12 May 2010

Patricia Scott, David Kalisch, John Walsh

Commissioners

Disability Care and Support Public Inquiry

Dear Ms Scott, Mr. Kalisch & Mr. Walsh,

Re: Support for National Disability Insurance Scheme (NDIS)

My story has already been told thousands of times in the hope of change and here I am again hoping that someone somewhere will listen. What is not often understood is that this story is also told over and over as you beg and plead for services. Desperation, abandonment, mental and physical breakdown are the only types of words that capture the attention of a system that has no long term plan. We are lucky that we live in this great country, but we can only be truly great if we look after those that can't look after themselves.

My daughter Sinead has an unknown neurological disorder which has resulted in a physical, intellectual and visual disability. Sinead loves life and I know this as she has always fought so hard to keep it. Epilepsy racked her little body for years and even though we have the seizures fairly controlled (she takes 5 different anti-epileptic medications daily) she still suffers from constant sub-clinical activity. Sinead's main mode of transport is her wheelchair, however she can walk on her knees and she has the huge sacs of fluid on them to prove it, such is her desire for independence. However that is where her independence ends, she has a feeding tube for all of her liquids and medications and is fully dependent in all aspects of her life. Sinead feels pain but has no way of expressing it, so someone could hurt her and they wouldn't know it, as she would not scream out or even cry. This affects the whole family, my other daughter also spent most of her life either in hospital or not being able to do what the other kids do as we simply did not have the funds (I had to go on the Carers pension) to allow this, besides the fact that her father left as unable to cope, and mother preoccupied caring for child with disability. Personally I have had to accept a life of being alone; caring for my child/adult, not enough support given that allows a carer to have a life outside of the carer role.

My daughter is just as valuable a human being as anyone else and deserves to be valued; she certainly has lessons that she could teach others. I am truly afraid of what will become of the two of us, I will hold on as long as I possibly can but I have seen others that also love and care for their children physically disintegrate and become disabled themselves. They should not have to wait, beg and plead to be helped.

Sinead is 14 and already I am trying even to get some direction as to what to plan for the future. To quote what I have been told by other families "if you think it is bad now, as soon as they turn 18, they are completely forgotten about". This is not socially right and must be rectified.

The proposed plan for a National Disability Insurance Scheme (NDIS) eradicates all fears of care. It is a full time job for most of those caring for the disabled, so the carers pension does not provide an opportunity to put away for the future that includes being able to afford a descent standard of care. The thought that when I die (which will be probably a lot sooner due to the physical and emotional demands) that my girl will end up wherever, being cared by whoever is really distressing.

My only concern for this scheme is that once again administration costs overwhelm the system. Currently my daughter receives a minimal support package (that I received after several submissions and interviews, to determine that I was about to fall over before it was granted). The service provider who manages this package receives almost half (44%) of the package in administration costs, if costs were broken down as far as the time spent managing my case, I know this administration cost could not be justified. These cumbersome administration costs, unfortunately most schemes like these are like the schemes to save the children in Africa, people are reluctant as the persons most in need get the smallest amount of the money. The amount of band-aids put on the disability system has not stopped the bleeding and is now suffocating the patient.

Having access to therapies would be beneficial as the more disabled the greater need for assistance. Currently minimal support is provided through the schools and once again once you are on a carer's pension you simply can't afford therapy outside of this. Allied health plan have assisted but unfortunately still fall short financially and also the fact that they have to be renewed, doctors are already overwhelmed with the paperwork that is required constantly from them in support of disabilities. We certainly don't go to therapy sessions unless we absolutely have to as the work involved in these sorts of ventures are extremely draining.

A great positive of the scheme is that it highlights the importance of a national community and is insurance for everyone should the worst happen.

I did not want this to be a sob story, rather an insight into the struggles that families and people with disabilities endure on a daily basis. This plan certainly provides hope that the years of desperation can be changed into years of joy where the quality of life for all those involved especially the disabled person can be lived.

Yours sincerely,

Suzanne Sutton