbsa Standards for Delegation of care by a Registered Nurse or Midwife to an unlicensed Health care worker: May 2005.

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The model draws on standards of Health, Education, and Disability service delivery in the effective use of the appropriate resource for a particular individuals need. It is health support designed around the individual who empowers the individual and their family. It uses only the resources required to safely meet health need for the individual in their chosen environment, and because of this is flexible, affordable, and transferable.

The RDNS Disability Service model that provides flexible, safe and affordable solutions to health support which draw on the relevant professional, industry, and government national standards and guidelines. It is responsive support with the right checks and balances.

The model is designed to ensure;

- Early identification and intervention in health care needs
- Continuity of care – clinical support
- Professional growth and interdisciplinary solidarity for nurses
- High level of training and support for care workers

The RDNS model delivers;

- Health support delivery to adults (>18 yrs) client locations and numbers as identified within the annual Service Funding Agreement.
- Provision of direct clinical care where required
- A flexible and responsive service delivered in conjunction with RDNS public programs staff.
- To RDNS clients have access to the out of hours phone line support service
- Provision of education and collegiate support to country based RN services when required.
- Education, training and assessment for care workers supporting level 2 clients.
- All disability nursing staff holds Certificate IV in Workplace Training and Assessment.

Key SA state-wide documents;

1. **South Australian Government; DFC: Direct Health Support of People with a Disability – Policy and Guidelines.** This policy provides a risk management framework for the disability sector.

2. **N&MBSA Standards: Delegation by a Registered Nurse or Midwife to an unlicensed Healthcare Worker.** These Standards provides minimum expectations of nurses engaged in delegated care.