

16th April, 2016

Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

Please find our submission for consideration regarding the INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER.

We have a five year old son diagnosed by Paediatrician Peter Eastaugh at 2 years old. Bailey would likely be classed as high functioning but has a cousin and uncle who are both lifelong dependants. Bailey also has a 20 month old sister who is high risk and is exhibiting some early red flags.

We chose, after significant research and deliberation, to engage Bailey in a centre based ABA therapy in North Melbourne at a significant cost of \$70,000 per annum as well as accommodation and travel cost in excess of \$25,000 per annum.

We chose ABA as the intensive play based therapy was the most comprehensive tailored program we could find.

ABA is still considered an alternative therapy in Australia but is still accommodated by Fehsia funding by virtue of the fact it is an evidence based therapy. The investment in this calculated leap of faith is out of reach of a lot of parents but the outcomes achieved by a vast range of his fellow participants, both low and high functioning, have vindicated our decisions to do so.

In Melbourne, ABA is much more accessible avenue for parents, many choosing to hire a therapist for at home sessions with an Autism specific Psychologist writing and overseeing programs for the sessions. This tends to range between \$35 and \$40,000 per annum which if the right therapist can be accessed, can be offset with Child Care Rebate.

We have spoken at length with our Psychologist team at Autism Partnership who would be willing to participate in working with Bailey out of Shepparton, however we were unable to find a single therapist in our region to provide the daily program and to work in with the psychologists. In fact, I have not spoken to a single parent in Shepparton who is familiar with the ABA therapy alternative. Even Peter Eastaugh had limited knowledge of the therapy.

The bottom line is that an hour or two here and there of OT and Speech is just not enough intervention for the most part, and the formative years are just so critical to be able to develop enough skills to allow a base skill set to enable later independant living, and the economic cost to the Australian public must be ridiculously high, not to mention the mental toll on the carers.

Bailey is now attending Primary School as a prep at Moomba Park, Fawkner. This school run an IDEA program, inclusive schooling in a mainstream environment, for autistic children where the aides are trained in ABA therapy.

Now this is obviously a unique public school and may be difficult to reciprocate in Shepparton, but it's meeting the needs of a lot of children on the spectrum.

Latrobe run a similar program which ABA is formulated from called Early Start Denver Model (esdm) but is fully funded and very difficult to access due to restricted numbers.

So for our family, this has meant my family are now based in Melbourne 5 days a week, apart from myself who has to work in Shepparton to support our choices. It puts additional strain on relationships and means my wife has little support around her and the kids certainly miss their Dad. Michelle is an educated and experienced child care worker and kinder teacher and at times has ran a local child care facility and worked for a local kinder, both areas our region has a shortage of workers in.

I am also under pressure to find means to spend more time in Melbourne to support my family and I could imagine the brain drain on the Goulburn Valley does not stop with our family.

ABA in the USA is federally funded up to 40 hours per week but not in Australia. This is what it is and whilst I'd like to see this federally supported in Australia, moreover id like our region to at least have the capacity to support this alternate therapy as a real option for parents and children in our region.

Please consider our submission as a call to arms for regional families living with Autism.

Kind regards

Ben Snow
On behalf of Ben and Michelle Snow

A large black rectangular redaction box covering the signature area, obscuring the name and contact information of Ben Snow.