



0357627643

Family and Community Development Committee
Parliament House, Spring Street
East Melbourne
VIC 3002

To the Family and Community Development Committee,

Our daughter was born in January, 1986, with Down Syndrome. During her first year, Bronwyn developed Infantile Spasms, an unusual form of epilepsy, brought on by the Whooping Cough vaccine. It took 6 months for this to be diagnosed; 6 months of heart-wrenching anguish for us as we watched her regress beyond a newborn in her disabilities. Today she has noticeable Autistic tendencies and has low functioning Down Syndrome. That part of our lives still affects us today, and Bronwyn still has spasms now, each and every day but does not need medication for this. However she is asthmatic and requires medication for asthma. We were told that she would only have a short time to live, but 21 years later, she is able to enjoy certain things in life and endears herself to many.

Bronwyn attends Central Access daily, Mon – Fri, 9am – 3pm where she participates in cooking, gym, ten pin bowling, attending the local library, “swimming” at the local hydrotherapy pool and multi programs. Unfortunately my husband and I suffer health problems which have been exacerbated by our daughter’s long drawn out medical problems and as a result we had to make the huge decision to look into supported accommodation on November 2007.

We were assigned a Case Worker through the Department of Human Services at Wangaratta to collate information about our daughter and ourselves to present to the Department so that Bronwyn’s name would be registered and hopefully she would reach Priority Listing for Supported Accommodation. Numerous mistakes were made and Bronwyn’s case wasn’t heard first time round as a supporting doctor’s letter had not been included. Oh! The case worker didn’t know to include that – the most important thing. We waited another month while I got all the relevant information needed. After all, the case worker couldn’t possibly seek out that sort of personal information. By July 2008 I was so stressed that my doctor told me my body was wired up and I was ready to explode.

My husband took everything into his control and whisked me away for a holiday. Villa Maria funded respite for our daughter. They have helped us to cope as we seem to be no closer to getting supported accommodation for our daughter. Bronwyn is still living at home with us and our 17 year-old daughter who is studying VCE. It is not easy for Bronwyn’s siblings to help with her and to continue with their studies... but they do. Bronwyn’s problems cause a lot of stress to each and every member of her family.

I have developed Rotator Cuff Disease in both shoulders and am seeing a rheumatologist in Melbourne as a result of caring for our daughters needs. I am due to have a second Cortisone injection under ultrasound guidance later this month and hope that this will ease the pain. I also have Epilepsy and have had 3 seizures in the last five weeks. My husband has Bipolar Mood Disorder and copes well, but like me he needs a good nights sleep. Late last year Bronwyn was extremely sick with stomach ulcers. These resulted from medication she was on at the time. She also was found to have thyroid problems and was hospitalized for a week. In March this year she was finally well

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enough to undergo a hysterectomy, something she had been needing for at least 15 months. In the rural areas, doctors aren't always quick to diagnose.

Unfortunately Central Access, the day centre where Bronwyn attends, has not catered adequately to meet her needs, and we feel that she would be better placed elsewhere. We have voiced our opinions about the running of the day care centre hoping for improvements. Respite accommodation has been a great help locally.

We have been told that supported accommodation could be found in Wodonga, Wangaratta, or Shepparton. We are waiting to hear from the department. Meanwhile, they feel that it is not necessary for us to have a Case Worker as Bronwyn has reached Priority Listing. Anytime that anything new happens, we have to contact the Department. As if we don't have enough to do already, running our own business! We are glad to have the opportunity to let you know of our situation.

Sincerely,

Bev and Ron Schulz.

Beverly & Ron Schulz
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