

HUGHENDEN COMMUNITY FORUM

NORTH QUEENSLAND REGION

22 SEPTEMBER 2008

MINISTER ATTENDING

The Honourable Craig Wallace MP Minister for Natural Resources and
Water and Minister Assisting the Premier
in North Queensland

REGIONAL PROPOSAL

POST HOSPITAL SUPPORT TO FAMILIES OF BABIES BORN WITH A DISABILITY

This Regional Proposal was raised at the forum held at Normanton on 16 June 2008.

The proposal was presented by the forum member Mr Ian Kuhl.

MINISTERS CONSULTED ON THE GOVERNMENT'S RESPONSE

The Honourable Stephen Robertson MP Minister for Health

The Honourable Lindy Nelson-Carr MP Minister for Communities, Disability
Services, Aboriginal and Torres Strait
Islander Partnerships, Multicultural Affairs,
Seniors and Youth

BACKGROUND

Forum member Mr Ian Kuhl sought support from Queensland Health to pilot a model of support in North Queensland similar to that currently provided through the Queensland Hearing Loss Family Support Service to support all families of babies born with a disability, who require ongoing medical intervention and therapy services, for up to the first 12 months post discharge from hospital.

In the development of this proposal, Mr Kuhl worked closely with the Umbrella Network - a network of young parents of children with a disability. The President, Ms Angie D'Arcy, who was unable to attend the forum in person, prepared a DVD statement supporting the proposal which was played at the forum. Parents who have received excellent support through the Queensland Hearing Loss Family Support Service provided statements to contrast their experiences with families who have not received support.

Mr Kuhl recommended that the Women's and Children's Institute, in conjunction with the Social Work Department at the Townsville Hospital, pilot a model of support to families similar to that currently provided through the Queensland Hearing Loss Family Support Service. It is proposed that this model be an action research project for a 12 month period in the Townsville District Health Service. In principle support for this proposal and the pilot was provided to the forum by Ms Vicki Carson, Director, Operations and Ms Chris Fox, Senior Social Worker, Women's and Children's Institute. A letter of support was also received from Ms Ven-nice Ryan, Director, Child Development Program, Community Child Health Service, Queensland Health.

Mr Kuhl elaborated that the family co-ordinator position be a hospital based social worker whose duties include:

1. local and face-to-face contact with families;
2. counselling and support to assist families adjust to the life changes that they will face;
3. provision of local, regional and statewide information;
4. work in partnership with families in an outreach capacity for 12 months post birth to provide a seamless response to families' needs that incorporates both health and community based service responses;
5. work with families to identify the most appropriate services and supports relevant to the needs of their child; and
6. coordinate access to these supports and services.

Following the presentation to forum, Minister Pitt said that government has a strong interest in providing support to children from early development; there are processes currently underway to make systemic change in the way services are provided; and to establish a continuum of inclusive support mechanisms over time to manage the disability, support the family and bring services to the family. Minister Pitt offered his support for referral to the relevant Ministers for response.

RESPONSE TO FORUM

Response from the Honourable Stephen Robertson MP, Minister for Health:

The Women's and Children's Institute, in conjunction with the Social Work Department at the Townsville Hospital, support in principle the approach to pilot a model of support to families similar to that currently provided through the Queensland Hearing Loss Family Support Services. Queensland Health will continue to work with partner organisations to explore options for funding opportunities.

There are a number of services available to families. For those babies born at the Townsville Hospital, Neonatology services provide initial medical intervention as required. Those babies who then require ongoing medical care or monitoring are referred to the paediatric services, or to a private paediatrician, as requested.

Families are also referred to the Child Youth and Family Health Services (CYFHS). The Hospital liaison officer assists in the identification of high need families that require follow-up. CYFHS provide a range of services, including Infant Management and Parenting skills, Intake officer for information and advice via the phone, individual consultations for parents with concerns, positive parenting program and early intervention specialists which include psychologist and social work support. CYFHS operate on a voluntary basis, so although CYFHS make initial contact with families, some choose not to access their services. This is more common in the early months where parents may not be aware of problems concerning their baby's well-being or progress. Often it is not until the baby fails to meet milestones and/or issues arise such as poor feeding, that they seek more involvement.

Child development speech, physiotherapy and occupational therapy services are provided by the Townsville Health Service District through both hospital and community services. Depending on the baby's needs on discharge, a baby may be managed in the hospital's outpatient allied health services, or referred as required to either Children's Community Therapy Services (CCTS), or an appropriate non-government or community service.

Other non-government organisations that provide allied health services within Townsville are:

- Cerebral Palsy League Queensland – provide a service for children 0-8 years of age with a primary physical impairment;
- Disability Services Queensland – provide services for children less than 6 years of age who are at risk of significant developmental delay (currently there are no physiotherapy services provided); and
- Downs Syndrome Association Queensland – provide educational and supportive role for families.

The Institute of Women and Children do acknowledge that although a number of services are provided they are somewhat fragmented, and families do experience difficulties in understanding what services are provided and how to access these in a timely manner. Information is given to families prior to discharge, however, many families are not in a position to assimilate this information so soon after the birth of their baby. Hospital based social work services are provided, however, the opportunity to provide preventative counselling and support is limited due to the priority given to crisis management interventions.

Government activity since the Regional Proposal was raised

Since the proposal has been raised, the Townsville Health Service District, Institute of Women's and Children's Health, have continued to work closely with the Umbrella Network and have organised a Children's Therapy Services Forum held on 16 September 2008. This is a joint initiative between the Umbrella Network and Queensland Health in associated with Disability Action Week. The forum informed families of community, government and non-government services available to them. The Honourable Lindy Nelson-Carr MP opened the forum and speakers included representatives from, the Townsville City Council and Inclusion Support on Council Services, the Umbrella Network, Queensland Health Children's therapy services, the Department of Education, Disability Services Queensland, the Cerebral Palsy League Queensland and consumers. Stalls from relevant services were present to provide people with the opportunity to network.

Recommendations or actions on behalf of the Government

- That the Family co-ordinator position be supported in principle, as outlined by Mr Kuhl and that the six duties proposed form the key accountabilities of the role description.
- While Queensland Health currently does not have the funding for this position the Department will continue to work with partner organisations to explore options for funding opportunities.

Response from the Honourable Lindy Nelson-Carr MP, Minister for Communities, Disability Services, Aboriginal and Torres Strait Islander Partnerships, Multicultural Affairs, Seniors and Youth:

The presence of a disability is often difficult to identify during infancy. Disability is usually identified once a child fails to reach key developmental milestones. In a minority of cases the presence of a disability is apparent from birth. Such disabilities usually relate to the presence of a congenital condition.

It is important that government agencies work together to provide coordinated services to children with a disability and their families. Facilitating access to services in rural and regional communities is often challenging because of issues such as the availability of local resources and skilled staff.

Disability Services Queensland currently provides multi-disciplinary support and therapy services to children with (or at-risk of) a disability (aged 0-6 years) and their families through 'Family and Early Childhood Services (FECS)' teams. The services provided by FECS teams include all those listed under the duties of the proposed family coordinator position. In addition, FECS teams deliver therapy services across a number of disciplines including psychology, social work, speech and language pathology, occupational therapy and physiotherapy. Demand for FECS is high and access to services is prioritised on the basis of relative need and available resources.

Disability Services Queensland understands the importance of effective prevention and early intervention services during the early years of a child's life. However, the department is of the view that it is preferable to provide services through a community, rather than a hospital based approach. This is important in supporting families to connect and engage with their community. It is also important to discourage parents from viewing their child's disability as a purely medical issue by encouraging them to adapt to parenting within the context of their broader community. This view is reflected by the initiatives that are being rolled out under the Queensland Early Years Strategy.

Strengthening services for families and children during early childhood is an important policy objective for the Queensland Government. The Queensland Early Years Strategy aims to give children a better start in life through early learning and care, supporting families and parenting, improving prevention and early intervention services, and creating child-friendly communities.

Significant consultation has occurred with parents and carers to inform the Queensland Early Years Strategy. The '*Summary Report – Towards an Early Years Strategy: Parent and Carer Consultation*' is available on <http://www.communities.qld.gov.au/family/earlyyears/documents/early-years-summary-report.pdf> with a copy at **Attachment 1**. The report acknowledges that the families of children with a disability face major challenges during the early months of their child's life. Identifying and accessing appropriate and available services is particularly challenging.

The Queensland Early Years Strategy aims to address the challenges faced by families during the first year of a child's life by improving access to parenting education and support programs and upgrading neighbourhood and community centres. An Early Years Centres will also be established in Cairns and three other key locations throughout Queensland. These centres will offer universal and targeted services for children from pre-birth to eight years of age and their families, and will operate as part of an effective, integrated prevention and early intervention service system.

<p>Prepared by:</p> <p>Pam Cameron Principal Program Officer 3008 8669</p> <p>Reviewed by:</p> <p>Karen Jones A/Manager 3404 3499</p>	<p>Endorsed by:</p> <p>Frank Gilbert Director Office of Rural and Regional Communities 4967 0976</p> <p>I certify that the Minister consulted on the Government's Response has approved this brief.</p> <p>Signed:</p>  <p>Date: 18.09.08</p>
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