Good morning,

I am a parent of a 13 year old son, Joshua, who has both Down syndrome and Autistic Spectrum Disorder.

Over the years I have found negotiating my way around the Disability Support arena very difficult. There are many things I have found out “by accident”, often too late for my son.

I believe we need and have wanted to create, for years, a “one stop shop” website for families where the guess work or finding things out the hard way is taken away. I have discussed my interest to create this website with many people and a number of parents in a similar situation and they all agree that it would be a very worthwhile and much needed service.

Let me explain a little further:

This website would be a generic disability website with a drop down menu for the diagnosis of the child/family member. The main page would list the government departments with a list of the basic services provided e.g. respite, child care, counseling etc, along with what Centrelink and funding agencies and payments are available.

From the drop down menu, a family would select the diagnosis, then a new page would load which will provide a list of all services, all child care and all support options available for this particular condition.

On this website there would also be testimonials from families, a kids games link and also a chat service that would enable families to contact other families in the same situation and chat and share information.

I also believe there should (somewhere) be a central database with all diagnosis information and relevant information on a child that all services can connect to, to save families from repeatedly filling in forms and providing the same information over and over again. I know a number of times I have had a “melt down” as I have to fill out another form and explain, once again, what is going on with my son. Often these forms require repeated trips to doctors which can be very stressful and expensive.

There is also not enough support (respite) and the support that we do have is so bogged down with “red tape” that it makes it difficult for parents and support workers to help there children. I have had such a traumatic experience with carers due to the agency not being organized or having to work a certain way, which has caused carers to leave and not provide a continuous, regular support service, which is very traumatic for my son.

I would very much like to see things improved for families and ensure that the new families, who have a child with a disability, don’t have to go through the same pain and suffering my family has.

Kind Regards
Paula Shaw