Productivity Commission Submission

I am a former US resident, and am sharing my experiences with Government disability related supports and services as the parent of two children with special needs in the hope that it might give the commission some ideas on ways to structure and support government assistance.

While I am a firm believer in Self Managed Funding and see that as the direction that disability related government fund should be headed, I am also aware that SMF is not what everyone in the sector wants or needs. I have put forward my personal experiences which hopefully reflect a large degree of choice, without a full SMF program.

I hope and plan to make other submissions to the Commission regarding special needs education, but am trying not to bite off more than I can chew at once!

California v South Australia

In California, people with "developmental disabilities" and their families are supported by a series of "**Regional Centres**" as mandated by **The Lanterman Act**, which gives those with developmental disabilities the right to services and supports that enable them to live a more independent and normal life. It means that Regional Centers are the "Payors of last resort" such that if a service or support is truly needed by a person with a developmental disability, and there is no-one else to pay, then Regional Center gets (and pays) the bill.

http://en.wikipedia.org/wiki/Lanterman_Developmental_Disabilities_Act

I'd like to share how my family have been supported by the Regional Centers and the Lanterman Act, and make some comparisons with our situation since moving to South Australia in 2006.

In 2000, my first child, a son, was born in California and was quickly diagnosed with Down syndrome.

Within a week of his discharge from hospital, where the hospital social worker had put in a referral to the Regional Center, an **Early Intervention team from that local Regional Center** had made an appointment with me and appeared on my doorstep. A social worker, developmental educator and an occupational therapist arrived.

The OT helped me with feeding issues, getting my son to nurse. I was fully supported and encouraged to breastfeed him. The social worker explained that we were entitled to **24 hours per month of respite**, which could be provided by any legal resident/citizen over the age of 18, including my extended family (thus further encouraging natural supports and inclusion), if they met that criteria. Respite was paid either to an agency of my choice, or at a slightly lower rate if reimbursed to me directly on a monthly basis after submitting the relevant timesheets.

As I needed to return to work quite quickly, I was also entitled to up to **40 hours per week of child care assistance** (plus travel time) – that is, they would fund the difference between regular childcare, and the cost of a nanny/in home care, up to a limit of $12/hour in total (that limit would be increased if he had needed nursing care)

As my son grew, respite dollars could be pooled to use for a respite camp, or Riding for the disabled day camps, or almost any activity with a registered provider where a parent was not required to be present.

During his Early Intervention years, we attended geographically based fortnightly support groups, with children with a wide range of disabilities, of similar ages. These groups featured an OT and a physio at almost every session, as well as a social worker facilitating the group, sharing resources. Each family had access to a counsellor, if required, and a bevy of services were available, according to the family's needs, which were updated in a yearly mandated Individualised Family Support Plan (IFSP) until the child stared school, at which point each person with a disability had a yearly mandated Individual Program Plan (IPP).

During the Early Intervention years, **all direct services (physio/speech/Ot etc) provided through the Regional Center were in "Natural Environments"** – that meant at home, the park or at child care – wherever the child would naturally be. They could take place at his Kindermusik or Gymbaroo session – whatever worked for our family! My son was also provided with fortnightly session with a qualified early education developmental teacher. These teachers were absolutely invaluable – from sharing resources, to teaching me how to expose my son to the world around him, and how to have great expectations for what he would achieve. They also carried out fairly regular assessments on my son's progress and reported the results to me.

My son also became eligible for a "MedicAide Waiver" also known as a Katie Beckett Waiver or "**Institutional Deeming**". This waiver provided Health Insurance and a host of services on the premise that if I chose to give up my son, it would cost the State a fortune, hence it was better to provide services to help me keep my child at home. The program is based on a similarly designed program which was originally designed to help keep elderly folk at home, rather than in nursing homes which cost the community so much more.

As a recipient of the MedicAide Waiver, we were eligible for "**In-Home Support Services**" through our County (local council). A social worker employed by the council visited my home, and each year (or more often if circumstances changed) worked through a "needs assessment" that essentially determined the extra hours required to care for my child, over and above a typical child of the same age, up to a maximum of 80 hours per week (at which point, I assume, they deemed that it was more cost effective to actually institutionalise someone (foster care etc).

I was then able to choose my own workers and get them registered, or interview and select workers from a pool of workers registered with the local IHSS support worker agency. For families on low incomes (as was in my case at the time) I could become my child's own support worker and be paid tax free, accordingly. (The rate of pay was quite low at $11.50/hr, and in the current CA budgetary crisis, is likely to drop, but that is another story)

By this stage, I had two sons with special needs who qualified for IHSS (my second son was born at 1200gm and quite premature), so the combined hours to support them came to around 50 hours per week. I split my IHSS hours according to how much part time work I could manage, and the acuity of their illnesses week by week. Most weeks I would work about 20 hours per week at my regular job, using IHSS workers I had found and trained myself (a neighbour, and a student) to cover those hours, and received the other 30 hours of IHSS pay, untaxed, myself.

Here is a link to a page on the SEIU web page. The SEIU are the union for Home Care workers in California. I think the final paragraph on the page speaks volumes. http://www.seiu-ultcw.org/Homecare/Default.aspx

It says **"Because California relies so much on homecare instead of nursing homes, California's per-capita Medicaid expenditure on long-term care is approximately half of the national average."**

A good overview of the IHSS program can be found at:
http://www.disabilitybenefits101.org/ca/programs/health_coverage/medi_cal/ihss/ and http://www.disabilitybenefits101.org/ca/programs/health_coverage/medi_cal/ihss/program2.htm, but please note that the income limits and eligibilities are less draconian for people who access IHSS through the Institutional Deeming/MedicAide Waiver. There is a "share-of-cost" for people with certain assets or income, and some hours can be used to support adults with disabilities at their place of employment.

To continue my story:

As a single parent by this stage, this was a very flexible way to manage keeping me in the workforce, as well as maintaining myself as primary carer, particularly when the boys were in hospital or ill. On occasion, I would make a private arrangement with the Support Worker to say, work two hours doing cleaning, but entering three or four of my allotted hours on their timesheet. Respite often worked in the same way, as occasionally what I needed far more than a break from my kids, was to get out and enjoy my kids, and come home to a clean house!

Through the CA Medicare (State run MedicAide) my sons were also entitled to **fully funded monthly physio, speech and Occupational Therapy**. As my younger son had a physical disability, he also received specialised OT and physio as needed (occasionally 2-3 times weekly) through **California Children's Service (CCS)** – a centre based therapy service offered to all CA children up to the age of 18 who have a physical disability (although this did not cover this with genetic disabilities, and was focussed mainly on children with Cerebral Palsy or brain injuries).

Through my employer at the time, I was able to set aside a portion of my income in a **Flexible Spending Account (FSA) "cafeteria plan",** which is a system that allows an employee to spend their cafeteria plan funds on a range of approved costs (which include practically all disability and education related expenses) and the funds set aside to that plan were "before tax" – ie: untaxed income. The only "catch" was that the money had to be spent in the financial year it was put aside or it would disappear – "use it or lose it". This FSA reduced my taxable income sufficiently that I qualified to earn the IHSS income as explained above. It also meant that I could spend that portion on extra therapies, tutors, equipment etc with untaxed dollars, as well as qualify for food stamps and other government assistance. http://en.wikipedia.org/wiki/Flexible_spending_account for more info.

It was a horrible shock to move back to Australia, in terms of disability related supports and services.

I did qualify for Carer Payment, but that was where practically all governmental support ended. **I waited on a list for more than two years for respite**, and was very very lucky to find a provider through the Family Day Care respite program who was willing to come to my home (one son has immune system deficiencies and could not safely be in a shared care situation).

We can receive **up to five sessions a year in total for speech, physio or OT combined from Medicare** through the Extended Primary Care plan.

In South Australia, my sons receive **no OT, no speech therapy and no physiotherapy from any government service** (apart from the five partially Medicare funded sessions each year). We receive occasional respite (four hours or so every few months) from the Commonwealth funded Carer Support service. We receive no disability related special support or rebate for the Nanny care that is required in order for me to work and still have my children attend their privately funded physio and speech sessions etc. **I cannot claim any disability related expenses as tax deductions**. My disposable income, while working full-time, is just a whisper away from being lower than if I stopped working and returned to the Carer Payment. **My passion for my work is only motivation for working. There is certainly no worthy financial benefit, particularly as a single parent.**

I won't pretend the California system is/was perfect – it was like pulling teeth to figure out what programs were available and how to access them.

I think the biggest, and most powerful difference, as a parent of two kids with special needs, between SA and CA, was that we had **a Social Worker/Case manager who we could call. Someone who actually laid eyes on us each year, and didn't change every three months.** An annual plan that was person/family centred, is a powerful tool indeed.

I thank the Commission for providing an opportunity to help improve the “system” in Australia. It is shameful that a country as wealthy as ours treats its people with disabilities with such comtempt.

Please contact me if I can be of any further assistance, or put the commission in touch with people who use or manage these services in California. I still maintain regular contact with many Californians with children with disabilities, as well as with my contacts with the board of the organisation that I co-founded “Special Parents Information Network of Santa Cruz County” http://spinsc.org/

I wish the Commission all the best with its mammoth task ahead.

Yours sincerely,

Sam Smith