**SUBMISSION TO NDIA ON A PROPOSAL FOR A NATIONAL DISABILITY INSURANCE SCHEME QUALITY AND SAFEGUARDING FRAMEWORK**

**FROM: GEELONG PARENT NETWORK**

**30 APRIL 2015**

**About the Geelong Parent Network**

Geelong Parent Network is made up of members who are lifelong family carers of people with intellectual disabilities in the Geelong Region. The Network was established in 2003 to provide a forum, support and voice for family carers. The current membership is over 70. Most persons being cared for have an intellectual disability of some form and often other disabilities as well. They receive services from a wide variety of disability and community agencies throughout Geelong. Being in the National Disability Insurance Scheme’s Barwon Trial Site, members have had first hand experience of developing plans and working with providers since the scheme commenced in 2013.

Most members are lifelong carers of sons or daughters with intellectual disability who have limited decision making capacity. A key principle to effectiveness in our role is stated in the NDIS Act 2013 (S.3(1e)) and referred to in the Proposal for National Disability Insurance Scheme Quality and Safeguarding Framework Consultation Paper (p.7): “enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.”

**Issues with NDIA support**

Our members are located in the Barwon Trial Site and participating in the National Disability Insurance Scheme. After nearly two years in the Scheme, there is concern that the nature and level of support being received particularly in the NDIA planning process, but also in implementation, need to be significantly strengthened to meet quality outcomes with appropriate safeguards.

Discussions among members have noted the following:

The experience and training of planners needs strengthening so that they better recognise and support the vital role families have in promoting informed choices of sons/daughters (cf. Consultation Paper, p.12).

Quality outcomes require better ‘supportive conversations’ with participants and their families in identifying current and future supports required to realise a person’s goals and aspirations (cf. Consultation Paper p.96).

Families generally have a good understanding of the functional limitations of their sons/daughters and the impact this has on their daily lives. A quality outcome requires a high level of listening and understanding from planners. The rhetoric (cf. Consultation Paper, p.16) of building capacity through plan development has been far beyond the reality experienced by many family carers.

Publications need to be more user-friendly, in plain English, and provided in hard copy alternatives and not assume people with disability and their families have online access. The Consultation Paper seems to assume that information will be generally accessible online. Approximately three-quarters of the membership of Geelong Parent Network do not currently have online access.

There needs to be greater support for families in the implementation of plans.

**Complaints**

We agree with the Consultation Paper (p.51) that there should be an effective and nationally consistent complaints mechanism that ensures:

providers of supports have adequate internal complaints handling mechanisms in place;

effective, fast and accessible external dispute resolution mechanisms are available to consumers; and

serious and systematic concerns are able to be identified and addressed.

We support Option 3 (Consultation Paper, p.54) that would require, as a condition of registration, that providers demonstrate they have effective complaints handling processes and there be a formal external complaints body. This should both support participants in having their complaints addressed and resolved and assist providers manage the complaints effectively.

We also support this function being implemented through a body independent of NDIA. We know the Disability Services Commission in Victoria is established independent of government, the Department of Health and Human Services and Victorian disability services to provide a free, confidential and supportive complaints resolution process and believe this works well. It has been especially important to people with intellectual disability and their families for whom the need has been amply demonstrated. Nearly two thirds of the complaints lodged with the Disability Services Commission have been associated with services for people with intellectual disability. Not surprisingly, the source of complaints has been families raising issues on behalf of their family member. These have comprised approximately half of the total number of complaints received. (Disability Services Commissioner, *Learning from complaints: Occasional Paper No. 2. Families and service providers working together*. DSC, Victoria, January 2014, p.7)

**Community visitors**

We believe there is a continuing need for community visitors and their public reporting. There remain serious issues relating to abuse, harm, neglect and violence particularly against more vulnerable people with intellectual disability and others who have less capacity to advocate for themselves.