



UPDATE 3 - June 10, 2005

New Qld Organisation for Ageing Carers of People with a Disability

Steering Group: Sue Boyce, QPPD (Chair); Toni Anderson, ARAFMI; Graham Schlecht, Carers Queensland; Guy Clarke, formerly Spinal Injuries Asc.; Marj Bloor, ARAFMI (Secretary).

Auspecting Organisation: ARAFMI

Life Long Planning Program Project Consultant: Bob Burgell.

The new Lifeways Organisation, designed to assist families with an adult child with a disability, is expected to be established in Queensland in the 2005 calendar year.

The organisation will help families to answer the question *'What will happen to my adult child with a disability when I/we can no longer care?'*

Lifeways will provide information, resources and facilitation around all aspects of planning for families. The organisation will initially be established in Brisbane and move into selected regional areas within its first three years.

The organisation is the outcome of the 2003-4 Life Long Planning Program Project undertaken by eight Queensland disability organisations with funding provided by Disability Services Queensland.

The LLPP summary report is available on the ARAFMI (www.arafmiqld.org).

This Project was undertaken in response to the huge number of Queensland parents who are now expressing serious concerns about the long-term safety, security and happiness of their family member with a disability.

Hundreds of families from all over Queensland have attended workshops run in the past few years by DSQ, the Office of the Public Advocate, ARAFMI and Mamre, among others.

The Project conservatively estimates there are 32,000 Queenslanders, aged 15 to 64, with a profound or severe disability in Queensland being supported by family and other informal carers.

The reasons for this 'new' need are complex but, primarily, people with a disability are now living in the community, not institutions, and they are more and more likely to outlive their parents.

The Project has examined overseas models and agreed that it's not money or housing or paid government services that keep people safe, although these are important. It's **relationships** that keep people safe.

Overseas this has translated into the establishment of a **personal network** around an individual and their family. The network gradually replaces the parents in their nurturing, service monitoring and planning roles.

Some families would establish their own networks. Others would use a paid facilitator from Lifeways for assistance in developing and sustaining their network.

Based on the Project findings, the Steering Group is committed to ensuring the Lifeways Organisation would:

- Be family driven
- Be flexible--to meet family needs wherever in Queensland the family is
- Offer only planning and facilitating services, including financial and estate planning
- Advocate for the improvement or development of services, as needed
- Seek funding from a variety of sources so it remains independent of government, sponsors, and the disability industry
- Charge reasonable fees, but ensure families were not denied access because of inability to pay
- Encourage families to start planning early in their child's life.

For further information:

Sue Boyce, QPPD, Chair Lifeways Steering Group
0428 715 553/ sueboyce@everhard.com.au

Marj Bloor, ARAFMI, Secretary Lifeways Steering Group
3254 1881/ marj@arafmiqld.org

The Project Group has agreed the following Key Operational Values:

Enrichment of Society

- When people with a disability are given the opportunity to fully express and contribute their unique qualities and diverse capabilities, all of our society is enriched.

Interdependence of Society

- Neglecting the potential and positive contributions of people with a disability and their families jeopardises the well being of the whole society.

Natural Authority of Families

- Parents and other family members have the most pivotal role and natural legitimacy in advocating for and supporting their loved one with a disability to be as empowered and safe as possible.

The Role of a Personal Network

- A personal network around a person with a disability supports the whole family by participating in, and ultimately sustaining, the planning of a meaningful life for the individual within their community.

Family Controlled Governance & Management

- An organisation governed by a committee/board of family representatives is the best way to ensure, into the future, that the organisation responds to the life long planning needs of families, not its own needs.

Flexible Design

- The internal design of the organisation must recognise the differing needs of remote, rural, regional and metropolitan families and the organisation must advocate for all other support and service arrangements to give the same recognition.

Affordability

- Any fees charged by the organisation will be based on a family's reasonable capacity to pay, but access will not be denied to families that cannot afford the fees.