

## **Inquiry into Accommodation and Intensive Family Support Funding for People with Disabilities**

**Committee Name:** Community Development and Justice Standing Committee

**House:** Legislative Assembly

**Members:** Ms Margaret Mary Quirk MLA  
Mr Ian Maxwell Britza MLA  
Dr Antonio De Paulo (Tony) Buti MLA  
Mr Christopher (Chris) David Hatton MLA  
Mr Michael (Mick) Philip Murray MLA

**Submission By:** Ms Neeva Stephen

**Date:** 22<sup>nd</sup> December 2013

The sheer irony that I am finally drafting my family's submission the evening before it is due, and with only 3 days until Christmas, should be indication enough of my general attitude towards the issues being addressed by this Inquiry. And the main reason I am actually able to get it done is due to the fact my significantly disabled son, Josh, has not been in my care the past couple of days, so I have had a reasonable amount of rest. Usually, at this time - it is just after 7 pm - I would be preparing Josh's 5<sup>th</sup> and final gastrostomy feed for the day plus medications before bed and counting down the minutes until I can fall into my bed.

### **Terms of Reference:**

#### **1. The adequacy of current processes for determining funding support for people with disabilities who live with their families:**

My twin sons, Jake and Josh, were born 11th June 1997, 11 weeks premature, both with bilateral clefts of the lip and palate. Josh remained in hospital until he was 1. Our first visit from DSC LAC was Oct 1998 and our first "Carer" commenced March 1999, 5 months AFTER I first asked for support. Late in 2004, after 6 years of regularly requesting more support, I finally lodged for CAP funding under the Intensive Family Support stream. I was requesting the equivalent of 33 hrs support per week. Every one of the 6 times I was knocked back (over 2 years), I struggled with the amount of help we already had, which equated to approximately 10 hrs care per week. The theme of ALL the applications was the imminent demise of my marriage. Personally, I also struggled with the fact that I was in direct competition for help with my friends, as there was never enough funding to help all those who needed it - this is a situation nobody should have to endure.

In Nov 2007 my marriage did fail, so I put in a "change of circumstances" for the Dec 2007 round. Surprise, surprise, I received the funding, due to being in crisis!! And yet DSC says they are not crisis driven... DSC talks about supporting the family unit, using "natural connections" to keep those with disabilities within their family home; it is such a shame they don't actually follow through with that philosophy.

## **2. The level of unmet need:**

I have now had IFS funding for nearly 6 years, however I am **still** regularly chasing my tail and responding to crisis. I submitted a request to increase support hours in the last (October) round, but - again, surprise, surprise - I did not have my application approved. This increase was an effort to proactively respond to treatment for a medical condition that I commenced 4 weeks ago and is expected to continue for up to 2 years. God help my children if I become hospitalised unexpectedly. I don't allow myself to think about what will happen if I should become permanently incapacitated, or worse.

## **3. The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future:**

Even though we now have funding, there just aren't enough Support Workers available. Despite Josh's funding being managed by a Service Provider, I have personally found 2 of the 6 current Support Workers. Also, there are insufficient Support Workers available in an emergency, so I regularly need to go without support or have Josh go to out of home respite and/or spend additional time with his Father. If I go without support, that means I need to reduce the level of personal care Josh receives, specifically showering and toileting. If he stays with his Father this means time off work, something he really can't afford to do very often. Out of home respite is my last resort, as I loathe shipping my son off to somewhere that isn't his home. It doesn't matter how much the Support Workers at respite love Josh - and I know they do love him - they aren't his Mum or Dad. Also, this last option is **only** available if the service has room for Josh and that isn't always the case.

## **Recommendations**

1. Increasing Support Worker base - ensure remuneration and conditions for Support Workers in this sector is adequate.
2. Clearly more funding applications need to be granted, so the State Government needs to find a way in the budget to make it happen. More individuals with disabilities and their families being supported will directly lead to more people - with and without disabilities - in the work force, thereby flowing through to the budget. I just don't understand the short-sightedness of State Government after State Government not realising that **adequately and appropriately supported** people with disabilities and their families are the answer to the future of this State (and country, for that matter).

There are many, many more issues I could raise and just as many recommendations I could make, but it is now 8:10 pm and, with Josh returning to my care tomorrow, it is time I went to bed. I would appreciate the opportunity to appear before the Committee, if deemed appropriate.

**Yours sincerely,**



**Neeva Stephen.**