



House of Representatives Standing Committee
on Family and Community Affairs

Submission No: 05

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Secretary: *B. Fisher*

Kiefel Family submission to Inquiry into Improving children's health and well being

Addressed to: The Standing Committee on Family and Community Affairs

Committee Secretary
Standing Committee on Family and Community Affairs
House of Representatives
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In response to: Terms of Reference dated 17 October 2002 and issued by the Minister for Children and Youth Affairs, the Hon Larry Anthony MP

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Submission date: January 2003

Summary

- This submission deals specifically with the issues facing our family since the recent diagnosis that our son suffers from autism.
- We have found the total government service offering to be totally sub-standard &/or non-existent.
- We have had to self-fund a home-based early intervention therapy programme at considerable financial cost .
- This cost is affecting our current lifestyle and our long-term objective to be able to invest toward our son's future (and the rest of my family). We have to assume our son will not be able to provide for himself in the future, yet we cannot invest for his future.

- This submission requests that the government completely overhaul all levels of the current service provision to sufferers of autism, so that:
 - there is a cohesive and integrated system in place to guide family's from initial diagnosis, through all levels of service.
 - at least 20 hours per week of effective early intervention service be provided
 - significant tax breaks to families who provide self-funded early intervention therapy where no alternate government service is provided
 - support through all levels of education, at the school of choice

Background

Our 3 year old son was diagnosed with autism 9 months ago. At the time of diagnosis our paediatrician wrote to the Victorian Department of Human Services asking them to help us. We have not received any assistance or service from that Department. Our son is one of the “lucky” children who “only” faced a 6 month wait to attend 2 hours per week at an autism early intervention centre. A charitable organisation and our family fund his attendance. The only other government assistance we receive is a carer allowance from CentreLink worth approx \$2,000 p.a. To compensate for the lack of early intervention service offered by the government, we self-fund a home therapy program. This year, the wages and consultant fees to deliver our home therapy program will cost us approx \$29,000. This is after tax money, with no tax breaks or refunds available. We also have the added responsibility as employers to comply to laws relating to employment.

As a parent it is heartbreaking to know that something more could and should be done. For an able-bodied adult it is like living your worst nightmare. Watching your child suffer affects your marriage, friendships, health, your relationship with your other children. If life is this hard for the parent, imagine how difficult it is for our son.

Terms of Reference Questions:

1. *How can children's developmental needs best be accommodated in this rapidly changing social and technological environment?*

- With respect to government service, children’s development is basically the domain of 2 types of government department; Health and Education. This is further subdivided across 3 tiers of government; Federal, State and Local. It needs to be recognised that these divisions create gaps for some children. Autism is an example.

2. *What is needed most to strengthen family relationships, parenting skills and confidence?*

- Anecdotal evidence suggests families with an autistic child have a greater risk of divorce than “normal” families. The Federal Government need to recognize there are contributing factors to this increase in risk, which are outside the control of the family. Examples are financial stress and lack of government services. The government needs to recognise that divorce will result in an even greater dependence on Government services (e.g. single parent allowance, shift from self funded therapy to government funded therapy etc).

3. *What would a family and child friendly community look like? What practical steps could be taken to strengthen community engagement with families and children?*

- With respect to autism, the community needs to provide a more cohesive and effective total service to the affected person and their family. From initial diagnosis we have encountered delays, misinformation, no information, and a fragmented, substandard service. This is not family or child friendly.

4. *What are the gaps in existing services for children and parents? How could tiers of government and the non-government sector work more effectively to enhance service coverage and delivery?*

- Early Intervention services for children with Autism are sub-standard. In our case, there was a 6 month wait from initial diagnosis, to the provision of Autism specific early intervention service. The service offered is only 2 hours per week. Whilst we are very happy with the quality of service provided (Irabina "I can't wait" program at Bayswater Victoria, which is philanthropically funded, not government funded), we are totally dismayed at the paucity of services available. Plus we are "lucky" that we "only" had to wait 6 months for placement. Clearly there is a major short fall in service offering, a short fall that we have had to absorb ourselves by setting up an ABA* home therapy program for our child. This has come at a significant cost (tens of thousands of after-tax dollars per annum), which has lead to a significant lifestyle change for our family. Not only do we incur these costs, but we incur employer responsibilities in the employment of several tertiary student aged therapists who deliver the home therapy program. These students are also gaining industry training relevant to their field of study (disability studies and psychology). As employers we get no tax break for employment, or for provision of on-the-job training. As parents we get no tax break for provision of a service that any parent would reasonably expect to receive from the government. Furthermore, we are spending all of our savings now, severely limiting our ability to start planning and investing towards providing for our son well into his adult life. There are no certainties for the development of people with autism. We have to assume our son will be unable to fully provide for himself for his lifetime. We want to invest on behalf of our son but we are currently spending our savings on his current therapy so cannot effectively invest for his future. It is our conclusion and request that the federal government recognize the following:
 - Offering for Autism Early Intervention services are inadequate.
 - Many families have to cover for this shortfall by setting up equivalent home therapy programs at significant personal cost.
 - Families who do so should be granted significant tax breaks to reduce the financial stress borne (both in terms of reducing operating costs and in terms of investment incentive).

* ABA – Applied Behavioral Analysis. Developed by Dr Ivar Lovaas at UCLA in USA. It is an intensive 1 on 1 therapy program, based on discrete trial and positive reinforcement. It breaks down skills into component tasks and teaches children these skills, component by component. ABA forms the basis of much of the early intervention strategies in developed nations such as USA and Canada, with some states providing ABA therapy programs. ABA is entirely compatible with the theory underlying early intervention, that is, teach children skills in the first 5 to 6 years of life whilst their brains are still developing, thus maximizing the opportunity to make re-adjustments that will yield life long benefits.

- The above is really focused on the issues facing families with autistic children up until about pre-school age. There are many issues that we will have to deal with, as our son gets older and many more systems (primary school, secondary school etc.) to traverse. We anticipate that we will be continually confronted with systems unprepared for, or indifferent to the issues that face people with autism.

5. *What additional effort is required to meet the needs of Indigenous children, children from diverse cultural backgrounds, children with disabilities, children in jobless families, children known to be 'at risk' and children in foster care?*

- With respect to autism, the lack of early intervention to me demonstrates that governments are locked into an institutionalized mindset. The less money spent at early intervention stage will directly result in more money being spent to provide for the person from primary school age through to death. As a tax payer I find this outrageous. As a parent of a child with autism I am beyond outrage. I think of all of the hundreds of thousands of dollars worth of taxes my wife and I have paid over the last 20 years and the first time we really need specific assistance from the government there is nothing!

6. *What national goals and targets for improving the health and well being of children and families could be developed to measure progress?*

- National goals:
 - Does the Federal Government know how many people suffer from autism and related problems in the autism spectrum?
 - Does the Federal Government provide an integrated plan that will assist these people, from early intervention, through all tiers of education and into adult life?
 - Does the Federal Government understand the total cost to the community across all of these layers of government and service?
 - Does the Federal Government believe that the total end to end service provision is fully effective?
 - Does the Federal Government understand what it is like for these people and their families to traverse these systems?

Signed: _____

Signed: _____

Peter Kiefel,

dated 21/1/2002

Wendy Kiefel,

dated 21/1/2002