

Submission  
No 58

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

**Organisation:** Fragile X Association  
**Name:** Ms Jocelyn Selwood  
**Date received:** 5/08/2010

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Dear Rachel

Thank you for the inviting the Fragile X Association to make a submission to the 'Inquiry into services provide or funded by the Department of Ageing, Disability and Home Care.'

Fragile X syndrome is the most common cause on inherited intellectual disability and yet is widely unknown. Fragile X syndrome (FXS) affects approximately 1 in 3800 males and 1 in 4000 females. 12 people each week are born in Australia affected by FXS. Many of our families have more than 1 child with FXS, some with 4 or 5. The average age of diagnosis in Australia is 5 ½ whereas it is 3 in the US.

Early intervention strategies from allied health professionals including speech pathologists, occupational therapists and psychologists are imperative and regular medical checkups also improve quality of life substantially. There are no extra government benefits provided to enable people affected by FXS access these services.

As an association we provide specialised multidisciplinary clinics of a cost of \$1000 per member, plus we also provide mobile clinics and workshops for areas not serviced by our clinics. These outreach workshops/clinics cost us \$12,000-\$15,000 per visit. We are not able to provide regular ongoing clinics to each person which is what they all require.

There is much more that can be done for these families as many essential services are not funded and families should be supported from cradle to grave. Areas of major concern for our members are employment, adult education and independent living. There is a major fear of what will happen to their child/children when the parent is no longer able to care for them:

Many of our members' concerns were raised in our submission to the "Inquiry into the Provision of Education to Students with a Disability or Special Needs" which we would be happy for you to refer to.

We would also be available for the public hearings if needed.

Regards

Jocelyn Selwood  
Administration Manager

**fragile X association**

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