

Submission to the Parliamentary Inquiry into palliative care services and home and community care services

6TH August 2012

Background

National Disability Services (Qld) (NDS) is a peak body representing organisations that provide services to people with disabilities and their families. Guiding principles include the promotion of flexible, individualised supports and services for people with disabilities and to promote service models which are well co-ordinated across government departments, holistic in approach and improve quality of life for people with a disability. It is on this basis that NDS provides the following submission.

Palliative care for people with disability in Queensland

National Disability Services has recently completed a series of conversations which uncovered many of the issues experienced by people with disability in palliative care. Seventy people from various parts of the sector in Queensland, including service providers, people with disability, family members, carers, advocates, allied health professionals and support workers took part in these discussions.

NDS's submission to the inquiry summarises key findings and makes a series of recommendations to inform the government response. NDS would be very pleased to partner with organisations with which it has already existing relationships, such as Palliative Care Queensland, Palliative Care Research and Education Centre at Royal Brisbane Hospital, and Queensland Kids, as well as other agencies, to deliver projects designed to address these pressing issues.

The experience of people with disability

Grief and loss is a huge hidden problem, particularly for people with severe disabilities who may have had significant experience of grief and loss as a direct result of their disability and marginalisation in the community and/or may not have had access to supports to enable healthy resolution of grief and loss experiences

Truth telling: many families keep the truth of a person's health status from the person, particularly those with intellectual disability, feeling that they will be unable to 'handle' it. This can cause great confusion and fear for the person and complicate the dying process.

There are few resources for people with intellectual disability who are dying to understand and make decisions about the process and the care they receive

Respite for families

No flexible respite options exist in Queensland for children and families experiencing life limiting illness or impairment in the child. Research into whole of family residential respite in such facilities overseas and in NSW, and anecdotal evidence, indicates that this is a highly beneficial support for the whole family.

Death-making

Anecdotally, death-making for people with severe disabilities occurs often in hospitals. This may be driven by assumptions about people's quality of life or by lack of knowledge of the individual's needs. Clinical staff may not refer to the person when making decisions, even when the person has full capacity to engage in decisions about their care.

Examples include:

- one person who required pureed food was fed non-pureed food and died from choking;
- people not being resuscitated or treated with basic lifesaving medication such as antibiotics because of medical staff assumptions that their disability made their life 'not worth living';
- one person who was conscious, alert and able to respond being marked Do Not Resuscitate without any reference to them.

Palliative care providers

Palliative care providers identify in their agencies and staff low levels of knowledge of disability in general and the specific needs of people with particular disabilities. They express frustration at not having access to training and to people with good knowledge of individuals.

Providers also report no access to tools or resources to support good practice in palliative care for people with disabilities e.g. pain scales for people who are non-verbal.

Finally, providers also report that many people with disability do not have available good social supports who can advocate for them or work with palliative care teams to provide good individualised care

Disability Service Providers

Disability service providers are rarely included in information-gathering about a person's specific needs, or in decision making about care, even when they are the only supports a person has e.g. when a person has no family and has been supported by providers for many years

Staff express great attachment to their long term clients and suffer trauma and grief when palliative care is provided poorly or provided in isolation from staff trusted by and known to the individual.

Funding models preclude staff in supported accommodation settings providing continuity of support when clients are hospitalised.

Finally, providers identify the need for training in basic palliative care and in grief and loss to support the dying, other clients and fellow staff.

Recommendations to the inquiry

To respond to these issues, National Disability Services recommends:

- 1. The provision of human rights and other specialist training in disability for clinical staff in the hospital setting**
- 2. The provision of skilled advocates in the hospital setting**
- 3. Direct contracting by hospitals of service providers to provide specialist support and advocacy for clients in hospital. Local Health and Hospital Boards would be ideal agencies to pilot this approach**
- 4. The development of a strategy for addressing the significant grief and loss issues in the disability community**
- 5. The development and delivery of specialist training in disability for palliative care providers**
- 6. Provision of training in palliative care for disability service providers**
- 7. The development of and access to appropriate, targeted resources about end of life and palliative care for people with disability e.g. easy English versions, picture based resources for people with intellectual impairments**
- 8. The development of and access to resources and supports for families to understand the process of dying, the supports available for palliative care, the special considerations for people with disability who are dying and the value of sensitive truth telling in this context**
- 9. The modification of palliative care communication guidelines (now widely available to GPs and hospital clinical staff) to ensure consideration of special communication needs of people with receptive or expressive communication impairments**
- 10. Development of resources to support good practice by palliative care providers for people with disabilities**
- 11. Family/service provider/palliative care team 'team' approach in provision of care of people with disability who are dying**

- 12. Transportability of funding (especially supported accommodation funding) to support people when hospitalised**
- 13. Specific funding to provide appropriate supports for people with disabilities who are dying**
- 14. Modified versions of advance health directives and specialist support through the process of completing them for people with disability**
- 15. Resources to support disability service providers and families to support people through grief and loss experiences e.g. practice guides**
- 16. Queensland government support for the operation of a respite house for children and families experiencing life limiting illness or impairment in the child. Queensland Kids is an established non-government organisation developing such a facility and service model.**

Home and Community Care

Since the responsibility for Home and Community Care (HACC) services for people with disability under 65 was returned to states and territories last year, there have been relatively few changes to the experience of service providers supporting people accessing this pool of funding.

The main feature of HACC funding for people with disability has always been its flexibility and usefulness in making up shortfalls in other funded services.

NDS recommends that:

The flexibility of use of this funding be maintained, and that HACC funding not be subsumed into other disability programs administered by the Department of Communities, Child Safety and Disability Services, but administered as a separate program.