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Submission No. 693
(Inq into better support for carers)

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INQUIRY INTO BETTER SUPPORT FOR CARERS

Cooinda Family Support Group Inc. is a NSW/Victorian government funded support service based in Albury/Wodonga. Cooinda was established by five families in 1976 and today provides a comprehensive range of holistic disability support programs to over five hundred and fifty families. These families live in Albury/Wodonga and outlying areas with a small number of families who have moved out of the area e.g. to Melbourne retaining membership. In the year 2000 Cooinda was noted by the Human Rights Commission to the Federal Attorney General as a model for rural and remote Australia.

Carers involved with Cooinda are from a range of backgrounds including grandparents; one and two parent families; young Carers/siblings; Carers who have intellectual disabilities; indigenous Carers and Carers of ethnic origins. These Carers are from a variety of family lifestyles and workplace and educational backgrounds. Together they make up the service that is Cooinda.

The family members cared for include those with intellectual disabilities; autism spectrum disorders; physical disabilities; vision and hearing loss; limb loss; genetic disorders; life threatening illnesses with accompanying disability and pervasive developmental disorders. The combination of family members cared for includes children, parents, husbands, wives and grandparents and often a combination of these.

Response to the Terms of Reference:

The role and contribution of Carers in society today is one of limited choice with little acknowledgement for the contribution that needs to be made in order for their family members to have any quality of life. There is no choice for primary Carers of family members with disabilities as to whether they 'care' or not. The lifepath that Carers have to follow is most often severely restricted due to the ongoing commitment that needs to be made. The Caring role is multi-faceted from managing day to day living and often personal care to ensuring safety and maintaining health where possible. One of the most difficult restrictions is in dealing with government departments such as Centrelink or state disability agencies and also the range of agencies, services and professionals that are required to be dealt with on a regular basis. The majority of Carers are living with ongoing stress and often ill health. For most families where there are Autism Spectrum and similar disorders we usually see depressive illnesses in Carers. In particular At Cooinda we see caring that is always carried out with love for a family member regardless of the loss of lifestyle, ill health, isolation and difficulty.

Of particular significance is the lack of recognition of Carers and their right to quality of life. Carers are often left to deal with very difficult situations due to the fact that they do not have any choice. We see many Carers who are undertaking nursing duties (with no training to do so), and situations where Carers are left to undertake tasks where due to O.H.& S guidelines agency assistance is unavailable.

Many Carers live with little sleep or the time and opportunity to care for their own health. Of great concern to Cooinda are the number of Carers who have back injuries from lifting family members and equipment.

Financial difficulty seems to go hand in hand with the caring role. Many Carers cannot work due to caring and are forced to live a hand to mouth existence due to the funds needed to provide care. We often see families who go without regular meals and the basic necessities of life.

We work with families who have up to five family members with disabilities including parents and children. The complexity of some of these caring situations is very challenging for Carers, with some agencies not fully understanding the situation thus providing inadequate support.

Of particular concern are the number of Carers who live in violent situations with unpredictable challenging behaviours a part of daily life e.g. Carers covered in bruises always; Carers who have to lock up their siblings to keep them safe; Carers who are forced down on the floor with knives at their throats regularly; Carers who are attacked by family members while driving vehicles; Carers who live with significant violence every day and are unaware that violence is not a part of general living.

Acknowledgement of Carers needs to be one of valuing and respecting the caring role and the significant contribution that Carers make to life in Australia today. A review of government financial payments for Carers is urgently required with acknowledgement and financial recognition given to those Carers who are undertaking this role in society.

Carers should also be recognised by more adequately supporting their family members financially and ensuring that the extra costs to family living that disability may cause are met.

Recognition of the Caring role should be made by providing appropriate education and information in order for caring to be made easier and more highly valued.

The barriers to social and economic participation for Carers are multiple with respite options often limited and competitive and structured around service guidelines and not the individual needs of Carers. The concentrated demands of the caring role often leaves Carers isolated with limited opportunity for community participation in any way. We continue to find older Carers who have no services and who care fully for family members. They come to our attention when they reach a level of crisis. These Carers have often been registered with government agencies but are overlooked in the system over time.

We work with a range of young and new Carers who are often referred to Cooinda by local paediatricians when a diagnosis is made. If this occurs it is possible to minimise the stresses that are part of the early years of the caring role by linking families together and providing comprehensive referral and information including practical supports.

A large number of siblings who care have ingoing difficulty with their education, having their life options reduced or limited e.g. siblings in their final year of secondary school not completing VCE due to caring requirements.

For many Carers to consider working is impossible. This should be recognised by government with the caring role valued and adequately funded. Many female Carers with government contributions means tested on partners income, feel neglected, angry and abused by lack of recognition of the support that they provide. This should be costed out and a dollar figure put on caring to bring clarity to decision makers.

If it is to be anticipated that Carers will be part of the 'workforce' then assurance of quality care for family members must be given.

Key priorities for action should include:

1. Recognising and valuing the Caring role at a government level
2. Seeking out and documenting all Carers are and their family needs for support. Too many Carers are overlooked and isolated.
3. Community education in order to provide a whole of Australia approach to supporting Carers. Providing a variety of comprehensive education and information at a local level.
4. Adequate funding to provide support and services for family members who require care
5. Providing an appropriate level of funding to Carers in recognition of their role.

6. Adequately funding a range of Carer Support Groups such as Cooinda Family Support Group in order to relieve the pressure on Carers and provide a basis for mutual support and independence.

Of significant concern to Cooinda are the differing state policies and funding options for Carers seen daily in the border region. Federal funding is often meted out by state government with differing guidelines e.g. respite funding, in restrictive and demeaning ways not always being supportive of Carers.

It is also demeaning for Carers to have to 'beg' from services as they so often do to be able to provide for their families. We see a number of families who regularly have to seek donated food parcels to be able to use existing funds for equipment and medication.

We appreciate the opportunity to be able to participate and welcome positive outcomes for Carers.

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(Co-ordinator)