

# The OTHER 100 conversations

share your thoughts.



# To our elected representatives -

Our Premier thinks that the WA disability service system is working well and that we do not need a National Disability Insurance Scheme.

Advocates, people with disability and their families have concerns that our WA Government has not asked the right people about their experience with the system. We want him to know our experiences before he goes to COAG on Friday to make decisions about our lives.

On Sunday, the Bolshy Divas sent out messages through their networks and asked people with disability and their families to tell their stories.

In two days, well over 100 people with disability and family members responded. We've included the first 100, which are predominantly from the Wheatbelt and Goldfields areas, and the autism sector, but which contain a cross section of stories from across Western Australia.

This book demonstrates that if the WA disability system is the best in Australia, we are possibly the best of a bad lot, but change is urgently needed for Western Australians battling through a crisis driven and fractured system.

There is no finger pointing, no blame, no politics involved in providing you with this information. We simply want the voice of people with disability and their families to be heard and for our most disadvantaged citizens to be supported to participate on a level playing field.

When we submitted our views to the Productivity Commission, we said this -

'The scheme is for people with disability, not for service providers.

Not for governments, not for empires or private agendas.

The scheme is for people who are as individual as their fingerprints.'

People with disability and their families have the smallest voice of all Western Australians. The women who have contributed to this book have found their voice to speak up for others and to send a clear message to you, as our elected representatives, that we desperately need disability reform in Western Australia.

Please read this today. All of our lives depend on it.

They are speaking. Are you listening?

Love,

*Bolshy Divas*



# An Open Letter to All Western Australian People With Disability and their Families

The WA Premier thinks that our disability service system works well and that we don't need a National Disability Insurance Scheme across Australia.

We don't agree. We want to know what you think should change in WA and what we should keep (what works well).

If you decide to tell your story, we will present it to the Premier to tell him the story of people living with disability and their families in WA and why we need a NDIS for ALL Australians.

You can remain anonymous and tell us about your experience, be profiled in the 'The Other 100 Conversations' story or go all out and tell the world (opt to be featured in a magazine, newspaper or radio story). It's up to you.

## About 'The Other 100 Conversations' project

In 2009, the Disability Services Commission commissioned PricewaterhouseCoopers to carry out a consultation that included one hundred conversations with people with a disability and their families and/or carers. But the 'conversations' were about experiences with the Commission and with the LAC service, not about their overall experience with disability services in WA.

We have less than one week before Premier Colin Barnett meets with COAG to discuss the future of people with disabilities in WA.

On Wednesday, we want to present him with 100 'other' conversations – from people with disability and their families who can tell the real story about disability in WA, not a story which has been filtered through a service provider or through the Commission.

We don't think that people with disability and their families have a voice, and we don't think the right people are listening. Help us bring your voice to the table when discussing the future of Australians with disability and their families.

Love,

*Bolshy Pivas*



# the OTHER 100 conversations



## 1. A Rockingham Story

'THE biggest barrier for people with a disability is having to battle for every thing they need.'

- Peter Darch, Young Western  
Australian of the Year, 2011

I WORK as a Youth Development Officer for the City of Mandurah. I studied psychology and I'm also a youth counsellor.

A Youth Development Officer, which is a full time position, is all about consulting with young people in the community about what they need, and feeding that up to people who make decisions. A major part of my role is youth leadership and developing leadership skills amongst young people.

I'm a bit of a larrikin, always have been always will be. Nine and a bit years ago I jumped off the old Mandurah bridge and wasn't concentrating on where I was in the water and swam underneath my friend, who jumped off the top. I looked up and wore his butt for a hat, which snapped three vertebrae in my neck. I was instantly paralysed. I did the whole drowning saga, got revived, was practically dead and ended up going to hospital

for six months. I got out of there and went back to school and then Uni and studied psychology.

Physically I can only move my left arm minimally, I can't raise my elbow or move any fingers and things like that. My right arm is practically dead. I can move my shoulder and nothing more than that.

I've got equipment here to set me up to be able to work. So I can do limited things here. For example if I'm doing up a brochure, or emailing I can do all of that. I do a lot of external stuff, so I need people to help me get places a lot of the time I just need some help with physical tasks, which I can't do.. Unfortunately that's where the biggest issues fall for people with my disability, is that there is nothing available for that really.

I probably need about 25 - 30 hours a week with someone helping me out. That's the maximum to be able to do a weeks work, which is 40 hour a week. At the moment the maximum support you can get for work is 10 hours.

If I was at home and not working then there are funding schemes available at a State level. I guess the situation that I'm in, if I went home and said I'm not working, I can't work, I'd get 40 hours a week of care. But the minute I say that I need to go to work and use that care at work, that's null and void I can't use it.

It makes me angry. I have a solution that is cost effective. If I'm at work I've got a carer with me. I'm not on a pension. My carer is paying tax. When you run the numbers you're making the Government 50 cents on a dollar.

I was told that it was up to my employer to cover these costs. It's just not realistic, they're putting another barrier on people being employed.

The biggest frustration I have with the whole thing is that everything is geared to be going bad before you can get help. You have to fight for everything. There is no one that is saying 'you're on a good path here, you've gone to Uni, you're going to transition and go to work and then get off the pension and have a pathway to independence'.

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No one looks at you and says you're on a pathway to independence we should support you 100%. They wait for that pathway to be cut off, and be in strife. Once it's all gone bad, then they say we better support you. It's just backwards. It should be make things easier before they get hard, not make things easier because they are hard.

When I broke my neck and first became paralysed, I thought everything is over my life is going to end. The whole paralysed thing, or quadriplegia is terrible. No one is telling you, 'you can do this or that', you just see the bad side because that is all you hear about. That is the level you have to get to. Why not start promoting the things you can do. Reward what you can do. So people who end up in that position aren't as shell shocked.

I had to fight my butt off to go to Murdoch Uni. I had to get from Mandurah to Perth. I had to plead with the State Government funding agencies for personal support. I've had to fight with people about going to school. They weren't prepared to support me in a normal class to start with. They were going to put me in a special needs class. I said, "I'm not special needs, just give me some support". You can get to Tafe or uni, and get support, but it all ends when you try and work. It's like dangling a carrot in front of a donkey.

You can send me to school, you can send me to uni with carers. And once I've learned how to use those carers and be productive, you take them out from under me and I've got to go sit at home to get anything. That's just the way it is and it's not right.

An NDIS is important because it can stop you having to for fight things. The biggest barrier for people with a disability is having to battle for every thing they need. If you need food you can go to the supermarket and get it. If you need power you can get power. But if you need support with a disability you have to write out lists, you have to do so many things that make it a problem.

We are the people who have difficulty in doing those things – it's just backwards. It should be something that is provided, so you don't have to fight to live and do the things that you need to do.

It's a common human decency thing, that it should be there and provided and easy. And that's what the NDIS is about. It's making things easy, making it flow rather than being a battle.

- Peter Darch, 2011 Young Western Australian of the Year



## 2. Lisa's Story

'WE were either the wrong age, the wrong sex, the wrong religion, the wrong colour...we were just wrong.'

- Sandy, parent of Lisa

LISA was born in 1991 a series of cysts on the top of her brain stem. It's a condition that mimics Dandy Walker Syndrome. Lisa attends up to 11 clinics and has had 40 operations during her 19 years. We live in Yanchep on the outskirts of Perth on the Northern side. It is approximately 70kms each way to Lisa's hospitals, and as she is coming from a child coming into an adult we have an assortment of hospitals that we have to visit, from Princess Margaret, Charlie Gairdner's to Royal Perth. Once upon a time we were entitled to patient assistance transport, but now they have changed it all and we're not entitled

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to it. We used to have to go through Moora District Hospital to get that.

Since then, DSC has put an LAC in Yanchep. I'm very lucky to have the guy that we've got - I've known him for 14 or 15 years so he has intimate knowledge of the family and the bizarre workings of this family! I quite often have my extended family stay here, at the moment I've got my brother with a fractured back, son in law with a broken leg hobbling round somewhere and Lisa. Lisa's needs change on a day to day basis.

Lisa has good days and bad days. An example of a bad day was yesterday when she was totally flat - unable to take medications or swallow. On a normal day, which I sometimes call a bad day, it is more about Lisa's fixations that you get, she'll fixate on something and then you cannot move from that until that's resolved.

Everything that we tried to get any assistance for - I've got a grandson living at home too - everything we tried to get assistance for to make life easier at home we were either the wrong age, the wrong sex, the wrong religion, the wrong colour...we were just wrong. We didn't fit into neat little pigeonholes.

And that's a major thing with disability services and other government bodies, you've got to fit a pigeon hole before you can benefit from anything - some people just don't fit.

In the future, obviously I'm aging, I would like to see Lisa live in a community where she can be sufficiently independent and get the support that she needs, for medications, hygiene and all the rest of it. A lot of work is involved with Lisa. Although she can walk around and hold a conversation, there's a lot she cannot do.

I don't know what Lisa's future will bring. I don't want to have to worry about what will happen to her - I want her eventually to be living independently or in a group home. Eventually, I want Lisa to be able to be independent and a valued member of this society.

- Sandy and Lisa



'About twelve months later, the wheels fell off.'

## 3. An Amputee's Story

I'M forty nine and I live in regional WA. I used to work in a pretty physical job.

I lost my leg when I contracted septicemia. I felt a bit crook and went to the hospital after being referred by a doctor. The next few weeks were a bit of a blur but I remember being told that my leg was going to be amputated below the knee. I didn't care much by that stage, my whole body was black and I've never felt anything like that pain.

I didn't see anyone when I was in hospital. They sent out a psychologist to talk to me but I told her to bugga off, politely. I didn't want to think about what had happened to me and I just wanted to get out of hospital and get on with it. The psychologist they sent was a girl who had just gotten out of uni. I didn't think she knew anything about having your leg cut off and I didn't think she knew anything about being me. Looking back, it would have

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helped if there was someone to talk to who had the same experience. There wasn't anyone and I was given pretty basic information.

When I left, I went home with no leg and no support at home. It was pretty hard. I had a wheelchair but I couldn't get to the toilet because my house wasn't cut out for it. Later on, I got a referral to a prosthetist and I told him that my job was very physical. He gave me this stock standard leg - no energy return, no anything. At the time, I thought it was good, because I wasn't given any information about anything better.

About twelve months later, the wheels fell off. The leg I had didn't allow me to do my usual job and by that time, everyone was leaving me alone. I didn't ever go to disability services - I didn't know anything about them. Besides, I could do things by myself, so I didn't need services or help. But looking back, I was not coping at all with going home with the stump of my leg bleeding from standing all day, not knowing what to do to make changes to my job, not knowing where to go for help.

I found out by accident that there were prosthetic legs that would have let me keep my old job, but they weren't funded under the WA government scheme. The one I got was the very basic one, but I could have been given the option to pay a bit extra and get something that would make my life a lot better. If I'd been in a car accident in Victoria or run over by a truck there I would have been given a way better leg, automatically, under their accident scheme and I would have coped at work and been supported. By then it was too late, I had quit my job.

When I wanted the help later on, it wasn't there. I was told to get on with it at work and people made flippant comments about it. There wasn't any help, even when I asked for it. The 'system' didn't work for me.

I'm now on the disability support pension and doing volunteer work. We need big changes in the system in WA for people who lose limbs.

- Name and address supplied, WA



'The one thing that I like about this plan is that it wouldn't be crisis driven, it would be focusing on what you can do, not what you can't do.'

- James Davies, Curtin student

## 4. A Student's Story

My name is James Davies, I'm 20 years old and I have spastic quadriplegia cerebral palsy.

I'm currently studying commerce at Curtin University. I am also working as a marriage celebrant and aspiring author.

My condition means I require 24-hour care which is currently provided by my parents. My disability affects all four limbs. I'm unable to walk at all, I can't stand. I use an electric wheelchair to get around and I need help with feeding, dressing, toileting, bathing and that kind of thing.

It's very difficult to plan things because I'm always having to rely on other people and fit in with their schedules and possibly if I had a bit more assistance and funding and it wasn't such a battle to get additional care provided it would be easier for me

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to live my life the way I want to.

The future is a concern because my parents are in their sixties now so basically I think maybe they have less than ten years of looking after me and then from that point on I'm not sure what will happen, I may need to go to some sort of nursing home or other out-of-home care.

So that prospect is really quite scary for me as time goes by. It can be quite terrifying. But that's why the NDIS would give people the opportunity to plan for the future. And not to have to worry about these transitions all the time.

My biggest issue to date with the system has been acquiring care for post-school study. At school I had a carer with me full time which was provided by the Education Department and when I left school in 2007 I assumed that things would just continue – I thought a similar thing would happen at TAFE and then at Uni.

When I went into TAFE for an orientation I asked the disabilities services officer what sort of care is available for people who need personal care, for toileting, opening doors, getting things out of my bag and so on, and she said "oh, we don't have the funding for that" and so over the next 6 months or so it was a bit up in the air what was going to happen with that, because if I couldn't go to the toilet, I couldn't go to TAFE.

So I wrote to the Premier, the Minister of Education, the General Director of TAFE and the Director of Disability Services and the policy was changed at TAFE, but then I encountered the same problem again at Uni, so I had to repeat the same process and I had to write to the Premier, the Prime Minister this time and the Federal Minister for Disabilities and Children's Services Bill Shorten and the Vice Chancellor as well. The issue is with these institutions is that because of red tape, their hands are tied.

I think the NDIS would be good in terms of smoothing out the way for people, removing those speed bumps that I've encountered. So there wasn't this battle all the time. My mum had to attend Curtin University with me at night. For a person working full

time that was very demanding for her and she was just trying to assist me in being integrated into the community here but I really felt very excluded, and all of that was due to red tape.

Transitions are usually the issue because that's when you switch over funding models. So with the NDIS that wouldn't have been a problem because you know what funding is already available and you'd have choice about how that funding is allocated so you could plan for 10-15 years in advance, you could have a lifetime care plan.

The one thing that I like about this plan is that it wouldn't be crisis driven, it would be focusing on what you can do, not what you can't do. Because I don't like to fill out forms and have to focus on the negatives all the time and paint a bleak picture, because I'm not a bleak person, I'm about what I can do and the things I want to do and how to get there, not what's holding me back.

As somebody said during one of the Productivity Commission hearings it could be any of us tomorrow. You know you could go out in the street and get hit by a bus – not that we want that to happen – but any number of varied things could happen, or you could have a child with CP as my parents did.

So I guess you just have to look at it from the other perspective and that's what I try to do as well. I think able-bodied people don't come across these issues and so it's unfair of me to think woe is me, you know, I just have to think they live a different life and this is my circumstance and that's theirs.

Together we've just got to do the best we can and integrate as much as possible, to close the gap.

## 5. An ASD Perspective

'So we went on the waiting list and we waited two years.'

I have an eleven year old boy who has an autism spectrum disorder. When he was five, he went to preschool and the teacher said, oh, he doesn't

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He didn't speak, he must have an intellectual disability. We didn't know that anything was wrong, we just thought he communicated in other ways. But then there were other signs that he was autistic, mostly things like not playing with other kids and being very fixated on particular things. He would play with toy trains for hours and hours and then scream if you tried to take them away from him. That would be normal behavior for a naughty little kid but he would also bang his head hard on the wall and try and hurt himself. He also used to spin around and flap his hands a lot. So we went to the doctor and the doctor told us we had to get a diagnosis. The school said the same thing, because he needed help at school and he couldn't be helped without the diagnosis.

He was aged five then. When we went to see the doctor, the doctor referred us to a paediatric neurologist. It took about six months to get to see him. When we met with him, he said that we would have to either pay privately for a multidisciplinary assessment - at a cost of about twenty thousand dollars, he said - or we would go on the state waiting list for the State Child Development Centre. So we went on the waiting list and we waited two years. I hear now it is a lot longer, about four years.

When he was diagnosed he was seven. He had started to speak and the main issues were the behavioural issues at school. He got some aide time but it was only for one day a week. By this time he had been kicked off the bus service to school because he banged his head on the window every morning, couldn't handle the noise, screamed and made noises that upset the bus driver. We rang the Disability Services Commission but they said they couldn't help because he didn't qualify for their service and when we rang the Autism Association they didn't really have any suggestions for us because we lived in an area where there were no services. Because we live four hours from the city, I thought we could take a day off once a week and get some therapy services for him, but when I rang a therapist (out of the phone book, I didn't know who to call) they said there was a six year waiting list. Now I wish I'd put his name down

as we would be getting close to the date that he could start therapy. But I was so upset I just hung up.

Because we didn't know anything about autism we started to ring around and found out that there were a lot of other people in the same boat as we were. I had to leave my job to care for him because he was often sent home from school and often refused to go to school. And it was very hard emotionally because he had very severe depression and anxiety. There are no mental health services for children in my area so if we were going to access services it would have to be at PMH but there was no funding to get us there. Even though my husband had a well paying job the cost of living meant that with several other children we couldn't afford to take him down to Perth.

For us the issues were not around having more money, there was no information and there was no one stop shop after diagnosis. I talk to hundreds of other parents in WA every year who have the same experience with their children with an autism spectrum disorder. And everything, even basic aides like weighted blankets, is expensive - a blanket with weights is nearly \$200. There are great communication aides but things like iPads are really expensive, nearly \$1000. I know families who spend thousands on quack remedies because they are not given quality information about their child's autism and then find later that it has little or no effect.

My child can't be supported at a specialist school because his IQ is too high and he can't be supported in life because there is nothing out there for him. Even basic information early on and fewer waiting lists would have made a huge difference. Now he has chronic anxiety at the age of 11 and he has talked about suicide. He has to go to high school next year and I now have to get a job, we are going to lose our house if I am not working too. I don't know how I will do this and the financial strain and the strain on my marriage is huge. I don't know what to do, where to go and how to fix it.

- Name and address supplied

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'I've been told, you're not really disabled enough. What does that mean?

Not disabled enough! '

## 6. A Mum's Story

My name is Claire. I'm a mother of a lively nine year old, a local councillor, an author and a life coach.

I also have a form of muscular dystrophy called Facioscapulohumeral, I was diagnosed at 14.

Muscular dystrophy is a degenerative condition. When I was diagnosed they told me a wheelchair would come one day. Over time my legs became weaker, it became more difficult to walk and climb stairs.

In my 20's it affected my shoulders and my hands. I started using a wheelchair when I was 29.

My daughter and I work together as a team. My Mum lives nearby and she comes over, and is the extra set of hands that we need.

Dinner is the main meal that I struggle to prepare these days. I wouldn't trust myself with a pot of

boiling water any more. It's risky. I simply don't have the strength in my hands to chop. If I did try, I wouldn't have the strength to eat afterwards and I would have to rest. My Mum takes on cooking of the evening meal. Having Mum live close to me is extremely important. She is that backstop in case anything goes wrong.

My Mum is 71 and she also has MD, it's a genetic condition. It's really started to kick in with her now. She lives with pain on a daily basis. She has trouble walking and lifting her arms. But she is my main carer.

Unfortunately I don't qualify for any extra help. I have two hours of help in my home once a week, that's all I'm eligible for. I've requested more but it hasn't come to fruition.

There was a period of time when I couldn't access my own home, I couldn't get in my own front door because I could not lift my arm to reach the key in the lock. I had to get in through the side gate, and come through the back door. But I couldn't put a padlock on it. I applied for some funding for alterations to my front door so I could come in and out. It took 12 months from the first phone call to the new door being fitted.

While I didn't have a lock on my back gate, I was vulnerable, and I had someone break into my house while I was home.

It was very scary – being a single woman on my own and hearing someone coming into my home in my back window. It took me quite a while to sleep again after that.

The system is not written for people with MD. You may get five people with MD, but we've all got slightly different needs depending on where our condition is. The individuals are not catered for. The system is too inflexible.

I've been told, you're not really disabled enough. What does that mean? Not disabled enough! I have a degenerative condition; I'm not about to get up any time and start dancing. I need this help at home so we can live the best quality of life that we can. It's just basic every day stuff.

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I recently tried to apply for air conditioning funding. But only one room could be funded. With MD I have trouble regulating my temperature. Once I'm hot, I'm hot. It's hard to sit in a wheelchair when you're hot.

When I couldn't get funding for AC for the house, I wanted to pay for the system and be reimbursed, but they said it would take months. My body won't cope with living that long in 38 degrees.

It makes me feel very devalued and frustrated. Don't I count?

My mother who is 71 is my main carer. But when she leaves I can't access any more support in my home. I've been told I can go and stay in a respite facility. But what do they want me to do with my daughter? She can't come with me. So I said no – you're punishing me for being a person with a disability, you're taking me away from my friends and my network and my home. That's being punished. If we had an NDIS in place, those things wouldn't happen.

I'm an Australian who contributes. I work. I'm a mum, I volunteer. I just want to get on with my day. I want to know that what I contribute to my community counts. And for me to be able to do that I need to have some support structures in place. It shouldn't be that hard.

If Australia had an NDIS when I was diagnosed at 14 I think things would have been very different for me as an individual and a family.

It was a very traumatic time being diagnosed with a degenerative condition, and we couldn't even process that, let alone thinking what I would need.

If we had had an NDIS as a family, we would have been able to plan, we would have been able to put support in place before we got to a time where I couldn't get out of bed, and my 9 year old is trying to get me up, and we're in a crisis.

If we had the NDIS in place, the stress would have been taken out of all of it.

An NDIS is so important because it gives everybody a fair go and that's what being Australian is. I want

to contribute to my community, to do that I need support in place. The NDIS will support me as an individual. It will give me a quality of life.

## 7. An Albany Story

'This is a prime example of a system which is both underfunded and inflexible.'



I would love for you to hear my story and then tell me how the disability system in WA is NOT broken.

I have a 13 year old son who has high functioning autism. I have been forced to homeschool him for the past three years

because he could not get the help he needed to access an education.

We were advised he needed intensive, weekly, and ongoing psychological intervention in order to help him manage his anxiety which was causing ongoing and severe difficulties at school. I will not go into details here about the heartbreak we endured day after day, other than to say, I had a 10 year old child taking four different medications (including an antipsychotic).

Although he was (and still is) registered with the Disability Services Commission (DSC), funding for psychological assistance was not available. Due to being a single income family, we could not afford the \$170+ per hour fee for psychology services. The irony is that I could access funding through DSC to pay for respite care, which would not have been required if he attended school!

This is a prime example of a system which is both underfunded and inflexible to the needs of the

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individuals and families it is meant to assist. This is WA's system. It IS broken.

- Suzanne Durrant, Albany, WA

## 8. From WA to Victoria

'It was easy to slip into depression and anger'

I've recently moved to Victoria from WA, where I lived for many years.

I have a severe physical disability and have several siblings with the same condition. When I first came over to Perth, I was living with my mother and grandmother on the outskirts of Perth. It was hard because Gran was getting old and Mum was really busy, and I used to go up to one of the service providers and use that as a base to look for work every day. Getting transport was hard because there was no wheelchair accessible transport.

Getting funding was a nightmare. I applied every year to DSC for funding and every year I was knocked back. I had no success with my application and I think it really affected me psychologically, doing the application every year. You have to pour out everything, warts and all, and it can emotionally consume you and becomes your whole focus. I found that I used to get overwrought and angry and upset and that even having a coffee with friends was no longer enjoyable - I'd be angry about some access issue or disability rights thing, because it was so traumatizing having to write it down and tell your story over and over again and focus on the negative. It was easy to slip into depression and anger.

In the end I was funded by three separate agencies and of course they all had their separate acquittal processes and their separate coordinators, it was like a part time job. I finally found myself a job and a house that was near the agency. When I found out that I had the unit, I was very excited that I would be finally out and living independently. But then I found out that my support would be withdrawn because I no longer had

a primary carer.

I went to the Disability Services Commission and met with staff to draw it all out, how many coordinators there were in my life, how much of a burden and how much stress it was coordinating my support. I really had to turn into a bit of a nightmare in order to get some help. They ended up drawing from some special pool of funds and agreeing to support me for the respite the other agency had withdrawn. I was still underfunded and finally I managed to self manage my funds. But I wanted to move to the East and part of my funding (through HACC) wasn't portable.

For me, the LAC program was a bloody waste of time. They'd come over and have a cup of tea with you, but never really do anything. I never found out exactly what they were supposed to do, when I asked if they would contact someone on my behalf they said that they didn't do that. I didn't need anyone to have a cup of tea with me, I needed someone to help with all the acquittal forms and reporting obligations and advocating for me.

There were always issues. At the moment, arranging my care and support requirements is consuming my life and basically I can't work full time because of having to arrange my own care and support. Back in WA, one day, the agency that was supporting me pulled all of my service while I was at work - I got a message saying that due to staffing constraints they'd had to reduce client services - I wasn't going to get a carer ever again. The LAC couldn't help and in the end another agency eventually came to the party.

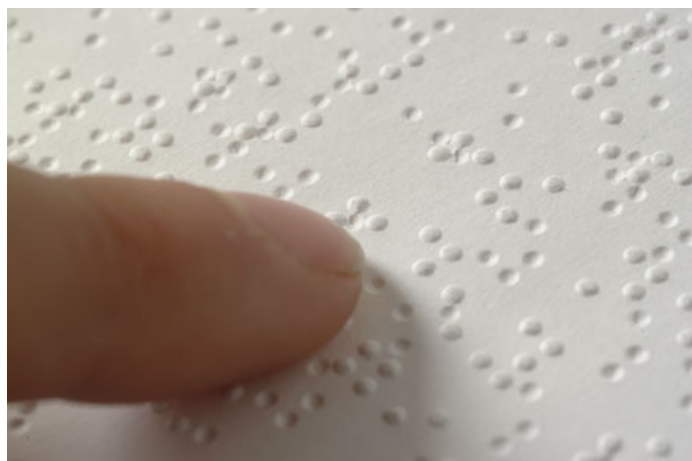
Privacy and confidentiality, there isn't any. Aids and equipment is another area - the Federal program for continence aids only pays for \$500 worth of assistance, you have to chase top ups for the rest of the funding. The program for aids and equipment is supposed to be competitive but they put out a tender and they contract one company that does all the purchasing and maintenance and repairs of equipment, the

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same one here (Victoria) has had the contract for thirty years. I've been waiting six months for a new cushion because there is a change of facilitators - it never ends, things aren't that different from state to state, there are always issues.

I don't think it is about which state you're in - whatever state you're in, it's a bureaucratic nightmare for individuals with disability. They have their head in the sand if they think the system is perfect.

- Name and address supplied



## 9. Bridging the Gap

'I love my daughter and want the best for her and have found the current disability system disappointing at times.'

My 5 year old daughter Chloe has Down Syndrome and has been receiving services from the Disability Services Commission since she was born to assist her speech, mobility/movement and understanding.

However, the high turnover and shortage of staff at DSC has meant long periods without services which I think have hindered my daughter's development in her early years. Also DSC only promote certain therapy methods which at times have fallen short of meeting my daughter's needs. I have during these times taken my daughter to private therapy at our own cost to bridge the gap.

My daughter is going to enter grade one at school next year and the services from DSC will stop altogether and although I have applied with plenty of time to receive services from school age service providers there are very long waiting lists. Chloe may not get any support at all during such a crucial year of schooling.

I love my daughter and want the best for her and have found the current disability system disappointing at times.

- Holly and Chloe Caldwell

## 10. From the Goldfields

'...making us question whether we uplift our entire family to move to the city.'

I am frustrated and disgusted at the current WA disability system.

I am a mother of three beautiful children, my youngest born with an eye defect that has caused a significant visual impairment. He has been diagnosed as legally blind.

I have lived in the Goldfields for over fifteen years and am now encountering a system which is inefficient and inadequate for the needs of my youngest child.

The Allied Health Centre in my area have therapists (occupational therapists, physiotherapists, speech pathologists) that are initially on two month contracts which can then be extended. As a result my child has seen in less than three years of his life many different therapists. Consistency and a build up of rapport are important in a child with special needs therapy and this CERTAINLY has not been the case.

Visual impairment is different in every case so being able to access the best experts in the field has been of the utmost importance. I have been made aware recently that my child because we live in a

# the OTHER 100 conversations

regional area is able to access SIX HOURS a year including admin time from The Association For The Blind Childrens Services Team (OT, Speech, Physio and Psychologists).

I can access "targeted services" (Orthotics, adaptive technologies, orientation and mobility training) through ABWA also as these services are not available in my regional area. (thank goodness!)

I am willing to pay my own travel expenses to commute to Perth to access expert Speech, OT and Physio therapy through ABWA . It has been heartbreaking and frustrating to be told that my child cannot access the experts in the field!

I have been advised that I am to access "comprehensive services," (OT, Speech, Physio) therapy in these areas from my local therapists who firstly are on short term contracts, secondly generally have very little experience in visual impairment and thirdly have very heavy caseloads resulting in my child not being seen regularly and in some areas not at all.

I have resorted to paying for private therapy to assist his speech development.

I come from a professional background and my family are encountering a system which is discriminatory towards children with special needs that live in regional areas.

It is totally inadequate and is making us question whether we uplift our entire family to move to the city.

I am hoping that by raising this issue that steps will be put in place for parents like myself to be allowed to access the best therapy for our child no matter where they live!

From a disheartened mother who is blessed and honoured to have a child with special needs that has and continues to enrich our lives.

- Name and address supplied



'...For God's sake, don't play politics with our lives.' Julie and Eamon Gilfoile

## 11. Eamon's Story

A FEW days before Christmas 1995, our lives changed forever when I gave birth to our identical twin sons, Eamon and Kieran.

Kieran was stillborn and Eamon was sent to neonatal intensive care as a result of complications of the rare disease of the placenta, twin to twin syndrome. We already had a toddler son. Although initial cat scans looked promising, at five months Eamon had scans which confirmed our fears: he had suffered a massive intra uterine stroke when Kieran had died. His disabilities included profound intellectual disability, very high tone spastic quadriplegia type cerebral palsy and cortical visual impairment and all the every day impacts of those

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disabilities on his mobility, independence and communication skills.

Since birth and for his entire life, Eamon will require 24/7 care to meet all his needs. He has a very high pain threshold and has endured serious surgeries designed to minimise the impact of these disabilities. He doesn't understand about having surgery so he awakens to his mum's voice and face and after the grogginess of the anaesthesia wears off he will come to an awareness of situations like having his legs splinted apart at an 80 degree angle and with plaster from foot to thigh and not know or understand that this is how it will be for six weeks or more. He won't be able to tell us other than by crying that he is itchy under the plaster or that he had a bowel accident and that slimy stool slipped down the upper part of his splint. He will become distressed and perhaps flail his arms about and scratch his face and bite his hands very hard, but we will need to discover the cause, if we can of his distress. For months after surgeries he will become frightened when anyone comes near the part of his body where he had surgery e.g. near his upper legs after major hip surgery.

Eamon has woken up to several times a night and at least twice a night for most of his life and is unable to reposition himself in bed. Our lives became dedicated to driving Eamon to medical appointments (hip clinic, scoliosis clinic, orthopedic clinic, x rays, cat scans, vision tests, dietetics, neurology, ophthalmology, gastroenterology, dermatology and many more appointments, and this is excluding therapy sessions) together with the emotional, physical and financial stress and trying to care for our older son. We were criticised by many when four and a half years after Eamon and Kieran's birth we had another baby. We had always wanted more children and we yearned for some joy amongst our grief, plus we wanted our elder son to have a sibling who wasn't a. dead or b. profoundly multiply disabled. Sadly, my mother died

unexpectedly when I was eight weeks pregnant. Without my mum's support we quickly found how difficult it was for own friends and extended family to understand our situation and to be in a position to offer any practical help. I lost both her and much of my father's practical and emotional support as my father grieved and then went on to make a new life for himself with a new partner. We found that despite loving our family very much, the lack of 'natural' supports was common amongst other families with children with significant disabilities as was the higher than average incidence of divorce.

As Eamon has become taller, stiffer (due to the damage years of spasticity was doing to his body) it became increasingly difficult to care for him at home. Home modifications just didn't cut it any more. We couldn't use a hoist properly in his bedroom as his bedroom was too small. Agencies which had previously provided some in home support staff said that they couldn't send staff to our home as it didn't meet the required occupational health and safety standards.

In the meantime, I was being hospitalised for depression. Letters to Ministers and even members of Parliament - bringing up our situation in Parliament didn't help. We wanted funding to help us to build an extension or granny flat to our home so that Eamon could continue to live with his family in safe, reasonable living conditions and in a way that we wouldn't be woken up several times a night. We knew that if we couldn't get help to fund this we would have to seek accommodation for Eamon outside of our family home.

By this stage Eamon was 12 years of age. What parents want to have their child live away from them at such a tender age, especially a child to whom they have devoted their lives and have a very strong attachment due to the constant day and night care they've given their son? We joined gatherings outside Parliament and told our story even though it was way out of our comfort zones.

'What parents want to have their child live away from them at such a tender age - 12 years old?'

# the OTHER 100 conversations

Eventually, we applied for accommodation support funding for Eamon to live in a group home - even though this wasn't our preferred option - so that our family didn't fall apart. We were hanging on the flimsiest of threads. We knew we owed our other children the benefits of a good night's sleep at least. At first, our application was rejected. The second time we applied to CAPS for accommodation support funding it was granted. Then come the guilts for families you know who need it just as much as you do, and then how are you going to tell your other children that the time has come when you are heartbroken too? We thought that a lot of the hard stuff was done...how wrong we were. There was nowhere for Eamon to go....eventually we had to phone DSC and say we couldn't have Eamon at home anymore. The day he was due to be moved from the respite we had placed him in - and we didn't know where he was going to be moved to (we weren't allowed to know) - I went to see him at school. He wasn't there. I made phone calls. No-one, including the service provider of the respite house, knew where he was. Any other mum would have been hysterical. I couldn't afford that luxury. I asked another mum to ring around and three hours later we had located Eamon - at an adult institution.

That was seven weeks of utter hell. The staff resented Eamon being there said they didn't know how to look after kids, some of the other residents who were verbal told Eamon in no uncertain terms that he wasn't welcome there. We weren't allowed to take him out of the building for a walk. He was put in a room by himself with a tv blaring when he cried and he cried a lot because he was miserable, disorientated and so on.

Thankfully after seven weeks i went to DSC and said i don't know what the answer is but my child is miserable and it's tearing us up. This was the only time to this point that we were allowed to have any say in his life. ....now Eamon is 15 and lives a half hour drive away from us in a group home. He is well cared for, though there are considerable restrictions because there are five people with high support needs, problems with being short staffed fairly

regularly. When we have Eamon home with us on weekends or in school holidays we can't have any help...even to go away on a weekend with Eamon...Eamon's funding is only for care in the group home setting, not in his family home. consequently, because our home and places we go do not have proper access for pad changes (Eamon can't sit on a toilet, he needs to lie down) and because we need two people to lift Eamon (since the hoist is unusable, no space for it) we get physically fatigued and cannot give any attention at all to our other children when Eamon is home we have him home much less than we would like.

We and our many friends, families, service providers, doctors etc. know that the system in WA is flawed. Please don't pretend that it isn't ...I could give many examples of things like Eamon having two sets of therapists to handle his significant equipment and therapy needs...this is because he lives in a group home and still goes to school (the system doesn't cope with this...you are meant to do one or the other.) The system doesn't cope with parents like us who want to be actively involved in our son's life now and in the future. We were offered certain things when the agency took on our son's care, but over time the reality and the expectations have slipped further apart. For example, Eamon has to be at the group home by 4pm on weekends so the staff can cope with their duties. So much for quality time with his family on the weekend!

We have zero say in how Eamon's personal funds are spent...we don't allow our own kids to have \$4 icecreams (we can't afford it), but Eamon is allowed to, but not allowed to spend any money he has on private therapy which would be of much more use to him. The problems are with the system, not with the individual service provider who do the very best they can with the limitations of the system. We are so much more fortunate than many others in the community, but we still want our son at home with us. We want to be able to say good morning and good night and give him a kiss. For many years Eamon would cry and scream when touched on his face. He now allows me to kiss him gently, but I see him just a few times a week now that he lives away

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from home.

The NDIS is a monumental opportunity to make life better for thousands and thousands of Australians.

For God's sake, guys, get WA fully behind this and keep the Feds. honest so that they roll out not just stage one, but the whole lot in time. Don't play politics with our lives. - Julie and Eamon Gilfoile



## 12. Sophie's Story

I am 19 years old and have brittle bone disease. I am a TAFE student and live with my mother who is also my carer.

I have had many 'horror stories' dealing with the disability service system in WA, but the most horrific would have to be my experiences with obtaining a new wheelchair when my current one at the time was faulty and negatively impacting on my life to the point where I was put in dangerous situations. I was having repeated problems with my electric wheelchair and after constantly having to get it fixed, explored how I could get a new one. Apparently at six years old, my chair, despite being regularly faulty was not 'old enough' to replace. I found myself scared to leave the house because I

was so worried my chair would break down in a dangerous place. This impacted greatly on my social life and I chose to study externally because I was concerned my wheelchair would not safely get me to TAFE and back. I had given up on the prospect of getting a new one because my pleas that I needed a new chair fell upon deaf ears. One day my worst nightmare came true. I travelled to my local shop and on the way back my wheelchair broke down in the middle of the road. It was a hot summer day (about 40 degrees) and I was stuck in the middle of the road. I tried to call family members for help as my chair wouldn't move. Fortunately, I was eventually able to contact my mother at work and after half an hour of being stuck in the middle of the road, my mother came to pick me up. I was extremely shaken and upset and felt that my dignity had been stripped. After this incident, I contacted my local OT about getting my chair fixed, and when I asked how long my chair would be away from me for (it's my legs!) her response indicated that I should not be 'demanding' to know how long I'd be without my only form of mobility. This was the final straw. Members of my family and I demanded a new chair. The man who regularly fixed my chair when it broke down advocated for me as well, as he had seen all the trouble I had experienced. Only with assertive phone calls to my OT and the help of this man, did I finally get a new chair. The whole ordeal was extremely frustrating. I feel that I should have been listened to before I had to give up face to face learning at TAFE, isolate myself in my home and dangerously break down in the middle of the road. My chair now is not even completely new, but a mish-mash of parts that have made my 'new' chair. This is the worst experience I have had with disability services system but I still experience regular disappointments. Just recently, I required new arm rests for my chair. I followed the appropriate process but the OT sent a 'default email' to the supplier so I ended up with new tyres. Little things like this happen all the time. I am offended and appalled that anyone thinks the system in WA is working.

- Sophie Keay, WA

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## 13. Rayna's Story

'It wastes our time and energy and prevents us from fully contributing to society.'

I AM 37 years old and I was diagnosed with spastic cerebral palsy at age two. Due to extreme abuse and neglect of me by my family I am now completely on my own, I have no partner and have been living independently since the age of 17.

The aging process kicks in very early for a lot of us with CP, and my abilities started deteriorating in my late twenties. I have been using a mobility scooter since the age of 19 and a quad cane a few years later. For the last 11 years I've been using HACC services for domestic care support - although I should have accessed this at the age of 19, I didn't know about this system, neither did my doctors. I used up a great deal of physical energy and strength doing things that were far beyond my capabilities because I didn't know I had any other options.

It has been a struggle to find accessible housing, and when I was evicted from my private rental 3 years ago, it took the DoH two years to find me somewhere accessible. This resulted in great physical and mental stress. Again, I have NO family support at all, and have to do everything for myself

- something that most abled-bodied people can't do, even yourself, Mr Barnett. Imagine your life, from teen years to now, without the support of your family. Would your achievements been possible, how much harder would it have been? Then imagine it with the addition of a significant disability and the discrimination of society. I have fought against suicidal depression for many many years, from the strain of not getting the assistance I needed.

My accessible house is in another suburb from the one I have spent nearly 20 years in. When I moved from one suburb to another, I had to reapply for HACC support, even though my disability related needs are the same, if not greater than at my previous unit. I had to be assessed by yet another complete stranger coming into my home, and was dependent on their assessment of me based on knowing me for less than an hour. I was denied assistance despite it being patently obvious that I cannot do the housekeeping tasks that stop me from living in filth. And I was denied this because of lack of funding and lack of appropriate training of the staff. Luckily I was able to find assistance through another agency, but the two or three months this took was another strain on my health and abilities.

I am acutely aware that accessing aids and equipment through the CAEP scheme is all about luck - if you apply at the right time of year, you will get what you need. Even if the OT agrees that you desperately need the equipment, if they have run out of funding, you will not get it. Many other people with disabilities I know have been denied essential wheelchairs, orthopedic shoes or other equipment, not because they don't need them, but because there is no money. If you are unable to work and are dependent on the DSP, you have no other options.

The new HACC system means that you have to have at least two identical assessments to get assistance and support, causing more strain and delay. I am exhausted every day of my life, and I am so tired of having to fight for the very basics. I am

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afraid of the future, of what will happen when I need more assistance and support and am dependent on the luck of funding rounds. We should not have to compete against others in the same desperate situation for what we need. It wastes our time and energy and prevents us from fully contributing to society.

The strain of everything I've dealt with will prevent me from ever working in reliable paid work. If I had had proper support years ago, I would be in much better physical shape now. As it is, I don't know how many more years I can do even the voluntary stuff I do now. I don't see myself being able to even keep doing anything productive or even enjoyable until age 50, which is still very young. I'm not even sure I'm physically able to do what I'm doing now, but it makes me very unwell emotionally not to do anything.

- Rayna Lamb

## 14. Identical Issues

'...there is no assistance for travel, loss of income or accommodation if we did travel to Perth.'

I am the mother of identical twin girls, both diagnosed with autism. I am a qualified early childhood teacher as well as a mothercraft nurse so I know a fair bit about child development and what is within "normal range".

The girls have always had developmental issues and it was very difficult to find the right help and services to assist their needs. I did have some initial support with the local hospital (I live in regional WA) with early therapy programs but it was very spasmodic and not coordinated very well. We had a few physio sessions and some speech therapy.

By the time the twins were 3 years old I knew there was a significant problem, not just developmental delays! I suspected autism and so tried to go down the path of getting a diagnosis which in turn would help. This process alone took almost a year and by then the girls had started kindy. When the diagnosis

finally came through I then had to deal with a lack of services as there was no one available to deliver the programs.

Another few months passed with limited support/respite or therapy. Our lives were total chaos, though once the diagnosis came through we were able to access our LAC which was a huge relief.

By the time the girls turned five and reached preprimary, therapy came in thick and fast from every angle. It was overwhelming. DSC had a program as did the WA Autism Association and then we had FaHCSIA for extra assistance. All was good for a year.

Then the twins turned six and it was the end of the line. We could still access FaHCSIA funding, which allowed us to use one speech therapist, the only therapy we had in our town. Things changed again when there was news of new funding for children with disability aged up to seven years, but we still had limited services in our town. We started buying equipment so that we could do some of the therapy at home, which is difficult with twins!

The girls have had no therapy this year. None. The school is trying to pick up the slack as best as they can, but it is very hard.

This is my story so far. I feel parents should be given support to choose the services their child needs. FaHCSIA funding is too limiting, especially if you're not in a capital city and there is no assistance for travel, loss of income or accommodation if we did travel to Perth. The Patient Assisted Travel Scheme doesn't cover many disabilities as it is set up for people with 'medical conditions', so that's not an option either.

The other major issue for us is the lack of communication/organisation with the various services. Parents are dealing with difficult children and do not have the time to look for what may help them or their family situation. The LAC and DSC have been helpful but often they know less than what other parents know. Networking is my best support ever!

- Jeana, Goldfields

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## 15. Still Waiting for Help

'Recently I was in crisis as I was absolutely exhausted and there was literally no-one available to help.'

My name is Kylie Johnson. I am 35 years old and my family and I moved from Kalgoorlie to Perth 18 months ago in order to access more support for my six-year-old daughter, Ellie, who has autism and an intellectual disability.

I am a teacher with the Department of Education and was fortunate enough to secure a transfer. My husband was not able to find a job, so I worked full-time to support our family of five. Unfortunately depression took hold of my husband due to his unemployment and this was a major factor that contributed to the breakdown of our marriage. I still work full-time because as my husband cannot work, he does not pay any child support. So I am a single mother who teaches full-time, while trying to raise Ellie and two younger daughters. I rarely have a break; school holidays are more demanding because I am tired from the school term, but I must care for and entertain my children. Please don't get me wrong, I love my children, but Ellie is especially demanding... I cannot even shower without her screaming at me for attention.

Recently I was in crisis as I was absolutely exhausted and there was literally no-one available to help. My parents were away and my sister and friends are all raising young children of their own. I rang my Local Area Co-ordinator from the Disability Services Commission in floods of tears, who told me about Home and Community Care Services (HACC). There didn't seem to be any emergency respite which included care for my two other children. After filling in paperwork and having a telephone and face-to-face interview, I was placed on the waiting list for HACC provided by Activ. Seven weeks later, I am still waiting.

As I write this, Ellie is screaming and pulling my hand, demanding attention and help. I am becoming

more and more run-down. I desperately need access to quality respite, but anything regular just doesn't seem to be available, despite the appearance that it exists. I am only just keeping my head above water because of my parents' support, but they are getting older and soon will not be able to help. What then for me? And what about my other children, who do not have an energetic mother who is able to do normal things with them, like go to the movies, because there's no way Ellie could cope. They miss out on a lot.

I don't think I am asking a lot to have some regular respite. An NDIS would help to provide vital services and support for people with disabilities and their families. - Kylie Johnson



## 16. Responding to Crisis

'I am still constantly chasing my tail and responding to crisis.' - Neeva Stephen

# the OTHER 100 conversations

I am completely disgusted - but not at all surprised - that Colin Barnett is trying to persuade people (including himself, no doubt) that all is OK here in WA regarding disability services. Straight up, I would challenge Mr Barnett to come spend 72 hrs in my home, taking 100% care of my son, and then see if he still feels the same way. I am pretty sure he wouldn't last more than 12 hrs, and that is with my instruction. Changing the nappy of a 14 year boy is quite daunting. And unless he has already been trained in tube feeding he wouldn't last three hours, as that is the time between Josh's feeds!

The NDIS is NOT all about throwing money at services for those with disabilities. I see the NDIS as a way of gleaning "best practice" from all over our country; in making sure that the service providers are looking after their clients at all times with the dignity, respect and care that all of us deserve. And, yes, it is ALSO about money, as the funding provided by this state has fallen well short for the duration of my sons' lives.

Jake and Josh were born on the 11th June, 1997. Josh remained in hospital until he was one year old. First visit from the Commission's LAC was Oct 1998 - I am now lucky to be back to my original LAC, after a couple of interruptions (her babies) along the way. First "carer" commenced March 1999, five months AFTER I needed support. Late 2004, after six years of regularly requesting more support, I finally lodged a CAP funding application under the Intensive Family Support stream. I was requesting the equivalent of 33 hours support per week. Every one of the six times I was knocked back (over two years), I struggled with the amount of help we already had, which equated to approximately ten hours 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... what a load of rubbish! If Mr Barnett thinks DSC and, therefore, the State Government is doing

such a great job, would he please explain why my requests for help to save my marriage went unanswered for over two years?? DSC talks about supporting the family unit, using "natural connections" to keep those with disabilities within their family home, but it is such a shame they don't actually follow through with that philosophy.

I have now had IFS funding for 3 years, however I am still constantly chasing my tail and responding to crisis. I have the money now, but there just aren't enough carers available, a situation I believe would be at least improved due to the NDIS ensuring remuneration and conditions for workers in this sector is adequate.

I had to give up work completely a year and a half ago, due to the stress and the lack of support. The effect on MY health has been almost unbearable. As I write this I am meant to be at a meeting for a support group - my way of still contributing to the community - but being almost continually unwell for many weeks now has meant I was unable to go. How does Mr Barnett think my unwellness, especially when their Dad is no longer in the home to help me, is affecting both of our sons? Jake, in particular, is increasingly called upon to take care of basic things and wears the brunt of my stress. It takes all my energy just to get out of bed some days, leaving nothing in the tank to spend quality time with either of my boys. This situation is unfair, unjust and eventually untenable. What sort of cost to the State Government does Mr Barnett believe me having a complete breakdown may result in?

There is so much more I could write. More examples of how and how often the supposedly adequate

'I challenge Mr Barnett to spend 72 hours in my home taking care of my son, and see if he feels the same way.'

# the OTHER 100 conversations

disability services in WA have failed us - me, my ex-husband, our sons, our extended family, our friends AND our community. The examples extend to every area of our lives - medical, respite, education, accessibility to name a few. In fact, I would be very happy to have a chat to Mr Barnett about it. He can bring the coffee and cake, though, because I will probably need to fold some washing while we chat - yes, on top of all the extra responsibilities those of us caring for someone with a disability also have "normal" household needs to take care of.

## 17. Hitting the Wall

'I hit more and more walls trying to obtain the support services our family desperately needs.'

I WAS born two months premature in 1956 and diagnosed with relatively mild cerebral palsy at the age of two. I worked full-time for 26 years while studying part-time for two university qualifications, owned my own home and drove an automatic car. I was also the sole provider for two years while my husband was Mr Mom to his two younger sons from a previous marriage. Life was okay until a series of five car accidents, none my fault, caused two hernias and the loss of my stomach, spleen and part of my small intestine.

That, compounded by my cerebral palsy, means that I am now on the DSP with my husband as my full-time carer. I survived both special school and public school education without assistance and pretty well left the disability sphere at 15, until at the age of 44 I had to find out how things worked or pay for what I needed. I received very little by way of compensation for the traffic accidents as the Court ruled I was already disabled and therefore not as severely disadvantaged by the injuries sustained. What about acknowledgement of the battle it took me to get where I had got to and compensation for its loss? Anyway, any compensation I did receive plus my cashed-in superannuation was used to modify the house and

eventually purchase a more suitable vehicle for transporting a wheelchair also self-purchased. Lack of transparent information and co-ordinated services cost me a lot more than it should have in trying to organize and sustain a workable lifestyle.

Through all the battles the welfare of our two boys came first and now they are fine young men. My marriage has suffered unbearable strain and we are now living in a caravan and basically broke because the only information you receive is through talking to someone else who has already been there and then there is the stress of dealing with uncaring government departments like Centrelink and Homeswest. I have become very interested in disability issues over the last two years as my medical condition worsens and I hit more and more walls trying to obtain the support services our family desperately needs.

- Roslyn, metro WA

## 18. The Lucky State

'... there is no one speaking up for people with physical disabilities who are on their own.'

People have been saying that this is the best state to live in if you have a severe disability. I wonder how bad the other states would have to be for that to happen.

I was injured over thirty years ago and it wasn't in a car accident, so I didn't get any compensation. My parents weren't able to look after me at home, so I started my teenage years off in an institution in Shenton Park.

Nothing's changed much there over the last thirty years. It was a horrible place to grow up and live. While my friends were out kicking a footy, I was trapped in a room that measured only a few metres wide with a television bolted to the wall. I think the accommodation situation has changed slightly since then, but the rest is the same.

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As a quadriplegic whose schooling was interrupted, my job prospects were limited. I spent over half my life in an institution in WA and the only place I could work was at Paraquad, the sheltered workshop that is attached to Shenton Park. Nobody really knows or cares about sheltered workshops for people with physical disability. It is not a good environment. I could only work for a few hours a week or they'd take the DSP off me and then my accommodation was automatically deducted from my pension. When I was in my twenties, the amount left over was about eleven bucks a week.

I became severely depressed and it wasn't until I moved out of the institution that I found my life again. It has always been a battle. I found a job but I would be better off on the DSP. The cost of transport to work and to be supported means that I actually would be seventy dollars a week better off on the DSP. That is just above the breadline for me, and I am living very frugally.

I need a new wheelchair but can't afford it.

My life is defined by my disability not who I am. Things that should be free or cheaper, like catheters, are expensive. When you need to get medical assistance, if you work and don't have a health care card it costs a lot more. And people who have quadriplegia have more medical needs than other people. I sometimes get bedsores. I often get infections. Getting a chest infection is a major disaster for me and involves going to hospital. Because of my disability I often have time off and that means leave without pay. My leave runs out almost straight away every year because support workers are often late and then I am late or miss the taxi I have booked. I never have enough funding to cover my transport.

Family members are always the people who shout the loudest and I hear a lot about carers and their problems, fair enough.

But there is no one speaking up for people with physical disabilities who are on their own.

- Name and address supplied

## 19. Wheatbelt Story



'Do I get assistance? Depends on what you call assistance.'

When I was 19, I had an accident in the country town where I grew up.

I was with a bunch of other kids in the back of a ute with a friend driving - we were on a racecourse. He hit a bump and I went up in the air and came down with my neck on a metal toolbox and broke my neck.

I spent two months in Shenton Park and nothing really changed for me. I'm thirty now and in the twenty one years since I was injured, I've never met anyone who works in the disability sector. I wouldn't know where to start if I needed help. I didn't meet with anyone when I got hurt - except for a psychologist whose job it was to work out if my brain had been injured in the accident. It wasn't. So two months later I went home to our country town.

It cost about ten thousand dollars to modify our house and in the end a local plumber made it all happen, it took ages. They got the money back eventually but it took a long time.

# the OTHER 100 conversations

I'm one of the lucky ones, really, because it was a motor vehicle accident. But it was still a bad situation because my lawyer had to look for someone to sue so that we could get paid out through third party. I didn't want him to sue my friend, even though third party would cover it. And I didn't want him to sue the racecourse, which was the other option, because I love the town I live in.

When I got my payout, I had advice from my lawyer about how to manage it. I was in my early twenties and you hear all these stories about people who blow their whole payout. I would have blown mine! So my lawyer advised me to buy shares, and that was okay until the recession hit - I lost a lot of money, which should be okay ten years or so from now. But in the meantime I'm living on a pretty low income. The problem is that you get precluded from getting any benefits for years so if you blow your payout or something goes wrong or you just spend it on things you need, you're stuffed. I got my first wheelchair for about \$800 through Royal Perth, because they help you out and apply for all the funding. But this year I needed a new wheelchair and it cost me over \$6000. I just paid for it outright in the end, I had to. I looked on Ebay and ended up buying it from a wheelchair place in O'Connor. I wouldn't know where to start with this stuff...when it arrived from America, they'd taken it apart and put it back together and stuffed it up. The wheelchair guy fixed it and says that he has to fix and maintain them all the time.

The other types of costs that are ongoing costs - \$35 a year for the ACROD parking, lots of money for continence products, lots of money for pain medication without a health care card. And things like gloves - they get used up very quickly. If you're using six catheters a day its about six bucks a day, its pretty expensive, it can be more.

After I got paid out I had to pay back all the support that I'd gotten before, I think it was about \$24,000.

Do I get assistance? Depends on what you call assistance. I've never met anyone from the Disability Services Commission and I've never met

anyone from the disability sector in a support role. There wasn't a question on the Census about whether you have a disability and just about whether you need assistance, so I answered yes - my friends carry me up and down stairs all the time, so if I'm honest, I do get help in certain ways. But not paid assistance. I have never met the local LAC and wouldn't know who they are and where they are.

I'm supposed to have physiotherapy, but I can't afford that. I have to pay for it myself so I just don't go. Same with my car modifications, that cost over two grand just for the hand controls.

In 2015 I will be eligible for a health care card. I don't know what will happen then. I don't know much about the disability sector, I wouldn't have a clue, but it could be a lot better.

- Franny Wacura, Wheatbelt

## 20. Now We Are Six



'Ministers really need to hear the true stories out there and talk to everyday real West Australians'.

Our names are Leona and Mark Fawcett and we have a son named Joshua aged five who has autism. Joshua was diagnosed at the age of three, but did not get any intervention therapy until he was four due to the lack of a therapist to provide him with the required therapy he needed. He is now in pre-primary and doing very well but is still non-verbal and has severe behavioural problems due to

# the OTHER 100 conversations

the lack of communication skills which is not only difficult for me also for the school to deal with. Just the need of providing our son with an aide full time at school has been beyond comprehension as to why it is made to apply for.

There needs to be more assistance for these children and others with disabilities after they no longer qualify for the assistance from DSC (once he turns 6 he is cut off from receiving therapy). So Joshua turns six in three weeks and he will no longer be able to receive the ABA therapy. Joshua needs this therapy and will need it long term to help teach him to communicate and deal with his behavioural issues.

Financially, we have had to have superannuation released early to assist with the lifestyle we need to provide for our son as the lack of government financial aid is quite poor, \$6000 a year is provided to assist with Private Early Intervention which only goes so far, with a therapy session costing \$60 per hour in two hour blocks at a time. So in hindsight, the \$6000 provided only goes so far and doesn't last all that long. We as a family are scared of how we are going to cope financially after Joshua reaches the age of six as he is going to require life long help which appears to be out of reach due to everyday living expenses and no where to turn for help. There are even more out of pocket expenses which are not heard about, but surgery for things such as grommets, which are quite expensive, even on Private Healthcare are needed or else children with autism can regress backwards quite quickly due to the difficulty from hearing issues and not being able to comprehend what they are learning in Early Intervention.

From reports that I've heard and read about over the years, in the United Kingdom a family only has to pay and maintain a child with autism for 1 year out of their own pocket after a diagnosis and then go to the High Court to apply for lifelong financial aid from the government. Why a system like that is not set up here in WA and more importantly Australia is beyond me?

Looking for help and where to turn initially was a nightmare and still to this day is not much better, even as informed as we now are. A central base needs to be established Federally where families can turn to and not get the run around to go from one place to the next only to be told to go back to the original point of origin. The state or lack of a functioning Disability system in Australia is really quite appalling and needs a mass overhaul. For WA to say that we have the best and most organized system in Australia is a joke and Ministers really need to hear the true stories out there and talk to everyday real West Australians.

## 21. We Need Change



'We need changes that will benefit all families that have a child with autism.'

My son who has autism and global developmental delay. He was diagnosed nearly three years ago and since then, our lives have been an emotional rollercoaster.

My son has a beautiful nature, is very perceptive and provides our family with so much love and happiness.

His smile brightens my day and it is one of the things that gives me strength day in, day out.

# the OTHER 100 conversations

My son didn't walk until he was 2½ years old and is still non-verbal. He has motor and oral dyspraxia which makes everything he does a huge effort, including the simple daily tasks of walking and talking that we all take for granted. Since he was about 18 months old, we have been to physiotherapists, occupational therapists, chiropractors, orthopaedic specialists, podiatrists, orthotists, paediatricians, GPs, neurologists, psychologists, speech pathologists, ABA therapists, naturopaths and swimming therapists to try and find the right therapies for him.

My son attends pre-primary five days a week and we pay for an ABA therapist to attend with him one morning and one afternoon to ensure that the significant effort we are putting into his private therapy is continued in the school environment. He is currently in an early intervention programme so the teacher to student ratio is reasonably high. I am extremely concerned about the teacher assistant aide time he will be eligible for once he is in a mainstream classroom.

The financial impact of structured therapy hours, specialist and doctor visits, biomedical interventions and the numerous other costs is a huge burden to my family. We were very grateful to receive the \$12,000 funding as part of the Helping Children with Autism package but we fully utilised these funds within six months – my son is only five so we have many more years of therapy costs ahead. We have had to re-mortgage our house and it is a struggle to live week to week.

The recommended minimum structured therapy time is 20 hours per week. The cost of maintaining this is enormous. When you live with a child with autism, every waking minute is potential unstructured therapy time – the physical and emotional impact of this is exhausting.

My "wishlist" for all children with autism would be:

- Increased funding for all therapy costs.
- The provision of full time autism specialist trained teacher assistants for students on a 1:1 basis.
- Incentives for speech pathologists, occupational therapists, ABA therapists, psychologists, etc to

specialise in working with children with autism to reduce the current waiting times to access services. The emotional, physical and financial burden of having autism in our lives is staggering. I hope that my short story will have an impact and lead to changes that will benefit all families that have a child with autism.

- Sally Strecker

## 22. No one is Prepared



'No-one is prepared for the disappointment of the underfunded and under resourced system in WA....

No-one is prepared for the news that their child has been hit by a car.

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No-one is prepared for the sight of their child lying in intensive care, hooked up to beeping machines and breathing pipes. They look so small lying in the white bed. You are told that they are in a coma but to you they look like they are just sleeping as you brush the hair back from their forehead.

No-one is prepared for the quiet talk from the compassionate doctors and nurses.

They choose their words carefully, deliberately. If your child survives they are likely to have permanent brain injury.

You don't really hear, because you are just praying that your child will survive. You don't want to leave the hospital so you find a spare couch somewhere. You try to grab some sleep in between keeping vigil over the child lying in the bed.

And then, as if by miracle, your child survives and slowly starts to wake up.

No-one is prepared for the years that are to follow. After all the care and compassion of the hospital, rehabilitation follows. The places are very limited so you are encouraged to take your child home early and continue the rehabilitation at home.

No-one is prepared for the violence and mood swings. The lack of inhibition, the compulsive and sexually inappropriate behaviour. This is not the child you put to bed the night before his accident. This is a 14 year old man-child with no control over his emotions, a look of fear and terror often in his eyes.

The strain tears at your relationship and that fails. You continue on, you go from agency to agency, you write to your local member, the minister, the Premier. You tell your story over and over and still there is no assistance available. You are sick of hearing the words "dual diagnosis" and "no funding"

Your little girl is seven and now needs to be protected from his irrational behaviour. You often have to call the police to control your son. He is preyed on by those who enjoy bullying the weak. Then the unspeakable happens and he is sexually molested. You continue on and your daughter hides in the

cupboard when your son starts shouting and threatening. You continue on and seek help from every agency, group, department.

No-one is prepared when that help is not available. There is no accommodation, no funds; your child doesn't fit into the criteria for those limited services which are available. Your child has turned to drugs and drinking which he is given by those who don't understand his vulnerability. He develops schizophrenia. He cannot stay in a Psychiatric hospital because his diagnosis is a head injury. He cannot be helped by Drug and Alcohol programmes because he has a head injury and not a drug and alcohol problem. He cannot be helped by a place in a facility for head injuries. Firstly the places are

limited and also because he has a drug and alcohol problem and suffers from schizophrenia.

No-one has the facilities or the programmes or accommodation to help and you slowly start to lose your own capacity to cope. Choices have to be made between your children. You cannot work anymore and all your years of study and experience are now focused on how to get help for your child. Costs start to mount up. Your child cannot continue to live at home, he is improving but you are advised that it takes years for a brain injury to stabilise.

You mortgage your house and purchase a unit for your son and visit him every day to ensure he is still alive, clean his unit, wash his clothes, help him with his toiletries. Ease your guilt at your choice. He is not coping, no matter how often you clean and

'No-one is prepared for the disappointment of the underfunded and under resourced system in Western Australia which has let my child down, let me down and let my family down.'

# the OTHER 100 conversations

teach, the lessons don't penetrate into his long term memory. You arrive to find strangers in his unit. He attempts his first suicide. He is now 17 and by the time he is 18 he has tried several more times. You wonder if he would be happier asleep forever than having to try to make sense of his agonising life. He feels trapped, you feel trapped, and your other children have had enough. Your family has had enough. His neighbours get up a petition, they cannot cope with his talking to himself and wandering around and the banging and noise in the night. They kindly suggest that he should be in supported accommodation. They assume that we live in Western Australia and that such facilities must be available.

You have become way too familiar with the staff at the psychiatric hospital. Your doctor finally agrees that your son needs to be Sectioned (admitted as an involuntary patient) to a psychiatric hospital. That only lasts for a few days when the stressed and overworked doctor tells you that your child has a head injury and is taking up a bed that should be for those with mental illness. He is discharged but you are not informed as he is now 18. He attempts to throw himself in front of traffic. Police are called and he is once again hospitalised in a locked ward at Royal Perth Hospital. He is calmed down with a cocktail of drugs and then discharged again.

You sit in the waiting room at the Psychiatric hospital and are told that there are no beds in the Juvenile wing but perhaps they have a place in the adult section, as he is now 18. You go to the adult section to be told they have no beds. Your son is pacing up and down and talking to himself. You refuse to leave and take up residence in the waiting room. Nothing embarrasses you anymore. Finally 5 hours later, someone comes and give him a bed for the night. The next day he is discharged. The next 5 years pass like a nightmare, your child is lost, you are lost, and your faith in the system is lost.

Finally when he is 23 and after I am diagnosed with cancer, I find a community group who are not prepared to see us suffer anymore and some funding is

found to provide intermittent care and outings. I have never been prepared to give up.

Charitable organisations finally step in to stop your descent further into a black hole of despair which at times seems bottomless.

No-one is prepared for the disappointment of the underfunded and under resourced system in Western Australia which has let my child down, let me down and let my family down.

- Name and Address withheld



## 23. I Needed Help

'I was told - you are double dipping...and then I couldn't get services for my child.'

I am writing to express my absolute disgust that the Premier of Western Australia is not supportive of the National Disability Insurance Scheme. I am rather appalled about his attitude and his obvious lack of knowledge regarding our lack of services for Australian Citizens, our children, our future generation.

# the OTHER 100 conversations

I am also shocked and sickened to hear that our Premier actually believes, or wants everyone else to believe, that our health system is adequate for people with disabilities at the moment. That Disability Service Commission and our Local Area Coordinators are sufficient enough support for people living and dealing with disabilities on a daily basis. I am saddened by the fact that people in our local Government have absolutely NO IDEA just how atrocious our support system is. Really, are our local representatives that ignorant to this disgusting situation, or are we ALL just a hindrance on our country, so we get pushed under the carpet and the problem is solved.

Firstly I would like to start by telling you a little about our family. I am married and together we have two beautiful children. Our son Zephan was born in 2004 and our daughter Saphyre was born in 2006. We live in the Rockingham area of Western Australia. We were just like any ordinary family, being happy parents to our children, working and enjoying life. Of course with Zephan being our first child, everything was new to us; there is no text book about how to be instant wonderful parents. So we thought things were going fine. It was during the year 2006 that it became rather obvious "things" were not fine.

Towards the end of 2007, our first child Zephan, was diagnosed with autism.

The initial problem that needs to be addressed right here in Western Australia, is our waiting lists. To try and have my child seen by the Medical Professionals he needed to see, to confirm our suspicions about his Autism was going to take over 12 months. Yes that is correct, over 12 months. Yet everywhere I was reading, how it is most important for these children to receive Early Intervention as soon as possible. This drives parents crazy – desperately trying

to help their children, but the system cannot help for 12 months. So we took the only viable option for our family in this disgraceful situation and we went private. Although this costs extra money, we are not prepared to sit and wait 12 very precious months of our son's life during his prime learning

years. The full procedure to have our son seen by the three different professionals to receive his diagnosis took almost 7 months. Well this was better than 12 months.

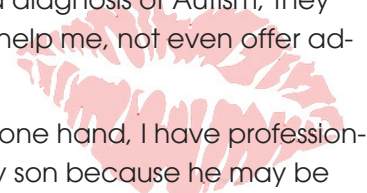
I had problems with the local Child Health Clinic whilst my son was on the waiting list - when I told them that it was vital my son receives his appointment as we are in the process of possibly having him diagnosed with autism, I was told that my child can no longer be placed on any list or receive any appointment as they do not have the trained staff or specialists to deal with autistic children. I made it very clear that he is not as yet diagnosed, and we are in the process of having our son assessed. However that made our son ineligible to receive any such help or

services from the Child Health Clinic. I asked why my child could not receive Speech Therapy, when other children are receiving it. I was actually told 'You are double dipping for your child and he can get these services from the Autism Association or your Autism Provider'.

One of the first places I phoned was the Autism Association. Very difficult to actually speak with someone, and my phone calls were never returned. It took me approximately one week before I actually spoke with someone to get some advice on how to help my son. However – because my son did not at this point in time have a diagnosis of Autism, they were NOT prepared to help me, not even offer advice over the phone!

So there you have it, in one hand, I have professionals REFUSING to help my son because he may be

'No-one is prepared for the disappointment of the underfunded and under resourced system in Western Australia which has let my child down, let me down and let my family down.'



# the OTHER 100 conversations

Autistic and they don't have the adequate training or services to help him, AND on the other hand I have professionals REFUSING to help my son because he is not yet diagnosed with Autism. So we are now totally falling through a VERY LARGE GAP IN OUR HEALTH SYSTEM. This is a major problem that needs to be addressed immediately. So for 7 months, we are totally on our own, WITH NO HELP!

I finally reached a helpful organization, Intervention Services for Autism and Developmental Delay, who actually helped me in my desperate crisis to find help for my son. I was frantic, and life was out of control. There was no help available nor did we even know where to begin to get this help.

During the end of 2007 our son Zephan was officially diagnosed with moderate Autism.

However because families are not entitled to any help, or service providers for Autism unless they have that official diagnosis, my husband and I decided to pay for private therapy for our son until he had access to the funding and early intervention he so desperately needed.

We were also paying for our son to receive private Speech Therapy because he was NOT entitled to the government funded Child Health Care Services. This placed extra unnecessary strain on our family, added onto the strain and stress of trying to come to terms with our sons diagnosis, then there are all the problems associated with our son, and the lack of help or services from the Autism Association. As you can imagine, our family was under a lot of stress at this time.

Once Zephan had his official diagnosis, we had to choose a Service Provider for our son. We had the choice of Autism Association or ISADD. I visited both of these Providers before making my decision. I do not feel that the Autism Association of WA is actually going to help my son, or my husband and I. They provided 2 hours, twice a week, up in Perth, for our son to have therapy. Parents are not allowed to be involved in this therapy. Well as far as I am concerned I need to be able to help my son at home. Two hours twice a week, to help a young child with Moderate Autism, is disgraceful to say the least.

Needless to say, we chose ISADD, who have a different perspective on helping families with Autism.

When you are enrolled with Disability Service Commission, you and your family basically become just another number. Well that is my experience for the last four years. You are allocated a LAC, Local Area Co-ordinator who is there to help you with your queries. To be honest, I really have not been fortunate enough to KNOW what the actual role of a LAC is. I remember someone coming to our home, briefly, filling out some paperwork, promising to call me in the future, and that was the last I heard from that particular LAC.

February 2008 Zephan attended a two year program for Kindy and Pre Primary. He attended North Mandurah Primary School – as this was the closest facility that provided this specialised program for children with Autism to receive intense ABA Therapy type learning. He attended Kindy twice a week, and then the following year he attended Pre Primary at North Mandurah School, in the Autism Unit, twice a week, whilst he attended mainstream school with an Education Assistant for the remainder three days a week. This involved much travelling however was necessary for our son to receive the services he needs. This entitled Zephan with .9 Aide time in total. In 2009 another Autism Unit opened in Leda, our local area and we had the choice of enrolling Zephan there for the second part of the two year program. We decided against this, because the staff were already trained at North Mandurah Primary School, the staff knew Zephan's strengths and weaknesses and Zephan was familiar with the teachers, the program and the school.

We could see no real benefit to disrupting our child's education just to decrease travel time. The cost of travelling to North Mandurah Primary School was subsidised, however our subsidy was removed in 2009 when we had the CHOICE to disrupt his education and enrol Zephan in the Autism Unit closer to home. Once again – another unnecessary financial burden being placed on our family. It was not in my son's best interests to move him from one Autism Unit to another. So we made the decision to pay

# the OTHER 100 conversations

for our own travel expenses, to keep our child from being disrupted. I did make several phone calls regarding this situation. Unfortunately if we did NOT want to be financially burdened our only choice was to remove our son from the North Mandurah Autism Unit (which was the only one available to us at the start of the program) and enrol him at Leda Primary School Autism Unit.

July 2008 – Finally the government introduces the Faschia Funding, the \$12 000 grant over two years. Thank Goodness – we can use this funding with ISADD to pay for a therapist to deliver the ABA Therapy. I am tired of being Zephan's therapist and I needed a break. I needed to be Zephan's Mum, not his therapist. Unfortunately that excitement was short lived due to the lack of staff and trained therapists working for ISADD. So now we had the funding – BUT couldn't use it.. How very frustrating this situation was. I continued with Zephan's therapy for as long as I was able. Naturally, there came a point where enough was enough and to save my own sanity I stopped being my son's therapist.

Another situation the State Premier should be aware of, is when the Faschia Funding eventually became available all of the Autism Services Providers increased all of their fees. How absolutely disgusting, that these Providers, who are meant to be helping MY SON, see this \$12000 grant over two years, as an opportunity to cash in and make money from my child's government funding. I was absolutely sickened by this outcome. Due to this disgraceful behaviour, every child in Australia immediately received LESS services and therapy while every Autism Provider in Australia received MORE money.

During this time our family was under immense stress, there were NO social outings, Speech Therapy was becoming expensive, I was drained, my husband was working hard to pay for these services and our

marriage almost became another statistic. I was informed by ISADD that if I could find someone to become a Therapist they would train this person, and they could become Zephan's therapist. After six months, I found someone that agreed to this situation, so our son finally had a Therapist, and I

finally had some much needed rest of delivering his therapy.

Of course- as parents do, we start to question what happens with our son once this Faschia Funding either runs out or comes to an end. Well believe it or not, at this time, once your child turns six years of age, the funding and Autism Provider Services come to a screaming halt. Your child is enrolled to mainstream school. Then your child becomes the Education Departments Problem !!!

Our child completed an IQ Test to determine if he had an Intellectual Disability or not. This is very involved and rather time consuming for a small child to complete, however so, it is necessary. It was determined that our child only JUST passed the

section of NOT having an Intellectual Disability, so he is eligible for Mainstream School. However he has gone from receiving one on one tuition with 5 other children in the classroom, into a mainstream classroom. He was receiving .9 aide time, but for some reason once the two year Autism Unit program was completed, he was thrown into mainstream schooling and his Education Assistant aide time was REDUCED from .9 to .5, so almost half of what he had been receiving for the last two years.

Once again, I argued with this decision. But for Zephan to have any chance of receiving the aide time he most desperately needs and SHOULD be ENTITLED TO, I had to dispute this decision with the Education Department. This, once again is a very time consuming process, and once again adds unnecessary stress to a family life. Not to mention in the mean time, while everyone else is wasting my

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sons precious education time, he is not progressing as well as he could or should be. Eventually Zeph-an's aide time is increased to .6, which was slightly better than the .5; however a far cry from the .9 he had been receiving.

So welcome 2010. Not only is my child thrown into mainstream school, with MUCH LESS Education Assistant entitlements, but he is NO LONGER eligible for any Government funding for the services he still so desperately needs. Yes Zeph-an turned 6 years of age, so the funding stops at the age of 6, or the commencement of Year One for these students. Unfortunately – Mr WA Premier – what you do NOT realise, is that my son's Autism did NOT just disappear at the age of 6, my son's Speech problems did NOT just improve once he started Year One in a main stream school. My son did NOT all of a sudden become bright and talented once he commenced Year One. My son did NOT all of a sudden become a social butterfly, nor did he lose his Autistic Traits, nor did he lose his obsessive behaviours, nor did he lose his angry outbursts, nor did he lose his self stim behaviours, nor did he lose his sensory overload issues. Hopefully, by now you get my point. Why does funding for these children stop at such a young age when their condition still exists? I am now talking from experience; the Education Department is failing my son, hence failing our whole family. We have worked extremely hard with and for our son for the last three years, and now what? He is left to his own devices with minimal Education Assistant time while placed in a mainstream school. Yes, I would like that question answered please.

The IQ test is available every two years. This is another disgraceful situation.

Welcome 2011. My son has not coped with his education throughout Year One, even with his .6 Education Assistant time he has received. He has NOT made much progress. Zeph-an has had intense therapy and homework during this time also, to help him meet the minimal standards of what might be expected from a Year One student. Zeph-an is clearly not keeping up with his peers in his mainstream classroom. There is nothing more we can

do. He is NOT entitled to outside ABA Therapy any longer. He is NOT entitled to Government funded Speech Therapy, he is NOT entitled to any extra aide time in the classroom. We as his parents are doing everything we possibly can at home to help Zeph-an with his Education.

The Education Department has a total lack of services for my child. There are no speech therapist entitlements through the school system. There are NO special therapists available to speak with my child about his anger outbursts. I'm not even sure that there are teachers who are trained in the field of Autism. I might also like to add that a certain respectable person at my son's school, asked me to have my son retested for Autism in case he has outgrown his diagnosis. I lose faith very fast in the Education Department when these so called professionals, who have NO CLUE what so ever, are the one's supposed to be helping my son. They don't even know that an Autism diagnosis is a life-long condition, yet they are in charge of providing the appropriate care and education for my son.

There is NO parental support available to help us with our child and to help us deal with the fact that our very own Government does not care about our own son. There is NO help when you are tired of fighting every single agency, school, therapist, who ever, just to get your child the help he desperately needs. Oh, yes, did someone mention Disability Service Commission. Sorry, who are they again. I have not heard from them since my son was diagnosed with Autism. Oh my LAC, well I don't have a clue who that is either.

Throughout 2010 and 2011, I made several phone calls to Disability Service Commission. I wanted to speak to someone regarding my son's situation; I wanted to speak to someone about getting help. I was having problems with my son's school and his IEP, I NEEDED HELP, but once again, no-one was available. DSC hardly returned most of my calls. Eventually I made contact with my LAC, who spoke with me briefly. He offered to attend my sons IEP Meeting with myself, which I greatly accepted, because once again we were going through a stress-

# the OTHER 100 conversations

ful time. My LAC was in somewhat of a hurry and late for a meeting during this phone conversation, so promised to call me back as soon as his meeting was finished. That was in 2010, and I guess it is a record long meeting because I AM STILL WAITING for him to return that phone call. Of course I DID NOT HAVE ANY SUPPORT for the meeting with my son's school. This is adding to the already massive amount of stress our family is under.

During 2010 and 2011 I have made many, many phone calls to DSC and several LAC's. Each time I speak to someone the LAC has changed. They don't have the information about my son. They can't find my son on the computer system. Some of the staff actually came to my home and introduced themselves, and we filled out more forms. I was constantly asking for some respite or some help. I have had enough. I am tired, I don't know what else to do to help my son. His education is not improving, his behaviour is becoming more and more aggressive towards myself, and my younger daughter. The LAC's have not returned my phone calls. The last LAC I spoke with has moved onto another position and this continues for the last 12 months. There have been approximately 7 different people filling the role of my Local Area Co-ordinator in the last 12 months. I have NO idea what has happened to our two different forms of paperwork, filled out on two different occasions, by two different LAC's.

I have no idea what the selection criteria or experience is for someone to actually adequately fill this position as a LAC. Disability Services Commission should be well aware we have a major problem with our LAC branch. There is still NO communication between DSC and the parents on their computer system. I still AM NOT AWARE of what RESPITE I am even entitled to if any. I need a break; I need some time out to recharge. Still no phone calls! Where are we, as a family suppose to go to get help, one, for our son, and two, for our family. Not to mention for my sanity.

We are now half way through another year, 2011. My son is repeating Year One in his local mainstream school. I know my son is not achieving to a

minimum standard. The teachers have expressed that Zephan is not progressing as well as they had hoped for. He is NOT entitled to repeat Year One again. He is not entitled to attend a special education centre within a mainstream school because he does not have an Intellectual disability. The last IQ test was 18 months ago. I have requested for Zephan to have another IQ test. This is not permitted until two years has passed since the last IQ test.

I am becoming more and more stressed each day as I am watching my son's education slip away into infinity. Right now the system is failing my son AGAIN. He needs help with his education, he needs help with his anger management and his emotional outbursts, and he needs help with his sensory overloads. He needs help with understanding instructions and listening. Zephan does not listen to instructions, he does not follow rules. He does not understand the consequences of certain actions.

I need help with how to parent my Autistic son, because I am trying everything I know how, and failing. I feel like a failure as a Mother, I do not know what else to do with my son. There is no help from my LAC, there is no help from the school or the education department, there is no help from DSC, there sure is hell has been NO RESPITE so I can recharge my batteries and refresh myself. I have not been sleeping. I am constantly worried about my son's future, about his education, and his anger outbursts. I am worried about my son when he becomes a teenager and does not listen to society's rules, and does not understand there will be consequences to his actions.

Half way through 2011 I end up having a break down in tears at my son's school. That is it, I have broken down, I am done, I am tired, and I am finished. There is not going to be any light at the end of this tunnel. We are stuck on this frightening, fast, and scary, out of control Roller Coaster Ride, and the person at the control panel has said "The people of Western Australia do NOT get to exit this ride". There will be no extra help from the Education Department, there will be no more funding for children once they attend Year One School, there will be no

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## 24. Exhausted, Frustrated and Scared

'What on earth faces the next child  
born with special needs?'

I am a mother of two living in rural Western Australia. My six year old daughter was born by emergency cesarean and the moment she entered the world it was obvious to all that all was not well. After a three week stay in the NIC at PMH we were sent home with a baby who was labeled as failure to thrive, suspected seizures and nasal gastric tube fed. We had no idea how quickly life would change.

Our daughter has an undiagnosed genetic condition, is non verbal and incontinent. She has been given "band aid" diagnosis of cerebral palsy spastic diplegia and autism with all the bells and whistles,

also suffering from recurrent pneumonia, grave's disease and a history of gastric ulcers.

Living with and caring for a child with special needs is a world one cannot imagine or properly understand without the first hand experience.

Before the age of five we received little assistance as she was then undiagnosed and the level of care classed as age appropriate so no assistance or funding was available until her fifth birthday, if she survived to that age. The amount of therapy and medical care required has had huge ramifications even though it is recommended that to maximize early intervention we should have been doing more. Navigating this maze is a full time job aside from the caring role.

The emotional and financial hardship of caring for her has ended in the breakdown of our family and extreme financial hardship with our home now in jeopardy.

I wonder what on earth faces the next child born with special needs and their family's future if ours is considered to be all ok and managing with the support and services already provided.

If my life is so manageable I wonder would you like to walk in my shoes to see for yourselves how exhausted, frustrated and scared many of us are as we look at the future and what it doesn't hold for our children?

## 25. Equipment Fail

'It breaks my heart to see families  
having to wait...'

Having worked in the disability field for over 10 yrs it breaks my heart to see families having to wait for specialized programs and equipment which is essential to their every day living and development.

I have seen parents wait up to 12 mths for walking frames/standing frames which is essential to a child's movement development progress. I have no idea why it has to take so long when to me it's simple ... if

# the OTHER 100 conversations

a child needs a piece of equipment then that piece of equipment should be made available in a reasonable amount of time .

I have seen children having to wait 12 months for wheelchairs and having to sit in ill fitting chairs because they have to wait for funding or wait for the chairs to arrive? How is that possible ?

I have had a case where due to red tape i was unable to find and supply a child with free nappies due to hospital red tape and watched the parent pay out of their own precious small pension having to buy nappies for their child. To me that is just another added pressure that these parents have to endure on a daily basis.

Why is it the Government can justify spending approximately 26 million in advertising for the Carbon Tax ~ But cant provide easily accessible/affordable or free equipment and services for families who are affected by disabilities.

I take my hat off to parents and families with children who are affected by a disability ... they are unsung heroes in my eyes.

## 26. From Qld to WA

'We have found navigating the system complicated...'

Our son Sean is 10 years old, in year 4 at school. He is diagnosed with low functioning Autism and intellectual disability. He is non-verbal, has an extreme bird phobia, high sensory issues, and is not toilet trained.

Since arriving in WA in 2004 we have found the services here I am sorry to say, slow. We had to move to WA as my husband got a transfer with the Army, already knowing that our son was autistic. Went into Disabilities Services Commission and sat through their intense questions which we both found absurd. Some of the questions were unrealistic, therapists were cold, when finished they wanted to send out a psychologist, we declined as we had already been

living with the diagnoses for over 12 months, but because WA would not recognise a Queensland diagnosis we had to go through it all again. The new NDIS system would mean that this wouldn't need to happen as the diagnosis and "package" goes with you when you move, especially significant with families moving frequently for work.

We have found navigating the system complicated, nobody does really seem to know what you are and are not entitled to in regards to therapist, schools, a child's rights to an education. Although you could bring in the "discrimination" word...the Principal will hold that against you..... We tried to send our child to mainstream school. It was okay for a while, but then we were forced out for many reasons. The main one was that the mainstream school felt they could not teach him....so here we are two years later and the special needs school is still doing kindergarten work with him. He has been abused by two aides and is only just settling down now. August 2011, this is an Education Support School...they did not use basic autism knowledge such as schedules, which set up Sean for failure each day. As Sean got the bus to school I did not see that there were no schedules on his table. So I asked the psychologist from Autism Association to visit the school as I have a relationship prior with her. As soon as she went in she dot pointed all the issues - no schedules, no toilet breaks, too many breaks. Trying to get an education for our son is difficult as the Teachers & Education Assistants are not trained enough in all areas of disabilities and don't know the children therefore losing valuable education time.....not extending the children's ability.

The attitude that children 'can't do' is very common.

We were granted IFS funding from Disability services Commission and chose Autism Association as the provider. We have had trouble since we started with them, so far 17 staff since December 2010, bringing home Sean burnt, not attending to his needs, stinger bite left untreated, stayed at the beach for 2 x 4 hour shifts, brought home dehydrated, etc. Lack of training for staff means

# the OTHER 100 conversations

there is the constant worry if staff are competent to deal with our son. Simply to take him out to the park is a huge issue - the great outdoors he finds overwhelming, so to find a carer who is compassionate who can understand this boys needs and keep him safe when he needs to feel safe is a constant challenge.

IFS funding was granted we believe mainly because my husband is now based in Darwin and away most of the time, but the funding is not now addressing the issues we originally had.

Dealing with organisations is very difficult. They can be very judgmental of our families circumstances.

With my husband now based in Darwin, I am parenting and dealing with all of the above issues on my own for much of the time. We also have a younger child and I work full time running a family day care business at home.



## 27. It Needs To Change

'I can't leave him with a regular babysitter as he needs specialised care.'

WHEN we first went to the Disability Services Commission, our new Local Area Coordinator asked us why we were in a hurry to get services? What would it actually change?

We got referred to the Rockingham early intervention team. We thought, great, some help. Wrong. We didn't hear from them for almost a year. We sought private therapy because of the lack of help from the team, then received a call to say we were being discharged from their boos as we were now using private therapy - as if we had a choice!

Its going well now with early intervention, but getting to this point has been a terrible struggle. I'm sick to death of having to beg and plead with these organisations - my pride gets in the way. I hate being made to feel as though I'm not as good as other people.

I'm not entitled to any ongoing respite, except for five hours every three months. That's a joke. I can't leave him with a regular babysitter as he needs specialized care. My child is non verbal and gets very frustrated so head butts, bites, scratches, squeals and hits - his behavioural issues mean that he needs to be cared for by a professional.

We've been doing this on our own for at least two years. We had to wait a long time for a diagnosis and then for therapy and taking care of my son takes all my energy and attention, weeks of asking questions made it very distressing and confronting.

It needs to change.

- Deborah Crone

## 28. Trapped in a Life

'We are trapped in a life that we did not ask for...'

I GUESS the easiest place to start would be the birth of my beautiful baby girl. Nice uncomplicated pregnancy (tried to do everything right), not an entirely straight forward birth, nonetheless a beautiful looking child.....life was peachy. It did not take any

# the OTHER 100 conversations

genius to figure out this baby had issues right from day 1. Very unsettled, feeding issues, sleeping issues etc etc. All came to a head on day 4 where her "dusky episodes" were figured to be full blown seizures, which quickly spiralled down hill resulting in induced coma, intubation, RFDS flight and three weeks at PMH in a city with no relatives, a husband off work and a confused three year old to take care of. Upon returning home on antiepileptic medication, life did not improve in the slightest.

Having a new baby often is difficult, but this is often matched with joyous times and happy memories. There is none of that for us. This baby was almost the death of us all. She screamed, never slept, had no interest in cuddles, didn't feed properly....the list goes on. The poor baby obviously had so much neurological pain it was unbearable.

(pause here,....respite....none,)

To condense the next couple of years – we basically had six different hospitals, Two RFDS flights and 14 ambulance rides, all before she was two. Just to jump a few more years.... Imogen is now almost six and this year alone we have had ten seizures. You may be thinking...big deal, some kids have many seizures in one day, but I must point out, that Imogen's seizure disorder is classed as severe and her seizures can last up to three hours – doing goodness knows how much more damage to her brain. Apart from the obvious stress this puts on our poor child.. the ramifications for our family are also huge.

My husband generally needs to take time off work, our older daughter get shoved from friend to friend (whoever is available at the time) and I spend yet another 24 hours sitting in a hospital chair. Usually normal everyday appointments need cancelling, obligations and sports gets missed. It goes on.

Seizures aside – Imogen has a significant global development delay / intellectual disability. I could talk for pages and pages about the lack of services we

have received for Imogen. Being completely new to the "system" and totally unaware of the need to push for what you want I stood back and got offered little bits of therapy in blocks – however, I have ALWAYS asked the question, what else should I be doing for Imogen?? We took it upon ourselves to

arrange a private speech therapist who costs a fortune, however it has been HER that has helped me open my eyes to places like the independent living centre and the like. I am now being asked questions from the school like "why haven't you had "private" physio and OT? Why aren't you doing this, Why aren't you doing that? I feel like the biggest failure as a parent. I now, after chucking in my career and everything I have ever studied for, devote my life to Imogen's different therapies and STILL

feel like I can never do enough.

We constantly have teachers, therapists, medical staff, specialists, even friends and family members telling us we should be doing this and that (each day) and we are totally overwhelmed. I would invite any one of them to spend a few days with Imogen and let them see how "challenging" the simplest task can be.

Imogen is nonverbal, non compliant, totally dependent and extremely destructive. Add that to the fact she is a poor sleeper and it makes for a pretty unbalanced, dysfunctional home. I am lucky I have an amazing supportive husband and a gorgeous other daughter, but I worry myself sick what underlying issues this is causing in the future, especially for my eldest girl. Our house is a circus and Imogen is the ringmaster in total control of everything.

I am now at the point where we hardly go ANYWHERE. We have a few certain "Imogen friendly" friends houses that we go and "Imogen friendly" sporting clubs, however, school assemblies, shops, any place that requires some self control end up being a huge mistake. Our family used to enjoy the outdoors and camping. we now cannot go any-

'... so many WA families are faced with daily challenges with people with disabilities and simply need more help.

# the OTHER 100 conversations

where “too remote” in case she has a prolonged seizure. We feel so trapped in a life that we didn’t ask for. Its like we have been given a life sentence and we cant see any light at the end of the tunnel.

Basically my driving force behind this letter is that so many WA families are faced with daily challenges with people with disabilities and simply need more help. We cherish our loved ones and want to protect them and do everything within our power to make life for them, and us, fulfilling and enjoyable. Sometimes this desire however, is overshadowed by so many variables that makes for unstable carers who are fatigued and fed up with their own situation, society and life in general.

Please consider not only my family but the families of thousands that depend on various types of assistance and at the end of the day this can indeed greatly be affected by any decision made by you. -  
- Robyn Martin

## 29. A Single Mums Story

‘Disability is not about competition’

As a struggling single parent with a child with a disability, I have battled non-stop since my child was born. I have had enough of the battles and the nagging and the chasing-up and generally the exhausting amount of energy I use daily just to get our needs met. The proposed NDIS offers me a solution to the daily grind that has worn me down.

I am the sole carer and parent of a child who has ongoing medical needs as well as needs for support in daily care and attending school etc. Every day I must attend to an issue or three because my child is labelled disabled. My life is full of correspondence and appointments with medical specialists, therapy providers, school staff, disability workers and disability service providers. There is no one else to help me with these appointments.

The current system centred around DSC does not work. For many years I did not know CAP funding was available and then was awarded it last year

(and yes, this was due to the efforts of DSC). However due to the broken system, I now have funding but no support workers to provide me the respite and support I so desperately need.

How are single parents of children with disabilities supposed to work and care for their children without support?

Local Area Coordinators at DSC can have up to 55 families to care for each. With such high numbers and fierce competition for funding, how can DSC provide what families need? Disability is not about competition but if the current DSC-based is retained then this is what families will always face.

People with disabilities in WA and their families deserve to be heard Mr Barnett. What you are doing is disabling, not enabling.

I enabled my future (or so I thought), by working hard to get two university qualifications and a professional career. But after the birth of my child I have had to give all that up to concentrate on getting my child's needs met. Both my future and my identity are uncertain - a universal scheme such as that proposed in the NDIS will provide me with much-needed security.

Do the right thing, Mr Barnett, and at the very least, meet with WA families before you make a decision.

- Delia Richardson

## 30. Working to Live

‘A pox on ‘consulting with!’

As a person who manages periodic blind episodes, and in a world that lacks the relative sophistication of willingness to hire people with disabilities, I found myself increasingly struggling with the ability to care for myself.

The resulting slide in my physical and emotional state is directly related to the compounding effects of the poor financial reach of people relegated to the fallback position of disability pensioner.

# the OTHER 100 conversations

The situation is worsened when services that we are more or less forced to apply and queue for, and eventually depend almost entirely on, are inadequately financed.

There is also the critical issue that funding is further decimated by policy change, change of govt, only periodic societal and media interest, the armies of fully abled people employed to determine the outcomes for the disabled, and the costs of maintaining the largest employment field in Australia - that of the social and community sector.

On top of that, we are frequently forced to rely on state housing, and the draconian restrictions on even part-time work, in order to help ourselves, and feel a part of the community.

Most of the disabled people I know are highly intelligent, and their sense of how little they factor in to their own welfare is keenly felt. A pox on "consulting with"!

My reading of the productivity commission's wider recommendations is that (a) we will be able to self-direct funding, and it is my great hope this will truly be at the discretion of the disabled person, upon reviewing all the parameters, and (b) that we may be able to "cash in" our public housing entitlements, to better tailor our housing options.

If the federal and state governments were also to finally require employers to begin hiring disabled people, I believe we may finally approach something akin to equality. It will need a government mandate, as it will not be forthcoming organically.

## 31. Working to Live

'There will be so many conversations that will not be heard because the parents are too tired...'

I HAVE six children. My third has Autism. She seemed to be a perfectly developing baby. Putting on weight, smiling, babbling, interactive, including recognition of me with calling out to be taken out of the cot after sleep time, arms outstretched and

"mumma" being spoken as I lifted her into my arms. She would even run to the bathtub when bath time was called. At 14 months, 40 degree temperatures followed with an outbreak of red spots (measles) and she was gone. No more eye contact. No more calling from the cot. No more running to the bath when I called out "bath time". And no more coming when I called her name. She was tantruming all the time, we couldn't go anywhere because something would trigger screaming and fear.

We as a nation want a system that our taxes can fund that will be used to take care of those who need it most including parents and carers as well as the those suffering with mental or physical conditions. How could any member of the community living in our rich country deny our most disadvantaged?

There will be so many conversations that will not be heard because the parents are too tired, time strapped and energy depleted to share their stories time and time again. After many years of their stories falling onto deaf ears, they think to themselves, "Why would I share it yet again? As before, nothing will happen, they will still deny our existence. So everything is not good, Mr Barnett and Ms Gillard! CHANGE NEEDS TO HAVE ALREADY HAPPENED YESTERDAY!

## 32. Don't Have Kids

'My marriage broke down. I lost my home...'

My son was diagnosed with autism at age 10, he is now 18.

DSC did not recognise his diagnosis as needing much support so I did it on my own.

My marriage broke down, I lost my home as the bank would not let me put the mortgage into my name. I spent the small nest egg in trying to find the right school only to have to homeschool from the start of term two year nine, due to education department stuff ups and bullying issues.

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Health professionals recommended that he home school and never return to school. My son is not employable at the moment and I struggle to get him to help out around the house despite the broken humerus i currently have.

Finally it looks like i might be able to access a little help through DSC but God knows how much help that will be.

In the meantime, I have less than \$500 in superannuation, no savings and no home of my own.

I would have to strongly recommend to people not to have children if this is the amount of support given to families with challenges. It is not worth it financially to destroy your life.

## 33. 36 in 100,000

'It's not what you know, its who you know...'

I'm forty two years old and I have a condition called CMT, which is a degenerative disease. My type is hereditary but my children do not have it.

Over the years my condition has gotten worse. I am one of those people who do not fit any easy categories - I can work, but it is hard because I get tired easily. I have foot drop, so I use a brace. I am a service user because I use health services, an OT and a physiotherapist, which are not funded and which I must pay for myself.

The thing that is missing in the WA system for me is a whole approach. It is 'bitty' - it is not what you know, its who you know as to whether you can get help. Getting help takes a long time and is not guaranteed, especially for adults.

Last year I had to have a hip replacement and I was off my feet for a long long time. I asked for help in the form of home help for my family. There isn't any available. I was talking to someone with cancer and disability caused by cancer and they said the same thing. You can sometimes get help from one particular agency or another but it is nev-

er the obvious one and they are 'doing you a favour' for a very short period of time. It is never a guaranteed or certain thing. And then there are extra expenses. To keep my drivers licence I have to do an OT assessment every year at a non refundable cost of \$540, plus a medical. That's a cost other people don't have to bear. Hand controls on my car, other things all add up.

Because this is a very common inherited neurological disorder, more than 36 in 100,000 in the world are affected, you would think there would be more help. But the range of need is very big and it is difficult for adults to access help if they need some help.

I don't know what the future will hold for me or my kids.

## 34. Blind Since Birth

'How much longer do I have to wait...for a decent level of service and support?'

I'm blind since birth. After spending six years in a school for the blind, where I was routinely bullied and harrassed at recess and lunchtime by kids from the adjoining regular school and where the so-called teachers were conspicuously absent from playground duty and failed to show leadership and responsibility when they were made aware of the problem,

I was thankful - indeed excited, when I was finally integrated and attended Westminster Primary School for the final year and then Mount Lawley Senior High School for the entire 5 years of my secondary education, busting my gut in the school's foreign language program, just so that I could gain the all-important precious TEE results to get into university and continue my language studies (more gut-busting over and above the level required of someone not contending with the pathetic inequities and inadequacies inherent in services for the blind and vision impaired). After a couple of years recovering from the burn-out, focusing on creative/

# the OTHER 100 conversations

musical activities (eg drumming), completing some short computer-related courses and being completely disgusted at so-called employment services - especially the "specialist" agencies recommended for the blind and vision impaired, I came back to do my second degree, studying Japanese and Indonesian, only to be burdened with even more stress and hassle despite the lesser number of units.

As well as tracking down resources and agencies in Japan in order to learn Japanese Braille and have my study materials transcribed into Braille (no one at the Association for the Blind had ever dealt with Japanese Braille), I was also contending with the bureaucracy of the relevant department on campus, who were dragging their feet when it came to organising what to do regarding assessment of my written work. (I couldn't submit it in Japanese characters, as there was no screenreader other than those used by the blind in Japan, which weren't compatible on our computers.)

I was eventually allowed to submit the written work in romanised spelling of Japanese, and I did very well in terms of results, marks etc; however, I remain more appalled and disappointed in the disability services in this country. A blind person seeking Orientation & Mobility (O&M) training from organisations like the Association for the Blind of WA is apparently supposed to feel honoured to get a measly once a week, let alone the luxury of twice a week training.

I'd like the Premier to contend with that when he wants to get around independently. The only other choice we have here in WA is paying a private mobility instructor (there is one practicing privately now and charging \$50 an hour!). And I'd really like to see him contend with the pathetic options available for us in terms of learning skills such as cooking. (Occupational therapists are still apparently quite OK for this purpose, even when their background in culinary skills is, well, minimal!) I am disgusted at this second-class citizenship and would like to know how much longer I have to wait til a decent level of service and supports is finally going to be afforded to us - especially if WA can apparently afford the big spend-up for CHOGM!



## 35. She's My Mum

'I break down and cry for more help, because my carers role will never end...'

31 YEARS ago I was placed in the arms of a lady. This lady is different she can't hear (deaf) she can't talk (mute). This lady is my mum!

We relied on a lot of family members to take care of us four children while my dad worked. We had lunch dinner next door at my aunties every night due to our mother not knowing how to cook. We got taken to school or outings by other family members as she knew no road rules or had a car license. We had to even take her and show her public toilets as she didn't know ladies from gents. The only books that were read to us was in school as mum didn't know how to read. The thing we kids found really hard was that Mum couldn't hear or say the words, 'I love you'. She needed 24 hour care.

We are grateful for who we are as we are very accepting to others. We are caring, kind and loving. But even though we were well looked after I wanted to know what it would be like if things were different.

# the OTHER 100 conversations

In 2005 I married a great guy Dave. We moved to Esperance and I must say I was a bit relieved just to get out of the carers role.

In 2007, I was flown to Perth by Royal Flying Doctors Service and was blessed to have a baby boy. Three weeks later, he was finally here - Cazaly Georges Jude Butchart. I am a mum! I dreamt of this day and the things we were going to do as a family. Those words 'Mum' and 'I love you'! As time passed he smiled, crawled, walked. But there was no 'mum' and no 'I love you'. My son didn't speak. He would grunt and scream and held my hand to show me what he wanted. People told me not to worry, boys were late talkers but I knew heart and soul it wasn't right. He was holding my hand like I used to hold my mothers hand to communicate. Right, I thought, I am going to the doctors and getting him checked out! We saw the pediatrician and wrote a referral to get assessed. We couldn't wait so we paid for private.

After three hours we heard the words I'm sorry Cazaly is autistic. Okay, I said with tears rolling down my cheeks but kept a brave face. That day I step back in the carers role! He was a very frustrated little boy. He would scream, hit and bite on his dummy really hard. I found it hard as Dave works away as well. Cazaly had no eye contact and wouldn't sleep throughout the night he woke up between 5-10 times. He didn't understand most things.

Going shopping was impossible. Going anywhere was and is impossible as he would strike other kids or adults. He is nearly four and attends daycare and has a support worker for five hours, we only allowed to take him there from 9-3 they can't attend to him once his support worker leaves. Cazaly doesn't sit still and constantly needs things to do. I also have a little girl Matilda and it's hard to juggle everything on my shoulders. I love my kids so much, it's the future is what I'm scared about I have no idea what it holds! Till this day I break down and cry and pray for patience or more help out there cause my carers role will never end...

'I wonder how much better he'd be doing if we had more services here.'

## 36. South West Story

We live in the south west.

We realised our little boy might be autistic when he was around 18 months old. He'd always been a very quite and seemingly cruisy little baby and although he didn't like being cuddled but we thought that was just him. Later we realised that he never looked us in the eye, and flapped his hands a lot and by 18 months old had never said mum or dad or any other distinguishable word. He also had some strange routines and liked to follow fences instead of play in the playground. He also ignored his sister, it was as if she didn't exist.

After researching autism on the internet and realising our son "ticked a lot of boxes" we went to a Gp to ask for a referral to a developmental pediatrician. The Gp thought my boy was too young to be diagnosed but wrote me the referral.

We waited for 4 months to see the pediatrician, who immediately agreed that our son was likely autistic and because of his age was considered to be a high priority for early intervention.

We then waited another 5 months for him to be officially assessed.

About another month later we received a letter saying my son was eligible for services from DSC. We were very keen to get therapy started as we had been waiting nearly a year since we had first thought he had an ASD.

Nothing happened and no one called so I did my own research and arranged for him to start some ABA therapy in Perth as soon as our Fehcsia funding came through. (Autism advisor was very helpful with information, but services in South West are extremely limited)



# the OTHER 100 conversations

We had to wait until school holidays started for an intensive 2 weeks of therapy. I also have a child in primary school and no family or support network here in Western Australia. ABA therapy started well so we decided to continue therapy and I now drive to Perth twice a week. I drop my other child at primary school, drive straight to therapy, drive straight back to collect my child from school. The carer's allowance I receive helps toward petrol costs but certainly doesn't cover it. It is also very tiring.

It is now eight months after his diagnosis we are STILL waiting for the services, we are supposedly eligible for, from DSC. We were sent one therapy assistant who quit after 15 minutes as she felt she didn't have enough experience and didn't know what to do with my son....that was back in May and we are still waiting for a replacement..or a phone call at least!

My boy is three now, so even though he is considered "high priority" for early intervention we had to wait about a year to get him assessed and we are STILL waiting for services that we are apparently entitled to, but don't seem to exist, or there is nobody to implement them.

We have had services from the South West therapy team and the people there are wonderful and have a lot of collective experience, but it is a consultative service so they only visit once every few months or so and base their advice on what they see in one visit. They do not KNOW my son and I have found their advice to be contradictory from one meeting to the next.

We are making progress with my son slowly, but surely, but I can't help but wonder how much better he could be doing if only we had some more options available to us in the south west.

- Name and address supplied

## 37. A Therapist's View

'I'm frustrated with this issue becoming a political football every election'



I have worked in the field of Paediatric Speech Pathology for 15 years in the public and private sector. In this time little has changed in terms of reducing the bureaucratic nightmare that parents of children with disabilities must negotiate to access services.

Most of my working life has been in NON-metropolitan centres where I have met thousands of families who report the following:

- \* Not knowing what they are entitled to in terms of services / financial support / respite.
- \* Not knowing who to ask for information about diagnosis / treatment.
- \* Feeling uncomfortable about complaining about services (or lack of services) provided.
- \* Poor access to specialist services (compared with metro area).
- \* Long waiting lists for assessment and therapy.
- \* High levels of stress and anxiety regarding available respite services.

I would also like to add that as a therapist I am continually frustrated with this issue becoming a

# the OTHER 100 conversations

'political football' every election. Departmental name changes, new letterhead font and rezoning boundaries DO NOT HELP THESE VULNERABLE CHILDREN AND FAMILIES.

- Name and address supplied

## 38. 57 and Still Caring

'This problem is an absolute disgrace...we need a scheme.'

I HAVE a 34 year old daughter who is intellectually disabled she has very little speech but is otherwise healthy and quite fit she understands what is being said but doesn't understand money, and can't read or write.

She needs help with personal care and can't be left alone, she needs a carer to take her shopping doctors appointments etc. I am her 57 year old mother We live in a unit after I had to sell my home as we couldn't afford the mortgage, and struggled to pay the bills for 9 years after my husband and Angela's father died of Cancer.

We have no other family help. I have been applying for CAPS funding for over five years now as she needs to be living with people of her own age,

I will not live for ever, the stress I live under worrying about what will happen to her if I get sicker than I already am or heaven forbid I die.

We carers in Western Australia with disabled children and adult children with disabilities are fighting an uphill battle for services, We still have carers in their 70's and 80's caring for their adult children in a country like Australia, our so called lucky country. This problem is an absolute disgrace and if a disability insurance scheme is going to help these problems we in Western Australia definitely need one.

## 39. What's the point?

'Getting cancer is bad enough.'

At the age of 19 I was diagnosed with cancer in my right leg. This resulted in weeks of anguish and eventually in an amputation of my leg above the knee. Since I had the surgery I watched lots of videos and clips on You-Tube because I wanted to know more about prosthetics. I also wanted to meet another amputee but no one came to visit me so I really didn't have any idea about what life would be like without a leg.

I'm now 25 years old and trying to study at Uni. It's pretty tough because I get tired using crutches all of the time. I was fitted for some kind of old leg back in the day and apparently that was the best that I could get. Apparently nothing has changed. I do keep checking but I'm told that's all I can have - so what's the point. It is very ugly, heavy and pretty useless; nothing like anything I'd seen on the net or what people who have work place accidents get. This is really basic and actually caused more falls than not. I don't understand why getting cancer is not the same as having a workplace accident. Like it's not my fault, it just happened. Just like I'm sure most accidents do. I'm frustrated by what is made available to me and I have so much of my life left to live.

Two weeks ago I was told that I would need surgery on my good knee. I'm scared. I won't be able to drive or get around unless I chose to use a wheelchair. If I'd been given better prosthetics to start with then maybe my good knee wouldn't be so bad. I would have at least been able to share the load of carrying the weight of my body. I'm so angry and frustrated and if one more person tells me to just get on with it I'll crack. Getting cancer is bad enough; not having money or being funded for something that would help my lifestyle, ability to work and pay taxes is even worse. - Megan



# the OTHER 100 conversations

## 40. Moved to S.A.

'The whole system needs to be looked at...for kids with special needs.'

WE have just moved back to South Australia, after two and a half years in rural WA, splitting our family up as hubby is remaining in WA for work and doing FIFO.

We moved because of the lack of ability to get diagnosis for our kids and the long wait for basic services. Both my children have appointments in SA within six weeks of our referrals going in. We waited between 3-6 months for some appointments in WA. I am sick of the differences between services provided in states. WA is way behind in the level of services provided in SA. I have also noticed that when we did use the private system we were out of pocket by a lot more than we were in SA - a \$30 gap for an ophthalmologist became a \$80-100 gap plus the cost of petrol from Kalgoorlie to Perth and accommodation, and frankly the amount that PATS gives is a joke - where can you possibly get accommodation for anyone for the amount they give you, let alone for a family?

The whole of the WA medical system needs to be looked at along with the services provided to kids with special needs.

## 41. S.A. to WA

'Consider a world beyond that in which you live, where things aren't rosy, rich.'

KIARA has autism and dyspraxia and was diagnosed at approximately 2 years old. She is now 8y8m

Fortunately for us the system has worked ok, and unfortunately in our situation WA was better than the SA system. But luck and timing are the only

things separating us from the total system failures experienced by others, this is not an effective, efficient and equitable system.

I have friends who can't get assessments, I have friends who can't get respite, I have friends who can't even get the basic equipment they and their loved ones need to function from day to day.

I am not someone who likes to point fingers but criminals in our state are treated better than those with disabilities (and the elderly for that fact).

When Kiara was first diagnosed we were living in Kalgoorlie, many of the specialists we had to see were based in Perth.

No I don't "expect" all the specialists in regional areas, but access to them, YES I do expect that. PATS is a joke, to the point that it is not even worth the effort trying to claim it back, it is cheaper and more effective to relocate elsewhere in the state, to be closer to the specialists, where is the equity in that?

By the way we did that, we moved to be closer to the services, rather than put up with the lack of support in accessing the services.

Any system based on diagnosis as the only entry ticket is flawed in so many ways, needs should be the key. I need support, I need a break, I need some help, I need mobility, I need to communicate, I need to not be writing to the Premier of the State and begging.... seriously, as a State Government employee, a voter, a tax payer, a carer, a parent, a person, I implore you to take the time to look into the real world, and consider a world beyond that in which you live, where things aren't rosy and rich.

Mr Barnett, feel free to contact me personally should you or your staff wish to discuss this matters I have raised.

Regards  
Kath La Nauze



## 42. The System Fails Us

'WA has the worst disability supports of the whole of Australia'

APPARENTLY disability services in the state of W.A. isn't in need of the help of N.D.I.S. Mr Barnett, if this is the case I have to ask, why it is when I arrived here on my own with two Autistic children, it was to discover that W.A. has the worst disability supports in the whole of Australia. You see the failures of a state's system cannot be found in the statistics, in the voting booths. It cannot be found in the welfare services, it cannot be heard at a dinner conversation. Because the statistics don't tell personal stories but numbers, polls never focus enough on disabilities for it ever to reflect the direction of the disabled and their carer's votes. The welfare services are stretched by a wide scale of people and minimally assist the disabled. And carers and people with disabilities are either too busy just trying to take care of themselves, too isolated or too unsupported and too broke to ever make it to dinners. And if they do, I am sure it would not be at your table, it would take knowing just one family with a person with a disability and listen to their story to know the system is very flawed.

It can however be clearly read on every forum on every social networking site you can imagine. Desperate families and people with disabilities and their carers reaching out for help, guidance, support and advice, and so often just to not feel alone. I encourage you to look at these groups and read how hard it is. Anyone with a heart would feel it wrenched on a daily basis.

I arrived here about 3 and half months ago, having lived in both Victoria and Queensland. Accessing services is paramount at times. And sometimes location is the difference between being eligible for this but not that. It all gets confusing and frustrating. However what I have learnt if you have special needs children, the last state you want to live in is W.A. The waiting times for assessments alone is ap-

proximately 2 years, unless you take the option for private assessment, which will accumulate to a minimum of \$2,000, this does include all of the therapies that the child might need over their life time. These therapies at times can make the difference of a high functioning individual and a low functioning, which inadvertently can see the government considerable money. With the right supports early on, children with disabilities can develop and learn and become working members of society, instead of reliant on the perpetual spiral of social welfare. It makes good sense to do the right thing now.

Mr Barnett, I don't even want to begin to imagine what it is like for families with more severely disabled children than my own. Some of these families have severely disabled children and have been waiting for 5 years for respite. Adequate respite isn't even dreamt of, no just respite, just someone at least a little bit qualified to care for their loved ones, so that they can catch a break, take some time to inhale, too breathe deeply rather than those rushed anxious breaths that barely keep them alive on a normal day.

Mr Barnett, have you ever seen what it is like for the families of people with disabilities? The system fails them, not just a little bit, a lot. It fails to support, to protect, to adequately educate,

I know for myself Mr Barnett, I have a 12 yr. old son who has HFA. He, dear sir, will one day be one of the most prominent physicists in the country. He has wanted this since the age of five and as he not only has HFA but he is a genius. You would think this would be a country that supports children who will not only be our future but could make our future. But no it isn't. How do you think my son gets his education, Mr Barnett? In one of your very inclusive schools? Because not just in W.A. but in the whole of Australia, inclusive schools are either too little, too expensive, or inclusion is not really inclusion at all. No he is home schooled. He is currently studying at year 8 level at aged 12. In fact he completed an entire term worth of year 8 math and English in a week. Do you know how many kids there are like my son that are being refused access to services, edu-

# the OTHER 100 conversations

cation and support so that they may flourish. Have you ever taken a look at how many incredible minds both currently and historically have had disabilities? For me I regularly look in on the famous people with Autism, just to double check that my son and daughter can both really be something incredible with the right love and supports. My favourite however is Bill Gates. I imagine you are looking at this via windows. A computer system you have bill gates to thank for, imagine if there are 1000's of Bill Gates' right here in Australia missing out. I know the N.D.I.S. isn't the be all to end all. But it is a help and a huge help.

I am searching every grain of my being to find what will actually be just the right examples to convince you that you that W.A. does need the N.D.I.S. and not even in 7 years but now. What can I say to you to make you see that a change needs to happen, but there are no words. There are no examples, sometimes it's like the floods in Q.L.D. or the fires in Victoria, both of which I witnessed, you really have to see it for yourself to believe it. The sad thing is, although the figure may not display it, the people who are failed by the very flawed system for the disabled and their loved ones, probably has much higher fatalities and costs than any of the natural disasters. It may seem insolent for me to say so, but the numbers of deaths and the costs are hidden, hidden in accidental overdoses, suicides, essential health services not being provided, accidents in the home, the cost of living for a person with a disability is hidden in the personal spending of that person and their families, most of which live in poverty or very close to it.

I have to admit for me, Mr Barnett, life isn't so bad. I have 2 children with Autism and I have Autism. I can home-school and study myself, so that I too can have a future. I enjoy my own company and being isolated. I am happy with the simple life, but I know we deserve better. However I am not writing to you for my benefit. I write to you because I think your state is a disgrace, because I think the health services in your state are a disgrace and I cannot in good faith live in a state that is run by a person who has no idea, no idea of what is happening under his

nose. But most importantly I want my voice to be added to the list of voices, my voice is calm and strong, I have had my darker days of managing disability and luckily had the support in a different state available. But so many the families in W.A. they have been living through this nightmare of a system screaming for so long they are possibly hoarse, and too exhausted to yell and too sore to jump up and down.

Mr Barnett, I truly hope just one thing I have attempted to articulate moves you. And appeals to your better sense of judgement. W.A. not only needs change, it needs the N.D.I.S.

Kind regards

Niki Lakerink



## 43. Nothing At All

'How soul destroying that must have been for him.'

The lack of therapy, for many years from early intervention through to leaving school was always a problem. In the early years we'd get maybe 2 visits a year from therapists, mainly to do assessments. Then we'd wait 6 months for the report to come out with a recommended program (for us as a family to do with our son) but by then, the program was out of date. We scraped together some money for some extra therapy and our DSC therapy was withdrawn. "Double dipping" they called it, and said it could be harmful to have two different ways of doing therapy. I felt we were being punished for not just accepting the little they offered.

# the OTHER 100 conversations

Even when he was going to a "special" school, the therapists on site were so busy that all we got was handout sheets on tying shoe laces. We asked for something more useful, but no, it was shoelaces forever, and we never got there anyway. So much for child and family centred practice. Incredibly, at the end of one year, we got a "report", more a letter really, saying that our son had been receiving therapy during the year. They put another child's name in the letter. Apart from the confidentiality aspect, I had to wonder if they just used the same letter for a few kids and just cut and pasted the names, but someone slipped up with ours. Who knows - I complained but never got a satisfactory response. I often wonder whether our son would be able to communicate better if he'd had the support he needed instead of all that bloody shoelace tying practice...how soul destroying that must have been for him.

How wrong is it that a child who needs various types of therapy can get only one type, and that isn't always the one they need. How wrong is it that therapists are so under resourced that all they can do is hand out program sheets, to kids with high support needs. And of course there's nothing once you leave school. Nothing at all.

## 44. Cold, Cold Voices

'...you are suddenly, irrationally tempted to veer into the tree beside the road.'

I WILL not do a good job here because I am unable to talk about this situation without crying.

As I sit and write, I have tears streaming down my cheeks yet again. It is very much like post traumatic stress disorder, this thing. Feeling like putting the words to paper brings all the feelings, the grief, the anger, the frustration back again...and it is not just about the failure to get funding. It is about so much more, having to paint your life as the blackest of the black every funding round and wondering if you should tell them that sometimes, when you are driving your car (on those respite nights that are so far

and few between) that you are suddenly, irrationally tempted to veer into the tree beside the road. You have a hysterical, fleeting moment where you think - yes! God, yes! Because then this pain would be all over! And then the thought, who will take care of him? Because there is no one, and he would go into care. I read of one woman recently who stabbed her son in the throat, and he died, and the woman lived, but God, at what cost? She wanted to take him with her, but of course the reason her life was so terrible was not the ties of love that bound her, but the failure of her state to help and support her properly, and support and help her son...and then I read this. That our Premier thinks it is all okay in WA and that our lives are okay.

I do not know how to tell you this, I do not have the words. I do not have the words to say that I hope, I hope that he is mistaken, because it would be far worse if he knew that his people in his state were in hell and he pretended that everything was all right. I read the newspaper and I was so upset. It was just like if you were on fire, and someone was standing nearby and they said 'oh, its okay, it's a bit of smoke, there's no fire at all...and I need this bucket of water in case I get thirsty later on.' I want to scream - can't you see? Can't you see what is happening to us?

I don't have the words to tell you how many tears I have shed over the lack of support and the lack of respite and the writing of forms and the trying to get equipment and the endless phone calls and letter writing to women with cold, cold voices, because they have heard it all before...sometimes you beg and you cry and your voice gets to hysteria and then you know they have heard you, because their voice gets slightly more human, and you get one more hour of respite or support or something that you have wheedled out of them yet again.

As I write this, my child is crying in the other room. I do not know why he is in pain, I have changed him and he has been (tube) fed and there is no reason for his distress. Soon I must go and sit with him again and rock him to soothe him. But my thoughts are often of a big gum tree by the side of the road.

# the OTHER 100 conversations

## 45. No Peace of Mind

'...what would become of him when we were no longer around to care for him?'

WHEN our son Will was born and diagnosed with Down syndrome, we knew we would love him and give him the very best care we could, but we were immediately worried, yes, even before we left the hospital that week, about what would become of him when we were no longer around to care for him.

We've been told not to bother applying for CAP funding; we'd never get it. Well, not til we're in our 70s anyway. Yes there is the Community Living funding, but I know people who have it, and their families still have to be very involved in managing the situation and being there when the support falls in a hole. I worry too, that our son's needs will increase as he ages – there's a very high likelihood of Alzheimer's at a relatively young age in people with Down syndrome. What will happen then? It's too scary to think about, but we must.

We've planned as much as we can, and our will and financial planning revolve around our son. Our other children understand that he will get the lion's share from our will, and they accept that fully. However you never know what's going to happen do you? Since writing our will, another of our kids' health and situation has changed so how do we react to that situation?

So here we are, 27 years down the track. The lack of adequate support, the ongoing need for so much input from us, and the additional strain of battling for services, have taken their toll.

Our son is a lovely young man, who has a lot to offer and has shown he has great patience, determination, courage and a love of life – great gifts. Those who know him, know they have been lucky to have him in their lives, for a variety of reasons.

We have loved him and cared for him as we knew we would when we held our firstborn son in our arms

that first week of his life and wondered what lay ahead. It is just so wrong that when we celebrate his 27th birthday this week, we still have no peace of mind for his future.

- Trish Weston

## 46. Lack of Support

'...they wonder why the divorce rate is so high in families with special needs?'

I HAVE a five year old granddaughter, who had a massive epileptic seizure a year ago in June. She has been left with severe brain damage and I can not believe that my daughter and family have been told that if she wants any funding for respite, carer, modified equipment etcetera, she needs to take her and get her diagnosed with a disability such as autism.

I am amazed at the lack of support that has been given to her since this happened. She and her husband lived at Princess Margaret for three months and her other two children lived with us. Apparently, having a brain injury does not qualify you to receive any help, according to the Brain Injury Association.

I am appalled at our governments lack of support, knowledge or lack of empathy towards families in this position. Her husband works hard, pays huge amounts of tax and they have had to beg for even a health care card for her. Her LAC has made no contact with her at all except one at the start who was filling in and even with me calling leaving messages urging them to make contact cause she needs support, she has not made contact. My daughter received a email today saying the LAC was leaving and the new one would make contact with her once she is settled I told my daughter to write back and say something about the fact that she didnt even meet her so whats the difference. They wonder why the divorce rate is so high in families of children with special needs, it is because the pressure is to much and especially with no support. I

# the OTHER 100 conversations

am so over Mr Barnett's lack of empathy for all kinds of needs in our state and can not wait for election time to get rid of him I am certainly not the only person who feels this way, that's for sure. It appears he is more concerned about sitting in a nice office than really looking after his people.

- Carol Bonner

## 47. Lack of Support

'...The waiting lists for all the specialists are far too long...'

I am the mother of an 11 year old boy with mild high functioning autism. My husband and I also have another son, who is 15 years old. For more than a year, I coordinated a support group for parents and carers of children on the autism spectrum. I have been a Development Worker in a supported playgroup for children on the autism spectrum and their families for the last year, and 6 months ago, I took on the task of coordinating an e-newsletter for parents, carers and those who work with people with ASD. It gets sent out every 2 to 4 weeks, depending on when I can do it. I have worked with children with ASD in schools as an Educational Assistant on a relief basis before my son started having severe difficulties at school, when he was 6 years old. I think all of this qualifies me well to comment on this matter.

As a parent, I find the systems frustrating and funding for specialist appointments inadequate. My son was not diagnosed until he was nearly 8 years old, so did not qualify for early intervention funding at all. The twenty sessions given for Allied Health Care appointments under the Helping Children With Autism Package was used up on social skills classes in only six months (and that was after we waited 18 months to be given a place). We now get five Allied Health Care sessions under Medicare per year. My son goes to a social skills group class every fortnight (like most of the families in the group, we can no longer afford for him to go every week). We see this as an ongoing necessary therapy for our son, but as I am unable to work more than a few hours a week, in case he has a meltdown at school, and I am

called to come and take him home, we are basically a single income family with two children, and are unlikely to be able to cover these costs indefinitely. It had been our plan that I would have been working 3 days a week by now, but that is impossible, what with calls from school and all the appointments – who would employ me? I currently work 4 hours a week, and two of those hours are from home. This is about as much as I can reasonably manage. The Carers Allowance from Centrelink does not go anywhere near making up for lost wages. Most families I know with an ASD child are in a similar position.

The waiting lists for all the specialists that our ASD children need to see are too long. I rang 3 developmental pediatricians this morning (for an appointment for my older son), and was told that there were no appointments available for nearly 6 months (one was nearly 9 months). As I said before, we waited 18 months to get into social skills classes with a speech pathologist, and the developmental psychologist that my younger son sees, has closed her books, taking no new clients for the time being. This is not uncommon. Thankfully, my son gets up to 18 sessions a year with her, but I am worried about the possible change coming that may lower it to only 10 per year. My son visits the psychologist for therapy every 4 weeks, and then she also visits his school 2 to 4 times a year to advise his school and coordinate the goals for him. We see this as absolutely vital, but many psychologists do not do this.

The public diagnosis procedure is often inadequate. I know of two children who were assessed by DSC whose parents were told that there was nothing wrong with their children. These parents (supported by their children's schools) were convinced that there was a problem, and paid for private assessments, only to be given diagnoses of ASD. Children of school age are also waiting far too long for assessment, many more than 2 years through the public system, with many unable to pay for a private assessment, which would get them a diagnosis (and assistance) much sooner. Valuable therapy time is lost and valuable learning time is lost, as these children miss out on necessary assistance at school.

# the OTHER 100 conversations

Catching up is extremely difficult for them.

GPs and child health nurses need more training in recognizing the symptoms of ASD. I took my son to the GP and the CHN when he first exhibited problem behaviours at about age 3, but neither asked me the right questions to get the information that they would have required to suggest that we see a paediatrician about the problems. As a parent (not a professional), I did not recognize the signs of ASD myself. The only children I knew who had autism were quite severe, and their signs and symptoms were much more obvious (most couldn't even talk). To me, he was just "difficult", and the GP even said to me "That's what you get when you have bright children" (my older son had already been formally recognized as gifted, and later we found that my ASD son also has an IQ of 131). School psychologists often lack the skills necessary to recognize potential ASD, too. The one that observed my son when he was in pre-primary (age 5), said that "It's a maturity thing - he'll grow out of it". So we lost more valuable time, waiting for him to grow out of the behaviours. Of course, he didn't. In fact the behaviours got worse when he started Year 1, ending in us pulling him out of school and home-schooling for 5 months while we tried to find someone who could identify the problem. When we did, it took another 6 months to get a diagnosis while we waited to see the private practitioners that could formally assess him.

I strongly believe that if adequate assistance is given to high functioning children before and during their school years, they have an extremely good chance of functioning well as a fully contributing, independent citizen as an adult, with a job and a family. Not given that assistance, they will be dependent on welfare forever, and may not be able to live independently. I know many placid ASD children who do not get the assistance they need in the school setting, because they are not a "problem" and don't distract their classmates or the teacher. These children drift through school, missing out on learning experiences, because they cannot fully participate, and fall behind their peers academically and socially. With improved help, this

would be less of a problem. I believe ALL ASD children should be given FULL-TIME ASSISTANCE in the classroom (funded by the government, no matter what school they go to) to be able to reach their potential. I recognize this is expensive, but I believe it is a lot less expensive than having them dependent on welfare and social workers forever, and the long-term social and medical problems (such as depression) this can cause, which affect them and those around them

Early recognition of the problem, quick diagnosis time, early intervention and adequate support are so important to those with ASD and their families. Unfortunately, at this point in time, most of this does not happen for a lot of ASD children and their families.

## 48. No one Bothered

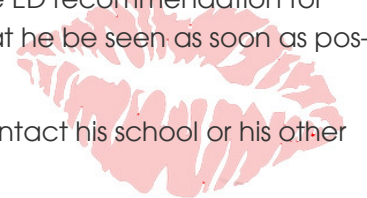
'...it was a note - 'Mum, I am sorry that I am dead.'

I AM writing in regard to my Son who is now 7 ½ years old and a patient of Shenton CAMHS. He was initially brought in to PMH in June 2009 after I found him with a steak knife to his throat. At this stage he was seeing a private clinical psychologist as he had expressed to his teacher at school and also at home that he wanted to kill himself.

He was not admitted to hospital but was referred to a program. I did not receive a phone call and called an agency to follow up. I was then told that "usually after this kind of thing, we don't come out for about a week"

He was seen just once a week for four weeks. He was not referred for services at family pathways for over 3 months. He was also not seen by a psychologist even though on the ED recommendation for they had requested that he be seen as soon as possible

No one bothered to contact his school or his other therapists.



# the OTHER 100 conversations

In this period he made countless attempts to self harm, including, trying to climb out of the car whilst we were driving, punching himself, head banging, holding a pen to his eye, biting himself, run onto the road, scream for over an hour at a time. We were no longer able to send him to school. He would have physical symptoms, palpitations, chest pain, sweats.

Seven months after his initial incident we were seen by Family Pathways. It took 7 MONTHS for anyone to begin to assess him, a 5 ½ yr old child tries to cut his throat with a knife and it takes 7 months for the system to even look at him.

I cannot expect you to comprehend what my family endured during this time, I couldn't sleep.

He would cry uncontrollably, He would go into bouts of screaming for an hour at a time, He would continuously wake during the night.

He was hearing voices tell him to hurt himself. I found this out after looking in my rear vision mirror to see him punching himself continuously in the ear. One night I tucked him into bed and went to the lounge room to watch tv, I heard him creep up the hallway. I saw him put something under and out of the front door, then he went back to bed. I opened the door, It was a note - 'Mum I am sorry that I am dead'

I ran to his room and he was sobbing in his bed, he told me that he had planned to kill himself while I slept, another visit to PMH, again He was sent home under supervision.

I couldn't leave my boy unattended, and furthermore I could not understand how a 5 year old who has been brought up in the most secure and loving environment could ever want to do this. I was not offered any support during this time. I have never felt so helpless.

It took a MORE THAN 10 MONTHS before He was seen by a psychiatrist.

After reviewing my son, he was given a diagnosis of severe anxiety, autistic traits and OCD thoughts, he

is now seen for 1 hour a week (this is nowhere near enough) My boy still has complete emotional meltdowns for up to an hour, He can be threatening and physical, he grabbed a butter knife from the table and held it to another child because... she liked peas. ( for the record, he is brought up in a very secure home with my husband and myself and our other 2 children, he has a stable and safe home ) I have been told that he has the emotional capacity of a 2 year old. He struggles within himself day to day.

We need a better system than this

## 49. Kat Speaks Out

'...So please don't think that this will be the last that you hear from me'



# the OTHER 100 conversations

Mr Barnett,

I have spent the last few days trying to write a letter explaining what it is like to be a parent of an Autistic child in Western Australia. The abundant support you talk about is not apparent in my experience. What little is available is hidden behind reams of paperwork and incompetent public sector employees. Trying to write about how difficult my journey alone with my son, on the spectrum, is proving to be more than I am capable of right now.

There is a reason for this, not one that I would expect you to understand. The reason being is that it has become blindingly apparent to all who know me that my son is not the only member of my family affected by an ASD. It has taken 32 years for the doctors to realise that I do not have depression, bipolar or whatever other medical condition is the favourite diagnosis of the decade. I have Aspergers Syndrome which is being assessed and treatment made available only because of the generosity of a few medical specialists who actually can see how difficult life is to be a single parent struggling to raise a severely affected child whilst also being on the spectrum.

In Western Australia if you are an adult female with un-diagnosed High Functioning Autism there is no wait list to endure because simply there is no public assessment so therefore no assistance and nothing more to expect than further social isolation and confusion available unless you have the money to pay for a private assessment. Thankfully I have previously been misdiagnosed in our woeful mental health system. Yes you read correct I am thankful for my misdiagnosis as this has brought my situation to the attention of the aforementioned specialists and I do have the prospect of formal diagnosis ahead of me.

Considering that the world's leading expert Dr Tony Attwood on Aspergers Syndrome particularly in the female population is an Australian, and has earned his world renowned reputation for his research in this field, I find it ludicrous that I have no other option but to rely on the generosity and curiosity of doctors to gain any further personal assistance. As my diffi-

culties have now been identified as a neurological condition rather than a mental health issue I have been informed that I no longer qualify for help or treatment in that health field either.

I am certainly not incompetent nor am I unable to raise my child, I have proven otherwise many times, but there is no reason why it should be as difficult a task as it has been.

A five year wait for respite, the need to fight for every little bit of funding my son has received, several public newspaper reports and the fear I have every day about my sons future have all contributed towards my current situation. As another stint in the rat infested ward of Alma street is no longer available to me, I will continue on as I am, not expecting anything from the uneducated public sector except for more uninformed opinions such as your own.

With the support of the autism community I am growing stronger in my self- belief with every passing day. Politicians who do support greater recognition and awareness of ASD and the impact it has on the lives of those affected, have already quoted me on the floor of parliament. So please don't think that this will be the last that you hear from me, or that I will quietly disappear into the realm of those who live with a disability. I have been publicly vocal before and have every intention of doing so again. Whilst I have had difficulties trying to expressively write about my lack of support during the last 6 years I have been inspired to begin writing a book about my own experiences and also those of my sons.

Whilst I doubt you will even read this letter it has been important to me and no doubt also the other missing adult women on the spectrum, for me to write from this point of view.

Ms Katherine Shuard-Banks

## 50. I've Lost Count

'...Mr Barnett, have you watched your child cry in pain?'

# the OTHER 100 conversations

In February 2004, I welcomed my beautiful little man Rylee into the world. On that same day, our lives changed forever. Rylee was born with a rare chromosome disorder, cleft palate, kidney and heart problems. I've lost count how many trips we've done to Perth / PMH due to the fact none of Rylee's specialists visit Kalgoorlie and none of his surgeries can be done here either.

I've lost track on the cost of travel and accommodation as PATS is pure crap. Mr Barnett, have you ever had to take out a personal loan just so you could get your sick child to Perth for surgery. NO of course you haven't. Mr Barnett, have you ever had to buy a bigger car to accommodate your child's wheelchair, of course not. Mr Barnett, have you watched your child cry in pain because his standing frame and AFO's are too small for him. Mr Barnett has your child had to wait for over two years for a new standing frame NO of course not. (And still waiting). Mr Barnett, you are one big JOKE !!!

## 51. I've Lost Count

'...How does the government think this is okay?'

To Whom It May Concern in our Government.  
RE: The disgraceful state of our Disability Services.  
I would like to write to you and let you know how we are affected by the Disability Services, of lack thereof.

I have three children who have moderate to severe Disabilities. We have to fight for every service we have, and the affordability is a killer. How is it that company's can make HUGE profits of one's suffering and us Carers will do all we can to provide this to our children at any cost. Carers such as myself fight tooth and nail to keep a roof over our children's heads and a stable home life amongst all the chaos, and make no mistake being on carers payment is a help but it doesn't help when your therapy bills out way the income.

My husband had to quit a full time job to help because I was not able to take all 3 to therapy as you can only have one child in therapy at a time so what could I do with the other two? I had to have them in Child care and do all therapy sessions for that child on one day and repeat for the other two the following days. When he stopped working we just made our repayments on our home (not a fancy home a small 3brd 37yr old home) and there were weeks we were in the red and our parents helped us out because they seen how tough we were doing it.

How is it that a government can pledge so much money to things that are not a need yet our most vulnerable go unnoticed? I am terrified of what our future holds to be honest because I know when my children are all in school I will have to try and find a part time job to fit around (to pay their therapy bills) them and getting calls from school because of issues will impact whatever job I am lucky to get. This is not just about seeing carers as sitting on their behinds doing nothing, we work very hard and sacrifice a lot for our families.

As an example:

My day starts at 2am, I get my husband up and start the house work as I cannot afford to do things on peak power. In winter our bills are high (gas and elect) and you keep trying to reduce them and they just keep going up. How does the government think this is ok? How do they expect us to do everything and not ask for help? There is so much money being pledged everywhere else and yet the ones who cannot talk for themselves get left in the dark and the carers get left to beg and plead for any service available? This is NOT OK. We need the governments help, we have been asking for so long and it seems to be the lets stick our heads in the sand and pretend its not happening. Your right! Its not happening, TO YOU.....

Its happening to me and my carer friends and their disabled children/adult children/their parents/siblings/friends/foster kids.

Ask yourself, how would I cope having 3 children with Disabilities and starting my day at 2am and not

# the OTHER 100 conversations

going to bed until 11pm (when I've put on washing to use the start of off peak power again to save money to help pay for therapy's). You then have therapy's to do with the children in the day, multiple appts and your husband sleeping for about 4 hrs or so in the day to catch up on time he has lost, while you don't get that. Someone has to do the housework and do the children's therapies, appointments, sort out food and everyday life on top.

If you honestly think the state of your disability services are ok your deluding yourself.....I get NO respite, why? Waiting lists to long and lack of service providers. My body is so used to getting so little sleep that if I sleep more then 4hrs I feel physically ill. I would love for some help, some respite but the simple fact is there is none available. This has to change, us carers need help. We get so burnt out and yet we have no option but to keep going. We need rest to be able to function and help, where is that help that you think is so readily available? Disabilities dont stop at a particular age, they keep going and then no help is available as the services are aimed at early intervention. What about the older children and the teens and adults? They deserve the right to be treated with dignity and have the same help young people do. Why are they forgotten? Shame on the government, these people deserve dignity and respect too....

I know people who have chosen to sell there homes and rent because they cannot afford the therapy costs, I am doing all I can not to sell my home because it's the only thing we have left. We don't own posh furniture or the like, we make do with what we have and whist we get upset at times that our life is not where we hoped it would be we are thankful that we make do. We do all we can to reduce costs and give our children what they need sacrificing our own needs.

The stress not having help has almost tore my family unit apart, my husband dose not understand as he himself has a disability. So its like I am looking after 4 children on my own and any service I have to fight and beg for is becoming out of my reach. What do I do when I cannot cope anymore? When I get sick it

takes months to recover because I don't have that option to rest. I had croup for 4 months this year straight and my Doctor wanted me in hospital to force me to rest but that was not possible because no one could help with the children and my husband.

Please do not think for a second that because carers are not banging down your door that we don't need help and your system is letting not us all down. Two words, IT IS. You can change this so please get your head out of the sand and see it for what it is and hear us when we say THIS SYSTEM IS NOT WORKING.

I am 26, I should have friends and be seeing people and working in a paid job but I don't get that opportunity. I am so isolated that I see family 1nce fortnight if I'm lucky and 1 couple who has not left cos of the kids issues and our time being so tight and no help available to do things. I have met some awesome people online who support me and I support them, they are invaluable to me keeping sane and just for that contact who is not a therapist.

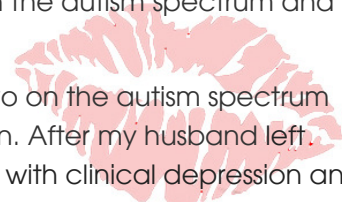
I just wish you could live in one of our shoes for a week with the lack of support and services we have and be treated the way we do when we ask for help. Its not fun and its no way to live, Australia is said to be the lucky country?? What is so lucky about people in power KNOWING there is a issue with there services and continuing to turn a blind eye? NOTHING LUCKY ABOUT THAT.....

## 52. Depression

'...No-one should walk away from an attempted suicide without calling for help'

Our story is relevant to people with depression and their families, people on the autism spectrum and all carers.

I have three children two on the autism spectrum and one with depression. After my husband left home, I became very ill with clinical depression and



# the OTHER 100 conversations

anxiety. I had lost my family home, the support of my mother and my financial security. Gradually I began to lose my sanity. The severity of my illness may be gauged by the fact that I attempted suicide twice in three months.

I was rescued by my son Patrick after the first attempt and treated in hospital. After the second attempt I was found by my former husband who brought my son home from an outing and found me in a coma but still breathing. He then left without calling an ambulance, and left Patrick alone in the house with me. Patrick has Asperger's Syndrome and was fifteen at the time. He is now 22.

My former husband then phoned my mother and told her of my second suicide attempt, and she subsequently rang my brother in Melbourne. None of them called an ambulance. None rang Patrick the following day to see if he was alright or if I was alive.

This incident, coupled with my illness and circumstances, was so traumatic that Patrick and I didn't speak about it for four years.

With a combination of treatments and finding supportive friends, Patrick and I gradually got on with our lives. I recovered slowly from my illness and now lead what I hope is a useful and productive life, but we both still suffer from the aftermath of this failure to assist in a life-threatening situation.

My brother committed suicide twenty-two years ago when depression and suicide still had a huge stigma attached. Things have improved but we still have a long way to go. Depression is a clinical disease, not a terminal illness.

I now do voluntary advocacy work in the autism community and have taken part in a six year Ph.D study on the effect on families of ASD.

Findings are that carers, and in particular sole carers with precarious financial support, experience depression and anxiety in unacceptably high numbers. In addition, they often have to care for someone with depression and anxiety.

Our story is about the overwhelming need for mental health services for carers and the people they care for, and for depression to become understood as a clinical disease from which recovery is possible. No-one should walk away from an attempted suicide without calling for help.

- Melissa Kelly and Patrick Barter

## 53. I'm Worried

'...There doesn't seem to be anywhere for her to go.'

I AM the mother of a 15 year old severely autistic daughter. She also has an intellectual disability and has quite extreme self injurious behaviours and very little independent skills. She currently attends our local high school education support centre. While she is there she has 3 aides rotate with her so she has an aide with her at all times at school. The high school is supported by the Inclusive Schooling Autism team, to help the school to address her needs and to support them with her learning down at the school and for strategies to encourage independence and to lessen her self injurious behaviour.

I do not work, as our daughter requires one on one care at all times when she is home from school, and there is no care for her over school holidays, so I need to be available to look after her. We currently receive some brokerage funds from GIFSA (which is partly funded by the DSC, I think) and this pays for a private carer to take her after school once a week on a Friday afternoon. This is the only respite I receive from her apart from her attending school. Last year, for some reason unknown, her brokerage money was cut in half, so for her to continue to go to a carer one afternoon a week, we had to fund this ourselves. I approached the DSC to see if they could help us out but they only made a once off payment to help to continue this, but it did not cover all of our costs, so the carer had to be paid for by ourselves.

# the OTHER 100 conversations

My daughter has only 3 years left of schooling and I am very worried what services will be available when she leaves school. We have not received much assistance so far in her schooling years, and I am concerned what is going to happen when school finishes. She has such high support needs, that I will need more respite from her when she is home all day, but there doesn't seem to be any support out there for her. I don't think we will be able to privately fund carers ourselves continually and can see this situation becoming very stressful.

Although we have quite a supportive LAC from the Disability Services, she seems unaware of what funding is out there and which would be the best for us to access. Recently we purchased an adult trike for our daughter which was quite expensive, as she can't ride a traditional bike, and was then told by the DSC that they could have possibly funded it though an independent living grant. This was after we had already purchased the trike, so not much help to us. It is frustrating when things like this happen, because no-one tells you what is really available to you and your family through the Disability Services.

Although this is just a brief rundown of our life at the moment. Our life is very stressful living with such a high needs child and there seems very little support for our family out there, and it is up to you to find carers that might be appropriate and then mostly fund them yourself. Always in the back of my mind is what is going to happen to her when myself and my husband pass away, there doesn't seem anywhere for her to go.

Jo-Anne Brown.

## 54. We've Been Failed

'...we should all be questioning how much damage has been done...'

The Western Australian Disability service system has failed our family completely our Son was diagnosed in April 2005 age 10 years as having Aspergers syndrome from that date on we were unable to access

services as Disability Services commission were no longer registering children with Aspergers syndrome unless they had an intellectual disability

This meant anywhere we went we were either turned away or had to pay privately to access help

This meant we had enormous financial pressure and emotional pressure on all members of our family cumulating in myself having to give up work and home educate him in 2010 we have revisited the diagnostic process and have been able to obtain a confirmation that he has High functioning autism and have now been able to register with Disability services and are receiving some assistance to try to obtain funding from our local area coordinator to help him become more independent and access the local community etc and to provide some respite for other family members however as he is now 16 and early intervention is too late and financially we are exhausted it is a bit late we also have a daughter who is 12 years old and has High functioning autism diagnosed 2010 and even though she is registered with disability services it is enormously difficult to find what services we are eligible for and access them and there is always a long wait if we do find any suitable and we should all be questioning how much damage the delay in accessing funding and services is actually doing to our children's long term outcomes and the families as a whole.

I am happy to let him know the system does not work.

## 55. I Want To Work

'...my chair is falling apart and I can't afford a new one, especially now.'

I can't believe that we are having this conversation. To find out that a national disability reform is proposed and the reason we will not cooperate with the rest of the country because of power and money, well that beggars belief. This is about my life and it seems to have gone without discussion that

# the OTHER 100 conversations

we are talking about the lives of Western Australians not about politics or service providers.

I have a physical disability and I use a wheelchair. I've never been in receipt of services because I haven't needed them. I have post polio and I have been able to look after myself for most of my life.

My experience with the system has been limited but not good. The types of services I need come down to dollars but not always. When we are talking about dollars, the issues that I have are with trying to get enough support for taxi fares or train fares. Trains are fine but you can't always get where you need to go.

I had a good job and then they moved to an inaccessible workplace. I couldn't get up the stairs and because I'd worked there for fifteen years they were nice about it, they said there is nothing we can do, we can't afford a lift. So I agreed to resign with full benefits, but it has eaten at me since.

Now I am looking for work again and I never thought it would be so hard. If you have legs that work you can go and doorknock. I can't do that because I can't afford a taxi to go from door to door. So I rely on the letters and phone calls and I never tell them I use a wheelchair until I get there. When I get there they look at me and I know I will not get a phone call back.

The issues I've had are mostly with equipment and consumables. If I'd been injured in a car accident I'd be covered by third party for some of the things I have to pay for like continence aids and repairs and maintenance to my chair. My chair is falling apart and I can't afford a new one, especially now. I went to visit an LAC once and they told me that they probably couldn't help me because most of the people they help are families and people with kids who have got medical conditions and who need support worker help. That's fine because those people need that help, but what about me?

I have severe arthritis in my hands now and it hurts when I go anywhere. Most wheelchair users I know end up with RSI like conditions in their hands and shoulders and arms because humans aren't de-

signed for wheelchairs. Funnily enough, now that I'm on a health care card (I never was before) I can finally afford pain meds. When I get a job I won't be able to afford them again. I don't know what will happen when my hands and shoulders become too weak to push my chair. That will be a whole new story.

We need disability reform in this state because it isn't good enough. I hear a lot of stories from people and it makes you bitter so that you can't go out and enjoy life and just live an ordinary life because you're constantly being eaten up by the things that are bad. Please think seriously about the introduction of a National Disability Insurance Scheme. Its about MY life.

- Karl

## 56. A Different Story

**'I am a mother, not a speech pathologist or therapy assistant.'**

Our son Mitchell was received his diagnosis of Autism at 3yrs of age. Shortly after this we moved to Australind. We received our letter of acceptance from DSC around about the July of 2004 and received NOTHING by way of therapy for our son until April 2005. This was only our measly allocated allowance of 4 hrs per week of ABA Therapy. Speech and OT were a completely different story. We couldn't access our local service provider at Hudson Rd Child Development Centre as services for children with a disability had been moved over to the Health Department.

The "perfect" system that the health department has is this.....A consultative service whereby a Speechie or Ot come to your house...ask what you think you need for your child..um Speech and OT and then proceed to "give you tips" on what I can do for my child.

I am a mother, NOT a speechie or OT and NOT trained as a therapy assistant. This "advice" was for a NON-VERBAL 4 yr old. Oh by the way, my son is a

# the OTHER 100 conversations

triplet. I have 2 other children who coincidentally are the same age and need my attention, yet I am supposed to toss them aside and implement the "speech and OT" therapy to my son with Autism. 7 yrs later...I have not seen a speech therapist or OT for 18 months and have NEVER had any hands on therapy for my child with Autism.

Now, according to the Minister for Health...School age children such as Mitchell are eligible for a regular review of their speech and language skills by a speech therapist and sensory needs by an Occupational Therapist. From this regular review.....the school and home (who spend the most amount of time with the child) are supposed to implement whatever strategies are recommended. This of course is done with NO guidance, NO equipment and NO training. Thanks for that.

Now the Regional Therapy Team who are in charge of school aged children with Disabilities have 1, yes 1 OT for the WHOLE south west division. Now that really equates to a great service doesn't it????

My son is now 10 and a half and is still largely NON-VERBAL and has MULTIPLE sensory issues which impact on his everyday life and learning ability. This is apparently satisfactory according to our government.

Mr Premier.....you can go and SHOVE your BROKEN system firmly where it fits. Your system has done NOTHING for my child....I and my family have done EVERYTHING for my child.

Michelle Robins

## 57. Blue Baby

'I can't see how our family is lucky to live in Western Australia?'

Dear Mr Barnett,

Do you really want to find out how the other half live? ...well here's your chance!

Zachary Thomas Broxton was born 20 November 1999 and was diagnosed with congenital heart dis-

ease the medical term being: Pulmonary Artesia, Tricuspid Artesia, ASD, VSD and a hypo plastic right ventricle along with chromosome deletion which the Genetics Scientist said will cause Zachary mental retardation and will mean that Zachary will never live a **NORMAL** life.

Over the past 12 years we have been through the wringer we have had many a sleepless night worrying about how Zachary would go with surgeries as he had 3 heart surgeries in the first few years of his life and not only has it caused me to go in and out of depression for many years but it has had a detrimental impact on our marriage because of the pressure. It has also affected our daughter Kayla who has for many years been a young carer for Zachary from the time she was 2 years of age changing his nappies and helping to feed him to help her mummy because she knew how stressed I was.

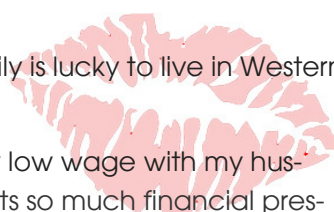
The times we have spend speeding too and from PMH due to a "blue" baby were countless, we even had a time where he "died" on my bed and I had to shake him back into existence because he had a febrile convulsion.

Zachary's health has improved since then but he still is a difficult child to raise as we have heaps of work to do on his speech and occupational therapy which has just started becoming regular after not having access to one for over a year through Rocky Bay due to lack of funding and we are still waiting for a Speech appointment at PMH due to the waiting lists.

On top of this I have let myself down with my health and have only just recently started seeing a psychologist to deal with my stresses and in particular my health as I have to have surgery to remove a cyst which was not detected that has been causing abdominal pain for many years without any formal diagnosis being found.

I can't see how our family is lucky to live in Western Australia?

We are on an extremely low wage with my husband's work and this puts so much financial pres-



# the OTHER 100 conversations

sure on us because I can't get a "REAL JOB! There is no possible way of me having a well paid full time job, no "NORMAL" out of school care facility will take a "DISABLED" child and no "NORMAL" employer will let an employee just take time off to take a sick child to hospital appointment. It doesn't happen in the REAL world, Colin!! Having one child with a disability is hard enough but added to that our first born (the most forgotten one) has health problems too which we have to constantly worry about as she was diagnosed a couple of years ago with **Nephrotic syndrome** (kidney disease) which she has already had 3 bouts of. So, Colin! ..... When does it end?? You come and live with us for a week and you will see what I mean!!

- Marie Broxton - Mother of a disabled son.

## 58. Its Hard to Ask

'It is very hard to ask for help, but the reality is that we need it to survive.'

It is hard to know where to start as there is so much I could say about the need for a National Disability Insurance Scheme. We have three children, two boys and a girl aged 6, 4 and 2. Our two boys have a formal diagnosis of Autism from DSC.

The parenthood journey is a roller coaster ride for most people but having disability issues takes things to a whole new level.

The stress and strain on each family member is enormous. The lack of sleep, lack of time to myself to meet my needs (some so basic as brushing my teeth and showering), the emotional strain, the grief as I give up on the dreams I had for my children and accept that there are different paths to take now, the absolute bone tired weariness from fighting, advocating, fighting and then advocating some more even when you feel you just can't take one more step but knowing that if I don't fight for my kids who is??

The government, the overworked LAC who we see maybe a few times a year, the teacher who has 3 kids with Autism in her class and minimal support??

The support is so hit and miss. One of my sons was on the wait list for Child Health Services but as soon as he received a formal diagnosis he was taken off because he could receive the \$12 000 (2 years of \$6000). Really aren't we just "robbing Peter to pay Paul?" It just sounds good to the general public that we are able to access \$12 000 but in reality other areas of support are just removed from us.

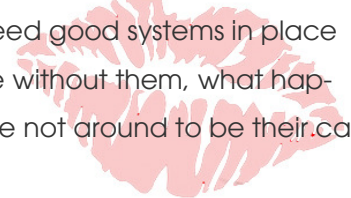
It is so frustrating because we all know that early intervention is so crucial. Money paid in early intervention will save the government, tax payers and families so much more money in the years to come, not to mention increasing the quality of life of people with disability and their families.

Every time I catch up with other mothers on a similar journey as me I am amazed to find out about a new way of accessing resources, support and assistance. It is the exhausted mothers (and other caregivers) who get on and help each other. But how long can we all maintain this?

There needs to be a centralised avenue of support. Isn't it time to be preventative rather than reactively cleaning up the messes caused in our lives because we didn't have the support when we needed it?

We are not asking for government assistance for our kids and ourselves because we want to. I don't believe any of us want to be on the disability journey that we are on and for some of us it is going to be a journey we are on for the rest of our lives as we care for our kids with disability.

It is very hard to ask for help but the reality is that we need it to survive. How much do you think it would cost the government if we weren't being the carers for our children? We need good systems in place for our families because without them, what happens to our kids if we are not around to be their carers?



# the OTHER 100 conversations

The National Disability Insurance Scheme is not something we want....it is something we vitally need in order to meet the basic needs of people with disability and their families.

Therese Bonasera

## 59. The Smith Family

'Over time, I have heard horror stories from families about waiting lists'



Our little family has been living with disability for the last 13 years, that is since our first child was heading towards a diagnosis of severe autism. He was diagnosed at 2 years 8 months, met 10 of the 12 criteria for Autism Spectrum Disorder. He has never been tested for his IQ as this has been deemed too difficult due to his lack of receptive and expressive language – at age 15 he's almost non-verbal. Ever since we started trying to find out what was "wrong" with our beautiful firstborn we have hit BRICK WALLS, have been INTERROGATED, have faced WAITING LISTS, have been IGNORED, have competed AGAINST other individuals and families, have been made to feel STUPID .....all when seeking the information, assessments, therapy, special school placements, accessing services, respite funding and places, Schools Plus applications, etc, etc, etc

We knew when he was about 20 months old that something wasn't right, he had been developing speech normally and within a few weeks lost the whole damn lot, went back to baby babble and leading (a common strategy for children who have autism). Many people tried to reassure us – boys talk later than girls, the family situation is stressed (company hubby was working for closed it's doors without notice, he was unemployed!), grandmother was sick, "he's being manipulative".....but all along a mother's instinct knew something was not right. Took him to GP, who referred us to Speech Pathologist who couldn't get a word out of him, GP then referred us to a Pediatrician who ordered a barrage of tests to rule out Mitochondrial disorders, hearing impairment, Chromosomal abnormalities, blood disorders, urinary issues, and an EEG for brain issues – all hugely terrifying for new parents. It took 6 months wait for an assessment for Autism at the State Child Development Centre, a free assessment since at the time we couldn't afford to do any private assessments, it was our only option. After this, early intervention was able to start quite quickly.

Over the time since then I have heard horror stories from families as to the waiting time/lists they have been on for therapy of any kind ~ this is dreadful, world research clearly shows early intervention is VITAL for long term positive outcomes. And just recently I have been told if a child is over 6 years of age in WA the wait time for assessment (then wait for accessing therapy) can be 3-4 YEARS. How can this be best practice????!!!! Not good enough WA. Along the way the best support and information we got about what's available was/is from other parents who have travelled this journey before and at the same time as us. Nothing is any different than when we started way back in 1998. There is still extreme frustration about accessing information and services. There needs to be a central hub for this to happen. I still hear weekly that parents didn't know such and such existed, or that they could access such and such funding or respite etc. This should not still be happening. Not good enough WA.

# the OTHER 100 conversations

A child with severe Autism should NOT be in mainstream kindy and pre-primary – no ifs and maybes – our first child should never have had to cope with mainstream kindy and pre-primary, even with a very good teacher and education assistant. And it's still happening in WA today!! Not good enough. After these 2 very tough years, we were VERY VERY lucky (yes it was LUCK, as we purchased land and built our home in our current location before we had any children) to have an Education Support Centre in our local primary school and now a purpose built Education Support School within our local intake High School – but most parents of kids with additional needs do not. And children without an intellectual disability do not have access to them anyway. Children in rural areas have even less access to these facilities. Not good enough WA.

By the way, I have a career – well I did have!!....a very good career.....when our first son was diagnosed I was an Acting Deputy Principal in a metropolitan Senior High School, I was really enjoying my job and was considered a very valuable member of the administrative team, and primed for substantive promotion. To enable my son to attend early intervention therapy I went on leave, and because this therapy followed through into beginning school issues (and a new pregnancy!) I took maternity leave followed with leave without pay. During this time of leave our second son was progressing but we realised not within the normal developmental milestones....so off we went and had him assessed – privately this time as we'd been told the waiting lists were 12-18 months, if not longer.

This cost us (even with Private Health Insurance) about \$600 out of our own pockets and we still had to wait a couple of months to have the assessments and final diagnosis. We paid for private speech therapy as we had to wait about 6 months for an early intervention placement. What we thought this placement was offering us, turned out to be false information, our son ended up with 1-2 hours of early intervention per week for only 8 weeks of the school term. The rest of the funding was gobbled up

in assessments and report writing. This compared to 12 hours per week for every week of the school term, 1 week of the school holidays and only three weeks off on Christmas holidays for our first son's EI.

By this time we were desperate – how could we get therapy for this child who was obviously far behind his peers, and was headed for mainstream schooling due to his diagnosis of PDD-NOS? We couldn't afford more private therapy. We had already re-mortgaged our home, borrowed money from our parents to buy a car and were living off a credit card from pay to pay. We applied for a Language Development Centre program only to be knocked back. We were extremely lucky when we applied and to have him offered a placement in a trial program – an Autism Unit run by the Education Department for kindy and pre-primary, an intensive one-on-one program for children with higher functioning autism. Without this wonderful program he wouldn't be where he is today – year 6 mainstream school – still struggling every day, but it gave him a great start. We really feel for all of those kids with Autism who did not get early intervention or specialised kindy/PP program. Not good enough WA.

Currently, the common story in WA is of families that they often have the funding for early intervention through Federal Helping Children With Autism Program (Fahcsia) but cannot access the therapy. And still the government thinks all is rosy here in WA. Just yesterday I heard of a family who will probably lose their funding because their child is turning 7 and they haven't been able to use it due to the wait times for therapy. They had to wait for assessment then this! They are devastated for their child!!!! Not good enough WA.

Eventually I had to return to work as a teacher in 2006 as we couldn't continue financially in that situation and I was also denied any further leave. Unfortunately, even though I was only working part time, and my children were both in full time school, I still required before and after school care, and some evenings and for parent meetings and school holidays for curriculum liaison. This was never reliable or consistent. My children's schools often needed to

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contact me during school hours. My husband works shift work and needs to sleep at odd hours, therefore he was rarely available when the children needed to be collected from school or to be looked after. We did have opportunities to apply for respite through ACTIV, one of the regular "interrogations" we endured. Carers through agencies like this rarely continued for very long. Staff would leave, recruitment was poor, pay is dreadful, the staff are overworked.....and they leave. Much of the carer cost over the first few years was carried by us. We've found over the years unless you scream and shout and give the worst possible scenario to a Local Area Co-ordinator of DSC, you get nothing - no information, no suggestions of support or resources, funding.....it took us having a mini-breakdown of our marriage before we received any respite funding. Then there is the ridiculous difficulties with finding and retaining carers privately. Not good enough WA.

I resigned from the Department of Education and Training in 2009 as I could no longer cope physically or emotionally - I was spent, our marriage was in tatters, our boys needs were being neglected, I almost ended up in a complete breakdown, seeing a Psychologist on an Enhanced Primary Health Care Plan for over 12 months. It has taken me since then to come back to feeling well again. Income of up to \$85,000 a year as a teacher would be very helpful in the scheme of things, but that is not something I can see happening in the current lack of support. No tgood enough WA.

We are currently in a holding pattern. My husband is working his butt off 6 (sometimes 7) days a week to support the family financially. He's 51 and expects to still be working at 70!!! I am also qualified as a Lactation Consultant and work in private practice from home, which means I can suit my bookings around our family commitments, but because the service I provide has no rebate for Medicare or private health insurance, I am not in great demand and am lucky if my business breaks even each year. Our children are progressing steadily at school - after ups and downs along the way. Next year will be a different story as #2 son enters high school - in

mainstream - this is going to be extremely difficult for him and we predict many meetings, and fights over what he requires to support his learning. He is one of the borderline kids, not able to access Education Support because he doesn't have an intellectual disability, but can't cope with mainstream because of his autism deficits. I hear many similar stories regularly. Not good enough WA.

Planning for our children's future is high on our agenda. They will both require 24 hour supervision and care for the rest of their lives. This will likely be long after my husband and I are gone. We will be relying on a circle of family/friends to support our boys. Hopefully what we leave behind financially will help them, but at this stage it's not looking too positive. Our thinking is that we as the older parents will probably be caring for our two boys in our own home until we are no longer physically able to - then we will be going into government funded and run retirement/nursing home accommodation and our boys will fall into state run facilities too because all of our family and friends have their own lives to lead and will not want to be looking after two men with autism. What a dreadful thought. And that should not be their future either....but so many are living that RIGHT NOW!!

NOT GOOD ENOUGH WA!

Mr Barnett

Please read our story (and all of the others) and realise it's vital to EMBRACE the Productivity Commission report into a National Disability Insurance Scheme for Australia and help our loved ones and our family live happy, fulfilled lives.

Del and Kevin Smith

## 60. Future Uncertain

'His extremely aggressive behavior...did not improve.'

I first suspected something wasn't 'right' with my son when he was around the age of 2yo. I had my GP put in a referral to the State Child Development

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Centre who then in turn referred me to the Armadale Child Development Centre (as I lived in that area). By the time that referral came thru though (many months later), I was moving out of that area (so were no longer eligible for services at Armadale CDC). Armadale CDC then referred us over to Southwell CDC who took many many months to even acknowledge the referral.

Finally I was contacted by a Senior Social Worker (Linley Head) at Southwell CDC and was finally given an appointment to see her. Despite the aggression that my son displayed towards other child in every setting (day care, at home, visiting friends, at the park) I was told by the Senior Social Worker at Southwell CDC that there was "nothing wrong with my son" that it was me who suffered anxiety and she needed to help me with that. Despite this, I pushed for a referral to an Occupational Therapist at Southwell CDC as the support services linked to day care centres had already identified my son had sensory dysfunction. Without even meeting my son, the OT concluded from a form I was asked to complete immediately after my dad had passed away, that my son did not have ANY sensory issues and as a result the Senior Social Worker withdraw my request for OT services (without my consent). She told me that I had too much going on in my life at that time (because my dad had just passed away and because we had been told my son could not return to the O'Connor Child Care Centre (private) because parents were complaining about his level of aggression/violence towards other children (and staff). Even when I pointed out we needed support, I was told the only services on offer were to continue to see the Senior Social Worker (Linley Head) at Southwell CDC for cognitive behaviour therapy (CBT) for myself to treat what she perceived as my anxiety. I explained that the anxiety she was witnessing was because there was something wrong with my son and I didn't know how to help him. At this time I also requested an appointment with their paediatrician to review my son when the Senior Social Worker told me my son would NEVER be seen by a paediatrician at Southwell CDC because "there was nothing wrong with

him" and as such other children would always be placed in front of us on the waitlist. As a result I was FORCED to see private therapists in order to gain services for my son (despite being on pension myself) and being able to only work limited hours to pay for services.

Soon after I began seeing a private Occupational Therapist, Jean Loth, who completed an assessment of my son (then aged approximately 3yo). The assessment revealed my son had SEVERE SENSORY PROCESSING DYSFUNCTION, contrary to what I was told within the public system. My son continued to have treatment for several years thru the private sector.

At 3yo my son was also assessed by a private paediatrician, Dr Peter Chavel, who is known to be a guru in the autism area. He concluded my son demonstrated many autistic traits and believed he was on the autism spectrum. As a result he referred my son for a full autism assessment through the Disability Services Commission, which was completed when my son was 3years and 9 months old. At the start of this year my son also began kindy at Newton Primary School where he demonstrated aggression towards other children. He was given minimal aide time in the mainstream class and the teacher instructed the aide to remove him from the class at least every 30 minutes (and had him picking up rubbish instead of doing school work). I removed my son from this school in term 2.

At the formal autism assessment, the speech therapist and clinical psychologist concluded that my son DID NOT have autism, rather he has severe speech impairment and recommended speech therapy which I did. The public system offered him 5 sessions that year so they suggested I apply for the Carers Allowance to help pay for private therapy.

I began private speech therapy with Roz Ward at Kidz are Kidz where my son was diagnosed as having verbal dyspraxia. My son continued speech therapy for many years. Whilst his speech improved dramatically, his extremely aggressive behaviour towards other children did not. I continued private speech therapy and private occupational therapy

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simultaneously.

By this point the only diagnosis I had was verbal and motor dyspraxia and sensory processing dysfunction.

When my son began pre-primary at Phoenix Primary School, he was not afforded any aide time as he did not have the right "label". His behaviour was extreme and SPER were called in to work with him and the staff to manage his behaviour. The school requested my son once again be reviewed for autism due to their belief this was the correct diagnosis.

In year 1, my son was diagnosed as having a severe generalised anxiety disorder by a psychologist Kyla Penfold, at the Child & Adolescent Mental Health Service (CAMHS) in Fremantle. He was then afforded aide time of 0.65. His behaviour was still not managed well and a further application for schools plus was required. My son had an aide with him at all times (even recess and lunch). Despite having great aide time, it was not used to my son's advantage. Children demonstrating autistic traits, are known not to cope with changes in routines and staff changes. Despite knowing this, my son was allocated two (2) aides – one working up until lunch time each day and the other worked from lunch time until the end of the school day. Each day, this caused my son to have extreme meltdowns where the teachers and deputy physically restrained my son (causing further anxiety/meltdowns). Changes in routines occurred frequently (despite the "inclusive schooling" policy) and I was often asked to keep my son home as they did not believe he would cope with the changes. The trauma that was caused by the mainstream school, led to me being forced to homeschool my son, because no other option was available to me. This placed me under extreme financial hardship, being a sole parent.

My son was assessed by Family Pathways (connected to CAMHS) and they recommended he attend a special education centre due to his learning difficulties, challenging behaviour and anxiety.

This year my son was accepted into Maddington

Special Education Centre but his behaviour is still thru the roof. Most days throughout the year I have received phone calls asking me to collect him as his behaviour is extreme and they need him removed from the school. At the end of Term 2, 2011 the school stated my son could only stay at school for 1 hour per day and that I was required to stay with him. This places enormous strain on myself, as it prohibits me from re-entering the paid work force, something I desperately need to do for financial reasons and also for my own mental health. Due to the stress of the situation I live with daily (based on my son's needs and the issues relating to services, funding and education) I am now on anti-depressants.

I am not eligible for funding for my son through Disability Services Commission because my son's IQ score is 71 ... this is ONE POINT above their cut off to acknowledge my son has an intellectual impairment and as such I would be entitled to funding.

My son is currently on the waitlist to be formally assessed for autism once again. Fran Tyler at Disability Services Commission has informed that due to my son's age (now 10yo), he will not be assessed for approximately 2 years, as Disability Services Commission focus on early intervention, so older children are not seen as a priority. Well, if the Disability Services Commission had got it RIGHT when my son was 3yo (instead of waiting until he is 12yo) we would have been eligible for services, respite and funding for early intervention.

But instead I receive no services and we completely missed out on funding for early intervention services and my son continues to fall apart every day at school and any other environment that is unfamiliar to him.

This places enormous strain on me, as I have no family to support me raise my son or offer respite or funding to pay for much needed services.

My son's future hangs in the balance all because of a system that is failing so many families with children with special needs ... something desperately needs to be done!!!!

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## 61. An OT's Story

'The local organization is doing the best that it can, however families need more.'

As a service provider in the paediatric disability sector (allied health therapy provider) for the past 11 years (public and private not for profit) I think it is evident that some services work really hard to meet families needs, but it seems that obstacles remain for ideal service provision. I have not seen any changes or improvements, in terms of on the ground support for families and their children over this time. Some glaring gaps include:

- Therapy services for rural families. If you are based outside the metro area, you are reliant on generalist pediatric therapists based at public hospitals, with only the support from disability early intervention specialist practitioners as consultants on regional visits. These visits may happen once or a maximum of four times a year ONLY, and these therapists do not provide treatment themselves to families. If the local therapists decide that they don't need the support from DSC, they can refuse the visits. Families do not have a voice here. In many regional areas there are no alternative private practitioners, and not all families can afford these. Therapy Focus is an organisation providing specialist therapy services to school aged children with a disability in METRO areas only. Why can this service provider not be state wide?? A small amount of money is filtered to regional locations for services in this area, however regional areas can choose how they spend it, and generally continue to focus services on 0 - 6 year olds.

- specialist disability service providers eg Cerebral Palsy Assoc, Rocky Bay, Assoc for the Blind do not visit regional areas. If your child needs these services you need to travel to Perth. Links between therapists from these associations to regional therapists are personality driven and it is not mandated that regional services use these specialists for children that

fit their criteria. In the end - children miss out. Also recently the Assoc for the Blind has made the internal decision that regional kids will not be seen by their specialist OT/PT/SP - they can only see metro clients. Regional kids can only see their regional generalist therapists!!!! Vision impairment is specialist area - why are regional kids missing out on this service??

- There is a situation locally at the moment where the health department allied health team is refusing to service an Education Support Unit primary school due to difficulties with particular staff members. All this means is that the children are missing out on a service and parents are too scared to speak up as it is the only Ed Support Unit for K/PP in the district and parents do not want to "not be welcome there if they cause trouble". Again, I feel that therapists specialising in the disability field would have more skills to ensure that situations like these do not arise.

- There is inadequate flexibility in respite options for families in Kalgoorlie and also for post school options. Again, the local organisation is doing the best that it can however families need more.

- LACs do a great job but again, cannot provide the complex support to all families that may be required.

- We need more psychologists to work in the field to support parents dealing with adjustment to having a child with a disability and what this means for the rest of their lives.

- The Autism packages and Better Start initiatives are a great move forward, but really it needs to include all children as families who children do not meet specific diagnostic criteria are still left without the support of these packages and in limbo land!

An Occupational Therapist



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Thomas was born April 19 2005, normal pregnancy, normal birth. He has Autism. By the age of 2 I knew he wasn't developing 'normally' so started the process of getting him into see the government clinical psychologist/pediatrician in our area. At least 6 mths went by before we got in to see her. At the appointment Thomas wasn't very co-operative (obviously) but all we got was, nothing is wrong. Another 6mths went by and I asked to see her again. This time we were told Thomas has developmental delay. By this stage Thomas was attending speech therapy as he wasn't talking and he was now 3 1/2.

Now since he has 'developmental delay' we have to do all the paperwork to get Thomas into the LDC in Morley. He starts kindy there in 2009.

During the year the psychologist and speech therapist get me in to talk to them regarding Thomas and his 'behaviors'. I tell them that I have had him assessed and they say its developmental delay but that I am pretty sure he has Autism. They agree. I make an appointment with a private pediatrician. I wait another few months and pay out of my own money to see him. He tells me that just by looking at him and his 'behaviors' that I have been right all along and he has Autism. Thomas is now 5 and I have just wasted 3 years when he could have been having therapy had he been properly diagnosed and not had to keep waiting 6mths or longer each time.

Thousands of \$\$ later out of my own pocket, Thomas now has his diagnosis and we are getting therapy. Unfortunately your government doesn't 'approve' ABA therapy that I believe is the best for my child so I can only receive the \$6k federal funding not the extra \$6 local funding so my son misses out yet again. When the money ran out in March 2011 (after only doing therapy since Oct 2010) I had to cut my son's therapy sessions from 3 x 2hr sessions per week to 1 x 2 hr session that I have to pay for. I could not afford to pay for any more therapy sessions as we could not afford it. Now we have the federal funding (no thanks to you) so Thomas can have more therapy sessions again, but this will run out soon and then next year he is 7 and

so then therapy will stop again due to the lack of money we have to do therapy sessions.

This is not good enough. Thomas has the right to be like any other normal boy, and could be that boy if we had access to a NDIS. It is every child's right to reach their full potential and by sweeping our children with disabilities under the carpet is a disgrace. What you do not do for them now will later become more of a burden as when they are older and we are no longer around then what happens, who is going to look after them and pay for them. What you do now impacts their quality of life, which everyone deserves not just 'normal' children.

Lee-Ann Robertson

## 62. A Speech Pathologists' Story

'...every day is a constant frustration, waiting...'

I have been a speech pathologist in the city of Kalgoorlie-Boulder since September 1999. In that time I have worked in both the public and private sector. In my time as a speech pathologist in the public sector, it was often very frustrating to not have the staff to afford people within the disability sector with sufficient speech therapy services, due to the region being a hard-to staff region. Children within the disability sector often require a team and family-centred approach to the communication difficulties that they are experiencing. I know of many families who were frustrated that the continuity of services provided was almost non-existent and that just as they were developing a relationship with a certain team member or therapy provider, this person/s moved on and a new relationship needed to be developed. This is particularly noticeable at the age children attend school as often this age-group is not prioritised and therapy was not offered. As a result, many families opted out of the service and at-

# the OTHER 100 conversations

tempted to provide communication strategies by themselves, often lacking the necessary resources and expertise. Despite younger children with disabilities being prioritised, providing a six week block of therapy per year is not ideal.

I have been in private practice since September 2004, catering for a paediatric population. As a private practitioner, it has again been frustrating to try and attend to the communication needs of this community. Providing a team approach for children is almost impossible in the private sector and as a result, many children with disabilities are disadvantaged despite the fact that they are now required to pay for services. In recent years, I have noticed that there has been an increasing need for private services due to a difficulty in recruiting and retaining speech pathologists in the region. This has put a significant strain on private speech therapy services and has even resulted in an extensive wait-list time. It is my belief that any child with a communication disorder should have access to services to improve these skills as it is well documented that if the necessary intervention is not provided in the early stages, this has many negative impacts on the child's social, emotional, medical and academic development. These services should be available at no cost or a minimal cost. In my experience, clients that I have seen with disabilities require regular, long term intervention and are often forced to leave private therapy due to the financial burden. Many assistive communication devices are often required to improve communication in children with disabilities however these are often cost prohibitive for a small private practice, once again disadvantaging this sector of the population.

Overall, as a speech pathology provider in this region for people with disabilities, everyday is a constant frustration at trying to provide the best possible services and support for families with many significant barriers preventing this from happening ie long wait lists in the public and private sector, recruitment and retention issues and financial burdens for families accessing private services.

## 63. Lee's Story

'...I fell over three times that day. I felt dizzy...the last time I fell I couldn't get up.'

On Thursday 21<sup>st</sup> August 2008 I fell over at home. I fell over three times that day. I felt dizzy that day. The last time I fell I couldn't get up again. So I pushed the button on my alert that I wear around my neck. The man on the line called the ambulance. One of my neighbours was there in a few minutes and she waited with me for the ambulance.

I was taken to Swan Districts Hospital. I told them I had Private Health Insurance but they came back and said that my card was no good. I was in Emergency all night. I didn't get much sleep because they kept moving me. They did x-rays to check for broken bones and talked about sending me home, but I had a temperature. In the morning I was moved to Royal Perth Hospital Emergency. Another one of my neighbours was with me when the doctor came. I felt very hot. He asked me "so you've fallen over a lot lately?" I said "no, I fell over yesterday because I was sick". He asked me again "so you've fallen over a lot lately?" I said "NO." My neighbor said to him that I had a temperature. He listened to my chest and told me that I wasn't allowed to eat anything until a speech pathologist saw me. He said that I might not be eating my food properly.

They did lots of tests and put me in a bed in a ward. I didn't see the speech pathologist until about 2pm the next day. She told me that I didn't eat properly. I said "I've been eating this way for 65 years". She told me that I had to stay in hospital until I learned to drink out of a cup. That was pretty funny, I don't think I can hold a cup to my mouth. I've used straws for 65 years too. I had lunch after she left.

That day (Saturday) some doctors came to see me. They came as I was getting off the toilet and the

# the OTHER 100 conversations

nurse was helping me. They gave me a fright. One doctor was kneeling on the floor with his elbow on my chair and his face right next to mine. He said to me that I would have fallen over if the nurse hadn't been there. The doctors said "we've got to assess your ability to walk before we even can think of sending you home because you know why - you've had a fall"

They asked me "do you know when you're going to fall over?" I said I wouldn't know when I'm going to fall over - how are you supposed to know that? I wasn't feeling too well that day. Even able-bodied people fall over if they're sick.

They said the doctors, OT and physio are all going to assess me at the same time so they'll be all of them against me, that's what it seems like. I don't think that it's necessary. If you're well enough to go home, that should be up to you.

I haven't been able to walk here. When I'm sitting at home for a long time, it takes me a while to get mobile. The nurses come to the toilet with me. They said they're not allowed to let me walk.

The doctors are looking only at my age and disability that's what I think.

I saw a physio on Sunday and she said I could walk and she'd take me home on Monday to see if my house was OK. But on Monday another physio came and watched me walk and she wouldn't let go of me. She said that she wasn't happy with my walking.

The same day three doctors came back. They checked my chest and back with a stethoscope and got me to walk across the room. One doctor kept holding my back while I was walking. He turned to the other two and said "How old is this man?" One of them looked at my notes and said "65". I was sitting right there, why couldn't they ask me that? He said "I'm not going to let this guy go home." They went and didn't say another word to me, not "how are you" or anything. But every time the doctors come they talk amongst themselves and don't ask me a direct question. They talk

about me like I'm not there and treat me as if I couldn't talk for myself.

I have lots of support at home, but no-one has asked me that except the social workers. I have carers that come and help me have a shower every morning and take me shopping and cook my food. I have a lift chair. I have a scooter. My house is made for someone with a disability.

This is what it is like to be old and have cerebral palsy in hospital. I was sick and I got better, but they didn't want me to go home.

## 64. Leonie's Story

'...there's no respite for older people with a disability.'

Last week I went round to my friend's house for a coffee and talk about her trip around Australia that she and her husband had just returned from. She commented to me how quiet her house was now that all her 3 adult children had left home and embarked on their own lives. She is the same age as me but I am the mother of a 25 year old intellectually disabled daughter and things are different for me. Very different!

When a person with a disability leaves school, things change dramatically. If work is not an option, then they may get PSO (Post School Options) or ATE (Alternatives to Employment) funding so that they have things to do in their lives. Which was the case when my daughter left school in 2004. However, you don't get a lot of funding and agencies are hard pressed to stretch it when providing services.

I was told by a visiting DSC (Disability Services Commission) representative at the time that my daughter could get up to 20 hours a week - whacko! It seemed to me that when she was at school she was there for 30 hours plus there was access to after school programs. I asked what they expected me to do as a single parent who had to work full time to put a roof over our heads. You know, he told me I could go on a pension! Well that solved that finan-

# the OTHER 100 conversations

cial crisis!

Already the system is unfair! These days my daughter links into other community agencies so that she is doing something meaningful with her week instead of staying home and doing nothing.

However, there is no respite! Not for older people with a disability. Cause you see, they get funding such as PSO or ATE so this disqualifies them! If you want respite you need to access the humiliating system provided by Silver Chain, so you end up being pretty desperate to ask for it and jump all the hoops to get it!

My daughter still lives at home with me. She would love to move out to her own place with a friend but she needs full support. We have had an ASF (Accommodation Support Funding) application in for several years now but have not been successful.

I had been told that she needs to be homeless before they will consider funding. You know this can be arranged based on her recent behaviour but as her mother, I can't bring myself to abandon her and DSC know it. I have a lifetime sentence of being the unpaid carer of my daughter without the freedoms that my peers have such as what work I do, where I can live and/or work and who I can live with to name a few. These are basic things that aging parents of people with a disability have to consider.

Just to have a normal relationship is difficult. Suffice to say that I have been a single mum for a majority of her life. I am a relationship now but who knows how long that will last! Got to enjoy life's little luxuries while I can!

The future is bleak for people with a disability and their parents as the only way an independent life can be achieved is for something tragic to happen to the parents and DSC is forced to do something!

I tell all young parents to start putting away money now for their child with a disability into a trust because that is the only way you will have funding for them when they are adults – don't rely on the government to help!

Leonie Amos

## 65. Dawson's Story

'...it was very much a hit and miss program rather than an ongoing process.'

We were living near Bunbury WA when our first born child, Dawson was diagnosed with an Autism Spectrum Disorder at 3 years of age. Although he was recognised as having gross motor delays at 12 months and speech delays at 18 months it had been difficult to access therapy and was very much a hit and miss process rather than an ongoing program.

As we were concerned that Dawson was falling further and further behind his peers and we were not convinced that Bunbury was going to offer the services he needed we made the decision to move to Darwin (where both my husband and I had lived and enjoyed previously). At the time we didn't see ourselves as city dwellers and couldn't imagine living in Perth but did recognise that living in a more populated area was likely to give us better access to services.

Once in Darwin we were able to access 2 and half hours a week of group therapy addressing fine motor, gross motor and communication needs for the next 18 months. Dawson was also accepted into the local special needs school at 3 and half years of age to help him to transition into pre-school. Both of these programs allowed Dawson to improve his motor skills and to develop functional communication skills.

At 5 years of age Dawson started full-time school and consequently he was no longer eligible to attend the early intervention program. Instead he was transferred to the school based therapy team which covers all schools in the Darwin area. This has meant that and OT and speech therapist review Dawson every 2 years and give his teacher and parents a report of recommendations. The unsatisfactory arrangement was further compounded by the lack of private therapists available to access.

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At 6 years of age Dawson was given access to the \$6000 a year of funding as part of the Helping Children with Autism package however as there weren't any approved service providers in the NT we were unable to use the funding before his 7<sup>th</sup> birthday.

Dawson is now 9 years old. He is fluently verbal and a very intelligent little boy. He does however have areas that are a challenge to him and impact on his learning ability. In particular he has auditory processing and sensory processing issues as well as high anxiety levels. He is still delayed in the areas of gross and fine motor skills. Although he is toilet trained during the day he does wet the bed most nights. For these reasons we have kept Dawson in a special needs educational setting although he does attend a mainstream classroom for up to 5 hours per week.

Aiden is our second child who is now 2 and 7 months of age. He was born with a rare form of spina bifida which went undiagnosed for 3 weeks before he was sent to Adelaide for investigation. Aiden has a hole in his skull and consequently part of his brain herniated through the skull. In addition to this his brain did not form properly. As a consequence Aiden has Epilepsy, Cerebral Palsy, Cortical Vision Impairment and we are in the process of having him assessed for Autism.

It has been a long hard couple of years. Aiden spent the first 12 months in an out of hospital. He had to have brain surgery at 3 months of age and he had uncontrolled seizures for a year. Once these issues were resolved we looked at our options for early intervention. Aiden was offered one hour a week of Floortime (this program is offered to all kids with special needs regardless of their deficits). I didn't feel that this was the right program to address all of Aiden's issues so I employed my own ABA therapist. I couldn't afford to pay for a consultant so I supervised the program myself. After several months I felt that this program wasn't meeting Aiden's needs either. We needed a program that was more global and had a focus on mobility. Eventually I came across a program called Conductive Education. I discovered that it was available in every

capital city except Hobart and Darwin. So I contacted a school in Perth that offered CE and arranged for my husband and me to go to Perth to look at it. We were convinced that this program was going to help our son and we made the decision to move to Perth.

However we had great difficulty in finding appropriate schooling for Dawson. It seems that to access a special needs school or a special needs unit in WA the child must have an intellectual disability based on IQ. Although Dawson had not had a formal IQ test done it was obvious to us that he has a high IQ but also has significant issues that impact his learning ability. We were also convinced that Dawson would not cope moving from a mainstream setting 5 hours a week to full-time mainstream without any transition period. We requested an IQ test be done by Student Services in Darwin which came back inconclusive.

So we made the heart wrenching decision that I would come to Perth for term 3 and term 4 to trial Conductive Education with Aiden and we would decide on what we should do as a family at the end of this year. My husband is now the primary carer of Dawson and I am the primary carer of Aiden and although in our eyes we are not separated we are technically living in different states.

I have only been in Perth 3 weeks so it is difficult for me to comment on what else we can or cannot access for Aiden. I do know however that we have to have new assessments as the ones we had in Darwin will not be accepted in WA.

The moral of my story is that families are being forced to move to where the services are which is extremely unfair. Those living in remote areas are distinctly disadvantaged. My hope is that an NDIS will give all families equitable access to services and all children with a disability will be given the opportunity to reach their full potential.

- Molly



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## 66. Sharon's Story

'...Sharon has lived in institutionalized care for most of her life.'

There is no one to speak for Sharon.

Like many other people with disability living in WA, Sharon has no carer, no friends, no ties. Her family forgot her long ago, and at the age of 43 she has very little of what the agencies like to call 'informal supports'. Sharon has no one to advocate for her and she has no friends.

I work for a service provider and something about Sharon touched my heart. She has a quick smile and a ready wit. Because Sharon has a speech impediment - she has cerebral palsy and a mild intellectual disability - people think she is far more disabled than she is. She has lived in institutional care most of her life. Because of her communication difficulties, she was not given much education and has been treated as though she cannot make her own decisions.

First she lived in a hostel. She said she wanted to try living in the community by herself. Then she was moved into a group home of six people. She had no choice about who she lived with or where she lived. No-one would listen to what she wanted and she would get upset, so she was branded a troublemaker.

It is routine for staff in group homes to withhold, for example, cigarettes, as 'punishment', although Sharon is an adult woman with her own funding. But that isn't the end of it. As a person with a disability, she was not allowed a key to her house. She was not allowed to cook a meal or get herself a coffee. She kept saying she wanted to move out, she didn't like where she was. She showed she was unhappy and was considered 'difficult'. She was only allowed \$10 a week from her DSP. She was lucky, after 20 years someone listened and helped her get a Homeswest unit. It took two years to convince people to let her try. Twenty years later, she is doing OK

## 67. Can't Afford Help

'...we can't bring her home, she is trapped.'

My sister has an Acquired Brain Injury which has left her with mobility issues. She has not been able to go home because her care needs are too high and our parents cannot afford the modifications needed so she is living in a specialist nursing facility. She gets someone come in once a week who is paid to take her out. In the facility she is not allowed to drink so she goes to the park.

She is treated like a child and we are all adults now. It has been four years since Kyli's accident and we can't bring her home, she is trapped.

## 68. Crash and Burn

'...its hard enough without having to fight just to live.'

I am forty six years old. Not old but I feel older than my years from battling the system.

Sixteen years ago I crashed my motorcycle through no fault of my own. I suffered third degree burns to my face and the accident led to me becoming a c3 quadriplegic. After fighting through the court system for eight years I finally proved I was not at fault and received compensation as a lump sum payment.

As a payment that money became my money and was not quarantined for my support or dished out annually to pay the ongoing costs. By this time I had an ongoing pain issue to do with my burns and my injuries. I used my money to build an accessible house and moved in with my girlfriend who was also my carer. Bad move as it turned out. A number of years later she left me and took half my money as her share of the relationship.

I now struggle to get the support I need and from

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day to day it is a battle, but I still have too much money to be eligible for other support.

Most weekends I spend in bed because I can't get enough support in the day, and I don't go out because I have to budget my support. I am trapped in my own home by my disability.

I won't be able to get Centrelink benefits until 2016 and after the bills and my expenses are paid it leaves me with about thirty five dollars a week for food. Its ridiculous, it is hard enough having a disability without having to fight just to live.

## 69. Don't Speak For Me



'...I am quite capable of speaking for myself, with more qualification, than you will ever have....I live the life, you do not.'

Mr Barnett. I am a mother of three children, two have autism, an adult son of 22, and a daughter of 7, who also has epilepsy, a severe sleep disorder requiring hospitalisation x 4 times, and also non-verbal. Three years ago, I under took a trek of 600km on foot, pushing a wheelchair to Perth, from Kalgoorlie, where I live, in order to raise awareness of lack of services for disability in regional and rural

areas, I raised 8000 signatures, petitioning for better services, and raised \$2000 for the RFDS on the way, another highly funded, and underestimated service.

Why would I do something so dumb??? Because that is how strongly I feel that our services are inadequate, underfunded, and ad hoc. Let me tell you, I lost 5 kilos and 7 toenails on the way to Perth, and I walked every single bloody kilometre of Great Eastern Highway. Along the way, and its a long, long way, let me assure you of that...I shared many stories of people in a like situation, and dismally, most stories were universal accounts of distress, despair and dismay at the lack of services they were able to access, either for themselves or for their family member with a disability.

I completely do not understand your stance in relation to the implementation of an NDIS. It is NOT, as you stated, a "corny, ill-thought out stunt" by the Commonwealth. The NDIS has been around twenty years in the planning, I know this, because I have been receiving the newsletters regarding it, for approximately ten years now.

I do not like that you speak for the disability sector of WA without consulting the people who live and dwell in that community. I have my own voice, and my own account of what our lives have been like, and they bear absolutely no resemblance, to the system of disability care and support that you talk about. I know what I want, and it is, an NDIS! Please do NOT presume to speak for me, because I will not have it. You CAN speak to me, on 0411174419, or contact me at jorussell@westnet.com.au, but until then do NOT presume to speak on my behalf, thank you very much!!

By the way, over the last two years, we have coped with a suicidal young man, a 3 hour seizure which did not stop, with our daughter and subsequent brain damage, job loss due to disability stress, income loss, home loss, almost there marriage breakdown, another stone lost in weight, insomnia, stress, anxiety, breast cancer, mental health referral (not that they contacted me for six weeks, another epic system fail), pretty much a screwed up life. We got through, thanks to our own resources, not thanks to

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the systems that were meant to support us in the first place.

You don't understand, do you? No one wishes to dismantle the DSC and LAC system we have here in WA...why would anyone with half a brain dismantle something that is working well? But everything can work better, and it should work in a uniform way throughout the whole country. I'm sorry, but your attitude reeks of ignorance, non-consultation with the community and political arrogance. Put it away Mr Barnett, I have waited long enough for something significant in disability reform. You will get to retire from your political life, I will not get to retire from autism, and my children and their needs, ever. Please do not EVER, assume to speak on my behalf. I am quite capable of speaking for myself, with more qualification, than you will ever have....I live the life, you do not.

## 70. Double the Need

'...the twins were diagnosed with Cerebral Palsy.'

Rosey has been a sole parent to her twins Kayla and Dylan since their father left midway through the pregnancy. It was a fraught time when they were born 26 weeks premature and Kayla had to remain in hospital for the next 9 months, and even more so when the twins were diagnosed with Cerebral Palsy. Under financial, physical and emotional strain Rosey asked for in home support and was told by the authorities that they knew the best way to give her a break. They persuaded her that briefly fostering Kayla would be the best way in which to do this by making her a ward of the state. Rosey did so reluctantly and then found barriers when she tried to make contact with her daughter. Eventually after much battling and enlisting lawyers and other professionals she succeeded in bringing her daughter home. It was an experience that left her understandably reluctant to ask for help.

Up until the twins were five Rosey was told she was only eligible for 2 hours assistance to help with bath-

ing or activities. A sympathetic health professional could see the obvious need and advocated for her at a crisis meeting with DSC after which funds were granted.

Rosey is very grateful for the funding and assistance but wishes that the system could be more flexible and give those receiving the support a greater say in prioritizing what they need. Now that the twins are 18, one of the biggest issues is transport. Because of mobility problems neither Rosey nor the twins can drive. Dylan is attending TAFE but to do so must travel significant distances. In current arrangements that means he is often walking with difficulty alone in dark areas and in bad weather. Both Rosey and Dylan could solve this problem if they had more discretion over how the money was spent. There is also little flexibility in the provision of the services to give the twins even a fraction of the freedom their non disabled peers enjoy.

Rosey went through a period of 6 years on dialysis, a recent liver transplant and has had a hip replacement. At all these times she needed help with personal care but was only eligible for minimal assistance which meant being rationed to a few showers per week. And of course during these times of even greater stress her impact to care for her children was compromised.

## 71. Valia's Story

'...fortunate, because for the last ten years she has been her daughters carer'

Valia is 72 and has Muscular Dystrophy as does her daughter. In fact it was only when her daughter was diagnosed as a teenager that she too was told she had the disease. In her case the onset was much slower, which was fortunate because for the last 10 years she has been the main carer.

Because of the lack of support available to her daughter Valia sold her own property to move next door so that she could be constantly available, particularly to help with her young grand child. She also gave up work resulting in a reduced income. She

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has for all of that time been providing help with washing, cleaning and cooking and in the last few years transportation. Her daughter is only eligible for 2 hours assistance per week. In the last few years things have become more difficult as Valia's own muscular dystrophy has accelerated. She now uses a walking stick and is unable to assist her daughter out of the car so their ability to get out into the community together has been very constrained.

Valia has been loath to ask for help, partly because of her own fatigue and her assumption that she will have to battle her way through the system as her daughter has done. She is also loath to 'hang out her family washing in public' but is prepared to be part of the this document because of her need and desire to make the whole process of asking for much needed help simpler and more dignified for her family and all the others.

She is tired of feeling like a second class citizen who should be solving this on her own. She is currently recovering from her third bout of flu this year which has been a difficult time for the whole family, emphasizing their lack of other support.

## 72. Help Us Now

'the support for our special needs to give them the best life, like everyone else...'

First I had to pay out of our own pocket pay to get a school psychologist do as there was a short in people to do them. and my son needed more help at school.. Only for when the report came back to be told it was the wrong one and out of date. I then had to wait a year to get the school to do the right one this has now put my son back in his learning... He was re tested and now has full ed support, but it has 'only' taken 4 years.

As a parent of a child with special needs we need the support and funds now not in years to come i myself would love someone like a prime minister to spend just one day in our lives with our children and see what its like.

So what do i want like other parents? The support for our special needs to give them the best of life like everyone else.

## 73. Help Us Now

'We live a nightmare, trying to put the jigsaw together...'

Dear Premier,

I write to you for support to help others like me living with a child with special needs unknown to many.

This syndrome is a disability someone is born with, something they grow up with and have to live with all their live until they die, something no one can help go away as there is no cure. My son has a rare syndrome called Bardet Biedl syndrome (bbs). I know though my own work there is about 15 others in Australia with the syndrome. I like other parents live a nightmare trying to put the jigsaw together...

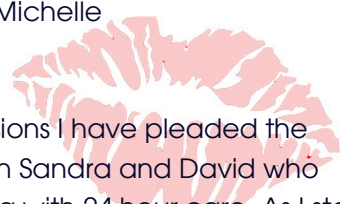
## 74. A Plea For Support

'If we are not funded in this next round we are in dire straits.'

The following is a desperate submission to Disability Services which we sent in 2008 after many applications for additional funding as our situation was critical. We finally received our funding after years of submissions and the children were at risk of losing their home and carers. I am sending this to make you aware of the struggle people with disabilities and their face without adequate funding support.

Re: Funding for Sandra Michelle and David Leslie Field

On two separate occasions I have pleaded the case for my two children Sandra and David who are in independent living with 24 hour care. As I stat-



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ed in my last correspondence our funding situation has reached crisis point but disability services has seen the urgency of the situation and not seen fit to grant an increase in funding. Our funding has not been reviewed in thirteen years and the funding applied to Sandra and David as a couple is even lower than that of an individual.

According to disabilities standards they deserve a standard of care which is their right but if something doesn't happen in the next round it will be dangerously compromised,

The option they have is ideal for them and for the whole family. They enjoy the best of both worlds with us living so close at hand and always available should situations arise which have happened on several occasions where carers were able to call on us for emergency assistance both medical and domestic. My husband does a lot of maintenance at the house saving considerable expense and the very regular visits and family get togethers are looked forward to by both Sandra and David. As I am becoming considerably more desperate and anxious of our situation I have approached my local member of parliament, Ms Margaret Quirk who has agreed to take up our case and who agrees that the situation is unsatisfactory.

I understand that there are many waiting for funding but I believe if funding is granted it must be reviewed and updated. It is very cruel to clients and families to give something once and then place it in serious jeopardy due to insufficient resources. I wouldn't be in your position for anything as I know the immense pressure our demands place you under, but please believe that if there were any other way out we would not be pleading for what I believe is only fair and reasonable.

Please consider our application favorably in the next round. I don't know how else to ask. We cannot afford to compromise their lives after all this time. As I mentioned in our last correspondence we aren't asking for hundreds of thousands of dollars, only enough to bring the option to an acceptable level.

When I attended the public forum on disabilities just

before the election the theme was 'catching up' and I was able to put my situation to the panel of politicians. Both the then minister for disabilities and the shadow minister for disabilities both agreed that our circumstances were not adequate and both stated that things should be resolved in the very near future. Please catch up what is already in jeopardy for the sake of my children. They deserve to have the life they deserve which is not unreasonable. If we are not funded in this next round we are in dire straits.

I look forward to a favorable outcome to my request. Michelina Field

## 75. More Pressure

'This would finally allow families to have confidence that they could access appropriate resources...'

I recently wrote to you on the 29th of March, 2011, about the unreliable nature of education services for students with an Autism Spectrum Disorder (ASD) in mainstream Western Australian Schools especially at the high school level. As you may recall, I am both a parent of a 23 year old son with an Autism Spectrum Disorder and educational researcher at the University of Western Australia (UWA) Graduate School of Education. In 2010 I completed a study investigating how West Australian parents deal with the education of their child with an Autism Spectrum Disorder over time.

My study revealed that government support services that were on offer to families from diagnosis and beyond were often confusing, fragmented and difficult to access in a timely fashion. Additionally, the quality and intensity of the funded programs offered often fell far short of what was needed to help maximize the progress of these children. Families were often burdened by the ongoing cost of privately funded therapies for their offspring with an ASD over the many years of their development so as to realize their best potential. These same concerns were previously expressed by the West Australian researcher, Sarah, MacDermott, in her 2008 report, Can you Help Us to Help You? Autism School-

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age Family Needs Report, regarding the needs of 92 Western Australian families who have child with a confirmed or suspected ASD.

Some early intervention, diagnostic and other support/education services have been provided through the Helping Children with Autism Package, but this federal initiative is scheduled to finish in 2012. The Disability Services Commission (DSC) Combined Application Process (CAP) and Family Living Initiative (FLI) funding packages also provide other potential support; however, families must endure a rigorous and competitive application process to access this funding. These application processes place even more pressure on these families who already experience very high rates of mental health problems and family breakdown. The overall difficulty of the lives of these families is exacerbated by the uncertainty that exists regarding accessing timely and appropriate ASD support services over a potential lifetime of need.

I urge you Mr. Barnett, to please listen carefully to those who are living their daily lives in the field. Unfortunately, your own experience and that of your advisors does not always capture the impact of disability on the child and their family across their whole lives. A scheme like the National Disability Insurance Scheme (NDIS) would provide certainty and security regarding accessing support over time for these families. This would finally allow families to have confidence that they could access appropriate resources over the entire lifetime of the individual with an ASD if it was needed.

Dr Jasmine McDonald BA DipEd MSpEd(Hons) PhD

## 76. No Support

'We receive no support from government assisted programs, except six sessions of OT that Medicare pays for.'

My name is Leah and I'm mum to Storme (15) who contracted HSV Encephalitis at 12 months. She sur-

vived, totally against the odds, but was left with an acquired brain injury from extensive scar tissue on the four lobes of her brain.

A typical day looks in our lives looks like this ; Get Storme out of bed - coaxing, pleading and at times physically supporting her to the bathroom, where we will undress her and put her in the shower, after two minutes of giving verbal prompts we then assist her out of the shower, for us to then dry her. In this time she is yelling abuse and physically lashing out at us. After assisting her to get dressed, we then prompt her to eat and remind her of the process until the whole meal is finished, this a task as she easily distracted and can have sensory overload from the smallest of things ie buzzing of the refrigerator.

By this time she is extremely agitated and making it difficult for others to get ready for the day, she gets verbal and physically violent. When her agitation escalates her ability to do the most basic of things goes out of the window and requires alot of input from her family to deescalate.

Then its on the special bus to school, if that happens to be a loud or busy time on the bus, it will then trigger Storme to have a bad day at school. More often than not, she will be unable to do a full day at school and will need to be picked up early, where she again will be physically and verbally aggressive. We then have to prepare food for her as if she was approximately 3 years of age again - little colour, mushy texture and more often than not actually feed her. We go through this process to try and get her to go to bed sometimes at 5pm so then her brain can rest and hopefully have a easier time when she wakes.

To understand why we find the above so difficult you have to understand the inconsistencies that Storme presents, some days she can take responsibilities for some of her own day to day care and other days not, so we never EVER know what to expect or anticipate. It's like meeting a new person every hour and never being able to plan.

We receive no support from government assisted agencies, except 6 sessions of OT that Medicare

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pay for. The problem is that Storme's psychiatrist and neurologist both agree that she needs intensive sessions weekly for the next couple of years.

It would be fantastic if there was a support agency that could have forewarned us of the kinds of issues that come from ABI particularly with adolescents and to assist us in parenting with different strategies and forward planning for Storme's future including vocation, personal development etc.

We have also experienced MANY Doctors/ Specialists saying it's not their expertise and they didn't know of anyone to refer us to. Add to that the amount of times that we have been told that there is no support or what there is so basic and minimal here in WA. We aren't even keeping up with other states in our country. I have recently been informed how well the UK govt deals with ABI from viral infection. Had I heard about it when Storme was younger we would have moved - Sad huh? that you have to uproot yourself to get disability support.

You know the thing that I ABSOLUTELY struggle with is the legal, mental and paperwork hoops that the "System" put you through for little or NO assistance.

This is a total waste of energies and the disabled person is the one that is left without any input from the "System" or their Carers.

That's why I want a better system.

## 77. Lynn's Story

'You would think I would be used to it (being let down) by now but each time it happens it is difficult to manage.'

My daughter who is thirty two years old has a severe intellectual disability and epilepsy. I have been her sole carer since her father left when she was thirteen.

I have been applying for accommodation funding for about ten years. Our need is not considered great enough. I work full time and

although my daughter receives ATE and IFS the amounts are not enough to cover her day placement fees and afterhours fees five days a week. My daughter's activity on Mondays doesn't start until 9:30AM which means I often don't get to work until 10:30AM. I have to make the time up and so now I get home between 6:10PM and 6:30PM. This means that there are periods of time when she is on her own before I arrive home from work. As the funding doesn't keep up with the increasing costs I can see that in the future this will happen for longer periods and on more occasions. This puts her at considerable risk. She is capable of opening the front door to a stranger but if there was a fire she wouldn't have the initiative to run from the house. Also when she has a seizure she often falls so there is also the risk of injury if there is no one to supervise her.

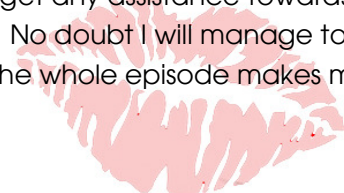
I can't afford to live on a carers pension as the house is still mortgaged.

After ten years I finally saved and organised to take a holiday overseas with my sister. I first applied, over a year ago, to a respite provider to see if my daughter could get respite for the period we had in mind. I was told yes. The holiday was booked and paid for and then last week, six weeks before I am due to leave I was told the respite provider doesn't have the funds to cover the respite for the full 27 days. My reaction - shock and stress. You would think I would be used to it (being let down) by now but each time it happens it is difficult to manage. A funded bed costs \$46 per night \$1242.00 for the 27 days.

I had applied to my LAC for help to pay this amount. The two nights that are now unfunded will cost \$800.00. The LAC has told me he can fund half of that and hopefully Commonwealth Carers might fund the other half.

However, now I will not get any assistance towards the remaining \$1150.00. No doubt I will manage to pay it off bit by bit but the whole episode makes me wonder if it is worth it.

Lynne Abbott



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## 78. Darrian's Story

'He had dietary and allergy problems, low pain awareness, high pain threshold, developmental delays...just to name a few.'



Hi my name is Di and I am a single parent to my son Darrian (15) and his older brother Nathaniel (16) and recently their baby sister Karra (2). We live in the small country city of Albany Western Australia. Welcome to a snap shot of my world of living with my Autistic son for the last fifteen years and battling the Department of Education and Training in Western Australia for the last Twelve years.

By 10 months of age Day care was questioning strange behaviours and unusual characteristics. By the age of four we had been through eight day-cares a mixture of Centre based and Home Day cares and finally gained RUCSN (Resource Unit for Children with Special Needs) help in funding a support worker for 20 hours a week whilst he attended fulltime day care.

Darrian started Kindergarten in 2000 with no support from the Department of Education. The first Kindergarten we went to for an open day he escaped

from after five minutes and they promptly suggested that due to this and the fact that he wasn't toilet trained that he wasn't developmentally ready to start. By mid year we had him attending a local Indigenous Kindergarten with 6ft high fences and a higher ratio of staffing for one 3 hour session a week gradually building to two 3 hour sessions by the end of the year even though the norm was four sessions a week.

Preschool was an adventure with my insisting on normal attendance but by half term the teacher insisted he have an extended long weekend, for the rest of term he attended three days a week. This was to be the pattern of attendance for the rest of the year. Subsequently this reduction in attendance time forced me to also reduce my available hours from my job.

During 2001 he was assessed by Disability Services Commission Autism Team and found to fall just short of the criteria required for a Diagnosis of Autism Spectrum Disorder even though by now we had Speech Pathologists, Occupational Therapist, Physio Therapists, Social Workers (DCP), GP, Paediatrician, Gastroenterologist, Psychologist, and Psychiatrist involved in Darrian's care. Darrian was suffering from Dietary/ Allergy problems, Low Pain Awareness, High Pain Threshold, Multiple Sensory Issues, Developmental delays, Self care issues, Poor sleep patterns just to name a few.

2002 and Compulsory Year one was a nightmare, behavioural issues became extreme and regular "Red Cards" (non suspension but school removal) were issued. Darrian was the subject of Staff and Student bullying and even cases of Staff Assault under the guise of Behaviour Management, exclusion and ridicule but little support from the School or Department was offered. Finding After school care or Vacation care was becoming increasingly difficult as his reputation was making its way round town.

In August 2003 aged seven Darrian attempted suicide as documented by his Paediatric Psychiatrist. Darrian's reasoning for this attempt was that "if I was hurt or sick then I couldn't be made to go to

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school" he was subsequently placed on Anti Depressants to help him better cope at School. Following this and the fact that no one was coping anymore the Department of Education provided him with 8 hours a week Education Assistant support. By year 3 this EA support had increased to FTE 0.5 equivalent to two and half days a week.

Life now was a constant merry go round of medical appointments, exclusion from school, IEP meetings, Therapists and search for a Diagnosis that would allow the Education Department to recognise his need for Special Education Support. By the end of 2005 and exhausted from constant harassment from the School principal regarding my "Naughty Child" I made the decision to move schools. In a town this "small" even that's not easy!

By now I was also pursuing a Discrimination Claim against the Department of Education through the Equal Opportunities Commission. Darrian's reading and writing was graded at approximately 4-5 years below his chronological age, he suffered clinical Depression, was still prone to suicidal tendencies, self harmed, had numerous behavioural problems and was socially and academically isolated at school.

This move had limited success because of the restraints placed on the school by the Education Department when it came to dealing with Darrian. By now Darrian had spent time in the Psychiatric Unit at Princess Margaret Hospital on numerous occasions to sort out medication issues so that he could better cope and attend school. By the end of 2007 I dropped my case against the Education Department as I no longer had the reserves to pursue this without serious adverse effects on my health, family and job.

Life up to now had been hard work and without the help of a few close family friends and a close knit family network I don't know if any of us would have survived. Yes both my boys and I were often at the edge and wondering if it was worth going on.

With the end of Primary school looming and the thought of sending him to High School plus the Education Department threatening to reduce his sup-

port time to FTE 0.1 or half a day equivalent we had to renew our fight to have some sort of diagnosis recognised by the Education Department.

In late 2008 aged 12 years and 7 months and after having spent over 2 years on a Health Department waiting list for re assessment of Autism I finally had Darrian reassessed by a private organisation as having Autism Spectrum Disorder. This diagnosis cost over \$2000 but when I received the letter from Disability Service Commission just before Christmas accepting the diagnosis it was a long awaited relief that I wasn't mad, a poor parent or simply had a naughty child but that my son was AUTISTIC he had a serious permanent disability.

Has life at High School been any easier since he was diagnosed? NO. The Department of Education wouldn't allow him to be enrolled in a Special Education Centre because he lacks an Intellectual Disability even though his WALNA score placed him well below the bench mark and even in some areas couldn't score him. With his extensive history of medical problems and ongoing mental health issues as well as the Autism the Department forced him into main stream schooling still with FTE 0.6 support (3 days). Darrian constantly feels excluded and deprived when he is removed from school/ classes to expediate school harmony.

Darrian has had numerous suspensions, red card days, request of not attending, and suggestions of day's home instead of sports days, excursions etc and regular mid term long weekends. What's changed? Not much!

Where to for my family now, well we are hoping to survive this week without a suspension or phone call home, and then next week the same and the one after that too because under the new laws Darrian has to remain at school until December 2013 and then when he leaves still unable to read and write above that of a six year old, with poor peer social skills, verbal communication issues and permanent psychological scarring from the trauma of been forced to fit in to a normal education environment we hope that he might finally find his niche in the real world.

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By the way I do get Carers allowance to help with my sons additional needs, but don't get any support from disability Services as without an Intellectual Disability he doesn't meet criteria, therefore no help with respite (ever), no holiday programs, no extra help with therapy or additional learning programs that may have helped over the years, Commonwealth Carers is a joke in our area as when ever I need help we still can't get it. Basically my family and I have had to do it tough and hard and yes I believe we are a stronger family for that but also recognise not everyone can survive this journey.

Our experience with the Education Department hasn't been all bad, along the way we have found some incredibly dedicated and committed individuals but never has the System accepted Darrian and his individual requirements.

By the way I am a High Needs Education Assistant and for the past 10 years have worked for the Department of Education and Training Western Australia.

Mr Barnett I challenge you to walk in my shoes for a while and see if you have the ability to still smile at the end of it and say the National Disability Insurance Scheme isn't needed in Western Australia.

Dianne Bailey

## 79. Liam's Story

'...Disability takes away so much choice...surely we deserve choice!'

MY 14 year old son Liam has Duchenne Muscular Dystrophy and stopped walking at age 10. He is dependent on us for all his activities, not even being able to scratch his own head! He wakes up to 6 times a night even with respiratory support and a high tech turning bed. My husband and I haven't had a full night sleep in 14 years. Apparently we are eligible for about 3 hours a week respite, but haven't had any in close to 2 years. At the moment we can't even get someone from our agency to respond to emails or phone calls. The last respite that

we had booked, the carer just "forgot" and didn't show up. I have had no contact from the agency since then. They say new mothers are at risk of many health issues including depression due to sleep deprivation, imagine what it is like when it continues for 14 years.

We have also had issues with our agency's "therapy". All the medical practitioners that we see (about 6 specialists in total) believe that we receive extensive physiotherapy and model their treatment around this. In fact we have had no "hands on" physio in years as our agency has modeled itself as a consultant rather than actual therapy. Without university volunteers we would have no help with daily physio at all. We are also not able to move to another agency as no-one else will deal with Neuro-muscular children.

We would love to be able to choose what therapies and help suit Liam and our family best, instead of having someone else make that decision for us.

Disability takes away so much choice. What house you live in, what car you drive, if you can work, surely we deserve the right to choose our therapy and help!

## 80. Far from Ideal

'Listen to those of us who have to struggle every day...'

I AM a mother of two children, one who is four and was diagnosed with autism two years ago. I was delighted to hear of the Autism Advisor Package, which would enable my son to access specialist therapy, or so I thought. I did note, this was funded by the Federal Government you are now disdaining, and not the State Government.

Turns out that the only way we could use our funding was to travel to Perth, a return trip of 1200km. Because I was desperate for my son to access the only solid help available to him, I lived in Perth for blocks of 8 weeks at a time, as there were no ser-

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vice providers where I lived. This meant separating from my husband, where he had no contact with his son for two months at a time. I had to stay with my mother, whose life was quite disrupted, because how could we afford accommodation for that period of time.

This went on for two years, until all my funding was used up. The separation to our family was quite traumatic, I wouldn't recommend it to anyone. At the end of our funding period, we remained in Kalgoorlie to find that any therapy available through the hospital entailed a waiting period of two months. To access private therapy was beyond our means. How were we to maximise the ghastly period of therapy we were able to access in Perth??

The system is far from ideal here in WA, whatever you have today. In the end our marriage broke up, because of the extended periods of separation, and now I have a lifetime of raising two children on my own, one with a disability that persists for the rest of his life, and that I am unable to fund even less than I could two years ago.

Put your political aspirations and ascendancy aside, and listen to those of us who have to struggle every day. There is a way forward for us, and that is the NDIS.....don't stand in the way of it....we need it desperately!

## 81. No Label

'We have to wait two years for another assessment unless we wish to pay for it.'

I live miles from Perth. My son has been classified as having an intellectual disability, but has not been diagnosed with a specific label. Therefore we are unable to access services for him, although it is clear he is struggling in school, and has difficulty coping. I have been told we must wait two years for another IQ assessment, unless we wish to pay for it. Good luck with that, we live on less than \$50,000, we do not have that type of income.

My newborn daughter now 13 weeks old, failed to be diagnosed with a tied tongue, now she is too late for the corrective surgery, and I have had to drive to Perth, with my two older children, with no funding, no assistance, to have her diagnosed. You might argue this is a health issue, and not related to the disability sector, let me inform you that disability assistance and health services are very inter-related in the country, we don't have the luxury of specialists. Because of that failure, I now am stranded in Perth for four weeks, away from my husband, my children's schooling has been interrupted, and we have developmental difficulties with our baby daughter. I don't care what you say, what we can access here is pitiful, so say the least.

Getting back to my son with his undiagnosed disability, we can only access graduate therapists and locum therapists who are here for 2 months max, and there is no clinical continuity or support. An NDIS will help resolve those issues, so I have an issue with the government, saying that everything is just dandy. It is not!

## 82. No Best Practice

'There is plenty of scope for improvement.'

I live in Kalgoorlie, I have three children, my eldest is 12, and diagnosed with autism. My husband is a mine manager, and thank God, he has a matching income, because without that we would have been screwed. My child was diagnosed nine years ago, and whilst I have a good relationship with my local LAC now, that was not always the case, we have had to pay privately for ALL therapies, and ALL interventions, which has helped our son reach some of his potential.

You state we have the best disability system in the country, it may be true that we have it better than some States, but I can assure you it falls far short of best practice, there is plenty of scope for improvement. The NDIS will be a unified, national ap-

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proach with out borders, and I believe that this is what our country needs. Your precious system does not provide what we need, and I am very angry that you feel you have the right to speak for us, when we hve not been consulted.

I lie awake at night, wondering what will happen to our boy when we are gone....the NDIS will give me the assurance that he will be taken care of, when we are pushing up daisies. You, Mr Barnett will be long gone after our family are still struggling to find the best for our child. I suggest you talk to people who have some experience in the disability life, before you claim that everything is just OK here in WA .

## 83. This Life is Forever

'My child is ill, very ill...they hand me a photo of a small blue bundle.'

SO young. Both of us so young to be parents, and no one really to guide us.

His parents drunks, and mine away. We only had each other, and then a baby girl.

The next child would be a boy, wouldn't it? I make blue booties, he buys a football. We look at the small marks on the ultrasound and wonder and hope, then paint the room blue in a foolhardy moment of hope and joy.

When the moment comes, we pack the booties, drop our daughter at a friends, rush to hospital, grinning foolishly at each other. It was to be the last time we'd grin like children, for a very long time.

That moment of pressure, then release - but no cry from our child. Concerned murmurs from staff, me craning my neck forward to see why they were crowded around our baby. And why was he so blue? Trying to sit up until a nurse pushes me gently down. My husband, white, silent, looking grimly at the crowd of faces around the team, who are working hard over his tiny body. Then movement as they bustle out with a humicrib and dangerously frightening equipment, leaving me alone with a nurse.

I am cold. My husband has gone with them and I do not know where my baby has gone. I do not feel the stitches and I try to wrench the drip from my arm, try to escape to be with my child. The nurse restrains me and murmurs comforting words, but I hear nothing.

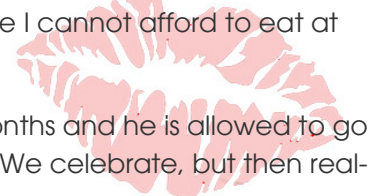
Later, they tell me. My child is ill, very ill. They will take him away, but I must stay, because I still need medical attention. They have taken him already and they hand me, cruelly, a photo of a small blue bundle lying palely in a humicrib. A nurse gives me a breast pump, and shows me how to use it. Important, she says, in case we are able to feed your child. And they leave me, clutching the photograph, in a ward full of new mothers who stare curiously at my pale face through the curtains.

The next day I walk out against medical advice. I call a taxi and rush to the neonatal ward. My husband is by his crib, saying little. We hold hands, children ourselves. It is terrifying.

And then we start our journey. Our child must stay in hospital for almost six months, but who will look after our other child? We had rent to pay and he could not afford to take any more time off work. By day, he worked and our daughter stayed in the child care centre at the hospital, whilst I stayed by our boy's bedside. By night, he picked up our daughter and I slept in the recliner rocker beside his bed.

They tell us that it is not going well. That our child has severe epilepsy, and they are not sure what else. They do tests, almost daily. When they do the lumbar puncture, I bite my hand hard to stop myself crying, because I cannot watch my boy in pain any more. Every three or four hours, he starts convulsing, and they rush to make him stop. And there is no diagnosis, and no help. No one comes to see us until one day, three months in, a social worker notices that I am making vegemite sandwiches in the ward for dinner because I cannot afford to eat at the canteen.

Our boy is almost six months and he is allowed to go home for the first time. We celebrate, but then real-



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ity sets in. What will we do to care for this child? He has disabilities but none of them are diagnosed. More tests, but they reveal little. We don't fit into any boxes. Our daughter cries fretfully all the time because she has so little attention. Our boy is stolidly silent, unlike other babies, until a convulsion sends us back to the hospital.

I sleep, not with my husband, who must work, but with my fingers entwined around the bars of his cot. I'm often afraid to sleep, for fear that the boy will start to convulse. I used to be a heavy sleeper and we used to joke about how a bomb could go off and not disturb me. Now a butterfly light touch will bring me awake in a second and I leap to my feet. Every day there is a convulsion and every day or two we are at the hospital or at the doctors surgery or going through the process of yet another test with yet another dough faced neurologist with no bedside manner. And our child, heavily medicated, starts to lose the few motor skills he had developed, and develops a far away stare, looking into a future we cannot see.

I am cheerily optimist. He is pessimistic about our child's future, so I start to research everything I can about my child's condition, searching for a diagnosis. I ring agencies, who tell me I do not belong with them. I ring information lines, who give me yet another number. I make hundreds of phone calls and nobody has an answer for me.

One day, I spring awake, terrified - the cot bars are shaking and I have the boy in my arms and I am running to the telephone before I realize that the whole house is shaking. It is an earthquake, a tremor. I sit down with him cradled to me and wait for the shaking to stop. The house stops, but I am trembling almost as badly as the boy does during a grand mal seizure. The worry - he could die, this could be forever. And finally, when we come to the realization that our dreams and hopes are gone forever, that this boy will never kick the football, that he will never be the boy we hoped for...the grief comes, and then the guilt, because we love this boy desperately, the way he is.

Ten years ago, no help, no funding. Ten years, but it only took five for our marriage to fail. This life is forever.

## 84. Crisis Point

'She was subsequently diagnosed with Huntington's Disease.'

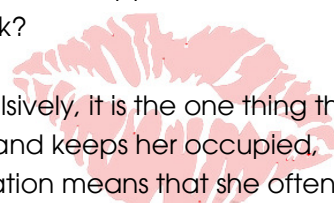
M and I have been best friends for about 20 years, M is 63 and I am 65 and we currently share a home in a regional WA town.

Two years ago I noticed that M was showing unusual behaviour and symptoms and she was subsequently diagnosed with Huntingtons disease . Since then I have slowly but surely become a Carer as M has deteriorated, starting by assisting her with little things then helping her with things like dressing properly to the full support I am now trying to provide her. During this time I was left in the lurch and struggled to get the medical help M needed. Trying to get her the Disability Support Pension was a very difficult and tiring time.

Eventually, when everything became too hard for me to cope with I finally sought some help from our Disability Services Local Area Coordinator. A CAPS Application has been put in for us but as M is 62, and the cut off age is 65, the LAC said that they will probably reject it and refer M to the Aged Care Assessment Team as she will be 65 in two years. I couldn't believe that I had to apply to one system in the knowledge that we would be rejected before I can apply to another system that may or may not help us.

Whilst I appreciate the LAC putting in this application for funding for us we really cannot wait three months for the application to be rejected and then wait for the ACAT assessment etc. to happen. I have told DSC that M is not safe living here anymore as I have to work shift work and M is at the stage now where she chokes on her food, often turning blue until I bang her on the back. I worry constantly about what would happen if this occurred while I am at work?

M chain smokes compulsively, it is the one thing that she gets pleasure from and keeps her occupied, but her lack of coordination means that she often



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drops her cigarette, burning herself, her clothing and the floor beneath her. We have had many small fires start but luckily I have been home at the time. The risk of a fire is huge and although we have smoke alarms in place I worry that M will start one while I am at work and in her panic not know what to do. I worry about her every moment I am at work and wonder what I am going to come home to every day/night on my way home from work.

I recently had my first short respite break, with support for M being provided by a local disability service provider. I didn't know that this was available until I had reached the point of collapse and despair.

Through contact with this service provider they made me aware of other services that could support me in my caring role. Things like the Companion Card, ACROD Parking, a Seniors Card for myself, Fuel Cards, Mobility Allowances, Carers Allowance and referral to other organisations that could offer me support and counselling.

Only through the service provider did I find out about these things to assist me and M. I feel that I should have been made aware of the assistance available to me when M was diagnosed two years ago.

If I had known about them perhaps I wouldn't be in crisis, about to collapse and looking for a nursing home to move M into. I am simply worn out myself and cannot continue to care for M.

I am now waiting to see what the outcome of the CAPS process will be in three to four months time, struggling along and hoping for the best while we have to wait for a process we know will fail so we can move into another different system that will hopefully support us.

If we had an NDIS I know that I would have been made aware of the assistance available to me all along, rather than having to wait for me to reach a breakdown, crisis point and for a not-for-profit charity to come along and let me know what help I can get.

## 85. In Binnu

'We were sent home none the wiser, even more concerned'

My name is Clara Harris. My husband Damian, Sam who's almost 12, his sister Sophie who's almost 5 and I live on our farm at Binnu, 50km North of Northampton, - 100kms from Geraldton and 550kms North of Perth. We crop about 6000 acres with Wheat, Lupins, Barley and Canola, leaving a paddock on which we run about 20 head of cattle.

Sam's story and our family's journey into the uncharted waters of Autism started back in August 1998. A visit to the doctor three weeks before our first child was due to arrive confirmed a babe in breech position. We were referred to an obstetrician who attempted to turn said babe around, but being a determined little thing even at that stage, wasn't going anywhere. Knowing it was a babe of decent size and with a big head, we were given a choice of being induced the next day or coming back in a couple of weeks for a caesarean. Being terrified, naive & to be honest, being made to feel a bit like a Caesar would be taking the easy way out (Believe me - it would be a different decision today) we made the decision to go back the next day to be induced. After a relatively good labour, all things considered, Sam Patrick Harris arrived, bum first, just after 7pm on a Friday night.

He was the perfect baby, 7lbs 11oz, contented and happy from day one. He slept through from 6 weeks old, was very loving and affectionate and melted your heart with smiles, giggles and his beautiful blue eyes. Once he reached 18 months though, things seemed to stall. We just knew that something wasn't quite right. His only words were 'who's that?', when he saw himself in the mirror and 'Deb...ra', the ABC newsreader who joined us in our lounge room every night. There was no 'Mum', 'Dad' or 'Sam'. No 'Drink' or 'Up' or any of the things that the other kids his age were saying. We ended up giving him his food (his total diet being toast, cruskits

# the OTHER 100 conversations

and chips) on square plastic lids as a round plate was immediately turned into a spinning toy – food overboard! Any cupboard doors were an opportunity to bang them loudly, playing open and close over and over again. We would sit in amazement, watching him sit and concentrate for up to an hour with his jigsaw puzzles or watching tapes of Wheel of Fortune, mesmerized by the lights, numbers & spinning wheel.

Whenever Damian and I raised our concerns with anyone, we were quickly dismissed with 'it's just a phase – he'll grow out of it', 'don't compare kids, they all do things at different times' and, our number one, all-time favourite, 'he'll talk when he's ready, my boy didn't speak until...'. Being first time parents didn't help our cause, we knew everyone meant well, and that they were trying to alleviate our fears, but we knew our little boy, and we knew that something was wrong. Looking back, Sam was displaying text book, typically autistic behaviour at 18 months old and if a health professional within an Autism field had have seen him, we feel sure they would have known immediately.

We drove to Perth and saw a paediatrician when he was 2. He underwent a cat scan to rule out a brain tumour due to his large head size. This showed nothing untoward and we were told that he was 9 months behind in his development but no reason was given for this and we were sent home none the wiser, even more concerned.

I had been taking Sam to see Kathryn, a Speech Pathologist in Geraldton. He hated these sessions and would begin to scream when we got to her front door. It was so hard to drive a 2 hour round trip and put him in a situation where he was so distressed but we had to give it a try. After a few weeks of torturing him & everyone within earshot of her office, Kathryn offered to come and see Sam at my parents' house in Geraldton where he was lot more comfortable but still not happy. I remember Kathryn one day telling Sam, "I know that you don't like me Sam, but I love you and I'm going to help you." In the November I asked Kathryn if he could

be Autistic, based solely on a curious interest I'd had years earlier after seeing Rain Man and The Boy Who Could Fly. Kathryn referred us to a paediatrician specialising in Autism at Disability Services in Perth. At the end of January, telling everyone that we were seeing a paediatrician and not mentioning Autism, we made the trip to Perth looking for answers but without a clue of what we were in for.

A couple of days later we were in the paediatrician's office. Early on he briefly left the room to get Sam a puzzle and Damian picked up a pamphlet from the side table. The pamphlet had a heading of 'Autism is Not Always Visible' and showed stick figure illustrations of typically autistic behaviour. Damian's jaw dropped as he said, "Clara, this is Sam." At the end of the visit the Doctor told us he was fairly certain that Sam had Autism, gave us some photocopied sheets of information and told us a psychologist and speech pathologist would be up to do a full assessment of Sam in the coming months.

That was it - no offers of counselling, no follow up phone call in a couple of days to see how we were coping, nothing. Our lives had just changed for ever and we were 500km away from home and left alone to deal with it.

We were in complete shock as we drove back to Carolyn's house. We spent the night lying on her lounge room floor, reading and rereading the pamphlets, cuddling Sam and crying. We decided we would wait and tell everyone face to face when we got home rather than over the phone. It was so hard when they rang to see how we had gotten on that day, as we lied to them, saying we were waiting on test results and would find out in a few more days. The worst part of **that** was that it tricked our hearts and heads into thinking the same thing.

We packed up and headed home, calling in to tell our parents and brothers and sisters on the way. We had photocopied the information for everyone to read. We sat Mum, Dad and my Grandfather down

# the OTHER 100 conversations

and told them we were almost certain that Sam was Autistic. I'll never forget my Dad looking at me, saying, "But what does that *mean*?" I managed to get out the words "life long," before I broke down. Wanting to comfort them but desperate to get home, we got back into the car, leaving our bewildered family in our wake. We were all exhausted by the time we made it back to the farm. Damian and I just watched Sam climb out of the car and walk off into the 'space' of home. In January our home is hot, surrounded by thousands of acres of dry, dusty, open paddocks, and to some is a fairly inhospitable place, the three of us just stood there and soaked it in.

I went inside to phone the family we had just left to see how they were fairing. My Mum told me they hadn't stopped crying since we'd left and Dad had vowed to teach Sam everything he could. We knew that our family would be right behind us, whatever we had to do. We then rang our closest friends and were met with stunned silence on the other end of the line. "What can we do?" they asked. Sam has always been such a gentle, likable little man, as we started to let everyone know, we were inundated with offers of support, help and love.

A couple of months after the formal assessment had been completed, the really tough stuff began. We were given a list of 4 service providers in WA and were advised of our government funding situations. 'But', we were told, 'you can't access any of these service providers for 6 weeks as you must take your time to look through what their programs have to offer and you need to take time to grieve'. AAARRRGGGHHHH!!!!

We had started this process in June the previous year, had been almost certain Sam was Autistic in January, had the assessment with the psychologist and speech pathologist in March and here we were in May being told to sit and ponder for another 6 weeks. Nobody seemed to notice that we could only access one of the service providers anyway, as the others didn't operate outside of the metropoli-

tan area! It was an abysmal, soul destroying period of time. We were desperate to get things happening straight away and we felt like we were wasting precious time with red tape. I sadly (especially considering my current location & lift home) remember the day our **then** LAC was sitting at our kitchen table going through all the paperwork and telling me what different forms of therapy were available and may help Sam. As Damian was working and I was trying to take all of the information in, I became so overwhelmed and just bowed my head and began to cry. The total sum of support I received from her was a tilt of her head, a sigh and an 'ohhh, it'll be ok", from the other side of the table.

Sadly, I know many people would be envious of what we considered too long to get things started. Some of the waiting list stories I've heard in the last few years, are just plain horror stories.

## 86. The Olney Family

'...a highly disjointed, underfunded, dis-organized health and disability system'

### RE: The Martin Olney Family

Sit back and relax (if you can) while you take a brief journey into our life. We are:

**Martin** Olney (D.O.B: 28/1/1967) Asperger's(undiagnosed)/Sleep Apnoea/Depression

**Thea** Olney (D.O.B: 24/3/1971) Scoliosis/Chronic Pain/Depression

**Sam(uel)** (D.O.B: 15/12/1994) Asperger's Disorder/Profoundly Gifted/Anxiety

**Rachael** (D.O.B: 1/2/1997) Gifted - academic, art, music

**Jackson** (D.O.B: 15/4/1998) High Functioning Autism

**Max** (D.O.B: 9/7/2005) Autistic Disorder



# the OTHER 100 conversations

## The Children

After the birth of Sam (Dec 1994) at 35.5 weeks gestation, I had mild/moderate depression, un-medicated, which I contribute to severe sleep deprivation. Sam had a urinary tract infection which remained undiagnosed for over three weeks, despite my continued insistence that there was something wrong. I eventually received psycho-therapy, through church funds, where it was also discovered that Martin had a memory disorder of some kind. This seemed to be consistent with ADHD. Sam remained a very colicky baby to say the least, first sleeping through the night some time after the age of two. I had begun to investigate ADHD in Sam well before this age. His behaviours escalated and I was not eligible to receive help from the Positive Parenting Program at 2yrs because it was for 3yrs plus. I had to purchase the text that the program was based on and studied it myself. I felt it was that or kill him!

Rachael's entry into the World (1997) proved to be uneventful, apart from initial complications of pre-ruptured membranes at 33 weeks gestation with hospitalisation until her birth at 34.5 weeks gestation with three days in KEMH Special Care Nursery. She was an easy baby.

Jackson (1998) (unplanned), born at 39 weeks gestation (following advice to stay off my feet from 32 weeks) was a difficult baby and toddler. I endured this quietly as I was now well experienced by Sam with undying patience and great skill in coping with sleep deprivation, severe and constant negative behaviours and multiple tantrum throwing, etc. I had read a lot of books, been involved with the State Child Development Centre for assessment and treatment of Sam's fine-motor skills delay and visited a paediatrician well north of the river about his behaviour. I had developed many specific relaxation and coping skills on this journey and remained unvalidated with my difficulties. Jackson was not nearly as challenging as Sam! Besides, I had been told that Sam was fine and it was just me. Maybe I was just better with girls...

Sam was diagnosed with ADHD at age 4yrs (late 1998) by developmental paediatrician, Helen Frearson. A part of this process involved administration of an IQ test, where it was discovered that he was profoundly gifted, all results falling in the superior range.

A few years later (2000) I had significant pain/fatigue/depression. I was medicated for the first time with 10mg doxepin and 100mg sertraline, both anti-depressants having effect with pain. I attribute this to the challenge of raising two difficult male children as well as another child with the addition of a pain condition. Also, Martin desired to be, but was not, a great support. This was frustrating and confusing.

Helen Frearson mentioned Asperger's Disorder when Sam was nearly 7yrs (2001), but said that a diagnosis would be unprofitable as he would not receive any aide time at school. I had no question in accepting her advice. She was an expert. I did not understand what Asperger's Disorder was and she advised me not to rush home and stress myself with an investigation. Normally I would anyway, but for some reason I was obedient to her advice. I did not have a computer or internet access. I was very busy with children at Kindy 4 half days per week over two years. Ritalin was first trialed for Sam.

At age 30yrs (2001) I discovered from a waiting room brochure that my physical problem was called 'chronic pain'. I then sought help for this and went to the Fremantle Hospital Pain Understanding and Management Program (PUMP). Learning about this condition and carrying out regular walking, stretching and strengthening exercises combined with the use of regular relaxation exercises changed my life and I was able to come off all of my pain and anti-depressant medication. The children were all of school age.

I had never been able to work as schooling was always problematic with Sam, involving parent interviews and almost daily interactions with the classroom teacher/s. I needed to be on call in case of melt-downs. But I was able to attend the gym regularly now. With no diagnosis I received no support

# the OTHER 100 conversations

form Education Department, Centrelink or any other agency. I received no advice on how to manage Sam despite my constant seeking.

By the time Sam was age 10yrs (2004) I was tired of the significant negative effects of Ritalin on Sam (meltdowns and aggression on the 'downer') compared with the minimal positive effects (neater hand-writing, minimal increase of concentration in the mornings). He was on a tiny dose as I kept halving it, so I eventually stopped it altogether.

Helen Frearson informed me that 'these children usually get to high-school and decide to settle down and get on with their work.' "I think he will be fine". Optimistically, I assumed she would be right and that this would apply to Sam.

With renewed zest for life from my pain condition being under control, and the news that Sam would be fine, I enrolled in and commenced a Bachelor of Psychology at Curtin University part-time (2004). I also begged Martin for the opportunity to 'somewhat enjoy having a baby'. Others seemed to have better experiences with parenthood and I wanted us to have that chance. Only having one baby and having three older children to help might even make it fun this time. And as I was healthier than ever I may not get as sick as I had for the other pregnancies.

I had a tubal ligation reversal (Sep 2004). I completed one unit in Psychology at University Semester Two 2004.

I became pregnant in January 2005. I completed another unit at University, despite the hyper-emesis (excessive vomiting) consistent with all my other pregnancies, and attended my exam with an ice-cream container!

In May 2005 I developed severe pre-eclampsia, undiagnosed for over two weeks despite two hospital interventions at Fremantle and Woodside Hospitals where I was sent back home very sick and with high blood pressure, with either doctor at Femantle or Woodside checking a urine sample, and quite frankly would likely have had grounds to sue both of them except that I did not have the time or energy.

Max was born at 29 weeks gestation (July 2005) and spent eight weeks at KEMH Special Care Nursery (SCN). His stay was uneventful. Following discharge he had significant feeding issues and two cases of hypothermia. I went back onto sertraline 50mg as life was stressful and there was no way I could get out of the house to exercise. I did try but ended up wasting most of my gym membership. Daily physiotherapy for Max due to his 11 week prematurity was to become a part of my life for the next 12 months.

Max went on to become an extremely difficult baby, measured by KEMH SCN follow-up program survey. The lady in charge of the program actually rang me as she was alarmed by Max's survey score. She discovered that I was very experienced and seemed to be coping okay. However, his sleep difficulties and constant high-demand behaviours continued and worsened and soon I was not coping and received temporary support through Red Cross, to which I had to pay a contribution which left us very financially uncomfortable.

I deferred from University and grieved the loss of my expected dreams. My husband continued to study part-time for another semester before deferring. He has transferred his Graduate Diploma goal to a Graduate Certificate.

I was very busy and quite tired but determined to push on and provide my children with extra-curricular activities such as gymnastics, swimming and movies, as well as pay for school camps and excursions. I took on a 3 year old toddler as a private babysitting arrangement to afford these activities whilst Max was two years old. This was going well.

Sam hit high school. Oops, I had had too many children.

I cannot bear to record the devastating effects this had on him and our family at this stage. Perhaps I will talk about it with you at some future meeting. Suffice it to say that Applecross SHS did a dreadful job at catering to his needs despite my attempts to help prepare the school for his transition and commencement at the school for 2007. It was a night-

# the OTHER 100 conversations

mare. Sam had clinical depression and anxiety by week 5 of first term and would pace up and down our very long driveway howling and moaning a most devastating cry. He also began to whole-body rock for the first time ever on our queen size bed. He was a pretty big kid by now; taller than me. He commenced on the anti-depressant fluoxetine. He was trying very hard to attend school but kept having panic attacks just before it was time to leave in the morning. I have extensive records of the dreadful process should you desire to see them. My pain symptoms slowly crept in, despite regular listening to relaxation tapes. Life was horrible and I spent hours on the phone and at meetings with two toddlers and often a broken teenager. These involved various school staff, Fremantle-Peel District Office staff and Centre for Inclusive Schooling staff.

I begged Helen Frearson for the Asperger's diagnosis. The school needed it for the additional funding from Schools Plus in order to supposedly support him. I desperately needed the validation. She reluctantly agreed.

I now had a computer and the internet (thanks to my University enrolment back in 2004) and the World at my fingertips. The more I researched the more angry I became with Helen. I had raised a child with an Autism Spectrum Disorder with no support; no validation, for all those years. My World was now open to other parents with ASDs through the parent support group Autism Solutions, as well as to Sam's beloved speech pathologist, Kathy Ziatas, and the invaluable communication skills group which she offers. Sam's World was now open to other kids like him. He was no longer alone either. I now had the answers to all those unanswered questions over the years. Sam received his diagnosis and I vowed never to speak to Helen again. I was hurt.

I learned that if you have one child with autism it is likely that subsequent children may be more severely affected by autism. It is often genetic. I began to understand my husband better, recognising his Aspergeric/autistic features. I learned about Cassandra Syndrome, the Greek mythology about Cassandra's curse that whatever she said no-one would believe.

I had been Cassandra. People just hadn't listened nor understood.

We have always been on the border of the low 'socio-economic' group, partly due to Martin's inability to progress in the workplace due to his communication difficulties and partly due to my inability to work outside the home, but with my at-home babysitting job and some after school guitar tutoring I was able to have Sam assessed privately to speed up the process. I was given the run around by the Medicare system though; with all their item number and referral requirements to be eligible for rebates associated with the Team Care Arrangements and Mental Health Plans or whatever they were called back then. Both parents and professionals are still unclear as to the confusing process. I did not get back everything I was entitled to as I was too tired, busy and confused to follow it up in the end. It was all extremely stressful, to say the least.

I did the whole Centrelink thing and began to receive Carer's Allowance for Sam. More stress, but a bit more money at last. This kid had always been so expensive to raise. I realised I could have been receiving this for about the last five years at least.

Max continued to be difficult and I watched his autism symptoms creep in.

Sam was now a complete mess. Of course Jackson was a bit odd too. He never seemed to listen. What would the future hold for him? And now Max. Super!

I began the diagnostic process for Max. More stress. All over again. A new paediatrician this time; Dr Richard Christie. All the appointments with GP, paed, speechie, psych; all the referral letters, bills, item numbers, Medicare runs, wrong item numbers, more appointments and phone calls. It just went on and on. Centrelink again. Then I found out about Carer Payment. More Centrelink. All while Sam was suffering high anxiety and school refusal and the school were not supporting me at all. In fact they were not so nice. And all with two toddlers, one with autism. And being at Centrelink is an ordeal in itself.

# the OTHER 100 conversations

The mining boom took hold with accommodation shortages, and rental prices sky-rocketed (late 2007/early 2008). We had to find cheaper accommodation. I contacted Department of Housing to discover that we would probably qualify for Home-swest housing, but that we could not specify the suburb we needed to be in, and the waiting list was long. I explained my desperate situation but it didn't seem to matter. I could not be transferred through to the man I had been recommended to contact. We didn't really know what to do about Sam's schooling, but we knew we could not live in a typical low socio-economic area as our sensitive boys would not cope.

At the eleventh hour (March 2008) we found a private rental house in Canning Vale and jumped at it to avoid living in a tent in my in-laws backyard. I lost my job with the little boy.

Sam left Applecross SHS and on his last day at the school I received three letters of concern in the mail from three teachers at the school (they obviously didn't know he was leaving) stating that Sam needed to put in more effort, display a more positive attitude (he had depression), focus, pay more attention and complete homework; the very weaknesses I had been outlining to them and requesting support for over the past 12 months. I was infuriated by this and requested an apology. I got a rather pathetic, shallow one in writing from the principal.

Sam was enrolled in the Autism Extension Program (AEP) at Canning Vale College. This went quite well with a slow re-entry process and things picked up until he was bullied in Term Three (2008). He was pushed off his bike and kicked in the stomach. He was punched in the stomach. He was threatened with a knife. He began to stay in the AEP home-room 100% of the time. He would not go to recess. He secretly obtained a knife from an old friend and began to take it to school until he was caught. The knife was confiscated and he began to school-refuse again. He no longer felt safe without the knife. The panic attacks had all returned. He started to reveal his bullying incidents. We were back to square one. This time not because of the staff but

the students. More and more and more meetings, phone calls, a stint with a Murdoch University psychology student who, along with her supervisor, had no clue about Autism Spectrum Disorders and treated me like a weak mother with an out of control disobedient teenager. This poor intervention damaged Sam's self-esteem further. Sam was going to school spasmodically and would not leave the home-room.

Some time during Year Ten (2009) I got tired of all the effort. I now had a three year old with autism and all this unpredictability was un-nerving to everyone, especially Sam and Max. I gave up and stopped sending him to school. It was making Sam so miserable. The school meetings were treacherous for me and I bawled the whole way through them. There was no answer. The AEP teacher had a light load for a time and was able to come to our house for two to three one hour sessions per week for some months. His Maths program was kept up to date and he continued to struggle through English. The teacher's load increased with the introduction of a new boy to the program and the home-visits ceased.

I was forced to abide by the law and to get my son to the school grounds. We arranged a week of leave for Martin to help me get Sam into the car and off to school. I gave permission for the staff to physically drag him from my car to the class room if necessary. I made the school promise me they would allow him 100% of his time at school to be in the home-room.

This was going reasonably well. The school attempted re-entry to classes but could not get Sam into a room for more than a one-off occasion despite many strategies with support from the school psychologist. His anxiety again increased, until they gave up on their attempts. He was attending one day per week at Hillside Farm, but when the group of children changed, he did not cope with the 'quality' of the new group of children and began to refuse attendance there. He is also hyper-sensitive to touch and could not stand the feeling of rain on his skin over the winter months.

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In October 2009 I was informed that the AEP support would cease at the end of Year 10 and that Sam must attend mainstream classes full-time for Year 11. Oh, my goodness. That was not going to work. A poorly delivered, somewhat negative, Person-Centred Plan took place at the school, where it was decided by all parties that CVC was not going to be appropriate for Sam for 2010. I began an extensive and exhaustive search for a suitable place for him to attend school and thus satisfy the law. He was not ready for TAFE or an apprenticeship. Education Support Units only took students with intellectual disability. Alternative Schools such as Montessori in Burswood and Kids Open Learning School in Maylands were not keen to take on Sam with his package of high needs. He was no independent worker!!! Armadale Christian College was too far away and too expensive. Other adult programs such as ALTA 1 and VIP Plus only delivered the Certificate of Graduation in Education for Adults (CGEA) ie the equivalent to Year 10 Maths and English only. These would not be appropriate either. Sam finished Year 10 in December 2009 with pass marks for Maths and English only. He is profoundly gifted. What a waste.

In contacting VIP Plus (Nov 2009) I discovered that the lady on the end of the phone was in my exact situation, and in fact, it was her son who was the new student to enter the AEP at CVC some six months earlier. We exchanged email addresses and began to come up with a plan of what our boys needed. We met. We created a website [www.springboardcafe.org](http://www.springboardcafe.org) of our dream. We are trying to set up a Registered Training Organisation for children who have or will fall into this gap like our boys have. It has been a slow and difficult process.

In December 2009 Autism West informed us that they would take us under their scope of services, offering us a base for our home-schooling and our work on setting up our 'school'.

## THIS YEAR

### Term One

We wrote our boys term plans, satisfying the Curriculum Framework requirements.

Two volunteers commenced to teach them while we began to apply for grants. Got a small one for a homework group, but not the big one that would have got us a wage.

Re-did the PCP with Margaret and Kathy Ziatas at no cost to me (because Kathy is too lovely).

### Term Two

I paid a tutor \$100pw for 4 hours qualified High-School Maths and Science teacher. I have no idea where I got that sort of money.

Speech therapist every second Monday morning at no cost to me except to colour in and make cardboard boats etc. (because Kathy is too lovely).

I then discovered that perhaps I had been under-supported by my LAC at DSC, who constantly said there was nothing she could do.

### Term Three

We tried Sam and the other boy at TAFE.

Max was at Beckenham Autism Unit Monday to Thursday 9am to 12pm. I felt that I may have had to stop this as the hours were too restricting on me and my attempts to meet Sam's needs.

Max was also at Kathy Ziatas speech pathologist's 'Friday Fun' group 9am to 12pm and Autism Association's Early Intervention Program 'Star School' Fridays 1pm to 4pm.

Rachael was in Year 8 at Perth Modern School in Subiaco.

Jackson was at the local primary school and was accepted into the Applecross SHS Gifted Art Program for Year 8 2011, but I was preparing to pull him out as soon as he showed any sign of distress. I felt that if we moved house to be closer to our other needs I would need for the local high-school to be a good one.

None of this is my fault. It is not in my nature to play victim or create drama. I am intelligent. I do not drink alcohol or take any illicit drugs. I am an optimist. I take responsibility for my actions. I do not take blame for other people's actions. I am proactive. I simply didn't think to have Martin undergo genetic

# the OTHER 100 conversations

testing before we decided to have children together!!!

I have a high resilience and ability to cope with high demands over a long period of time. I have a sense of humour. But honestly, I got to the stage where I was completely over it. I was one of the few lucky ones who was granted the CAP application as I was ready to drop my kids off at DCP or drive over a cliff with them all.

I do not have the time to continue with all the details of the three years Sam was enrolled at high school and the true nightmare it was for my family. External organisations let me down repeatedly. I attribute this to a highly disjointed, disorganised, underfunded educational, health and disability support system. I live it. I am well acquainted with it. It is a mess. I wish I had the time to continue to elaborate, but would be happy to discuss with whoever wants to know.

Thea Olney

## 87. Anthea's Story

'A 'fair go' for our children/young adults with disabilities.'

Mr. Barnett,

I am writing to you to reconsider your stance on Disability for children whether it is an State problem or an Country problem. It is a world problem with many families effected daily.

All these children grow up to hopefully have a place in our society. Intregation and acceptance are important and the burden of life after the parents have passed is always in our minds.

We (parents of children with disabilities) have always struggled on every level, from financial, education to resources. All our stories are different but with one common thread. The thread of inadequate human rights.

Many families have moved, changed jobs and had family breakups due to the ammence strain trying

to balance this problem.

I too have moved locations, enabling us to access better services. I too have had to change jobs to allow to be there for my child and i too have had a marriage break down with the stress of raising a child with a disability.

With a 14 year old daughter with a disability i am already seeking work for her with the help of her Private School her in Perth. I have taken matters into my own hands as only a parent will battle this long and hard for her rights. Services are different in Rural WA to City WA but never the less there is limited resources and time. Time we dont have and money we scrape together. But there is no structure for on-going care. We leap from one organisation to another seeking help and guidance and repeating our stories and completing more paperwork. Only to be hand balled to another who again pass us on. All with sympathetic ears but no ability or accountability. WA is an amazing state which i believe is prepared to stand up and voice your opinions. You have lead with great example over the Mining issue and i appeal you through your weight and considerable wisdom behind our plea for a "Fair Go" for our children/ young adults with disabilities.

I hope you personally had time to read this and it was not just given to a junior member of your team who will return with highlighted sentences and a summary.

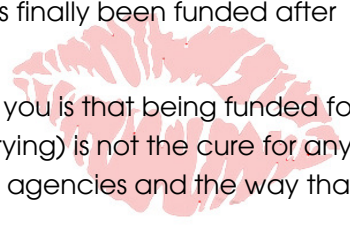
Anthea Dawson

## 88. Just Trapped

'Some people are just trapped'

My son Sean has mild cerebral palsy and an intellectual disability. He has finally been funded after years of waiting.

What I am writing to tell you is that being funded for support (after years of trying) is not the cure for anything. There are a lot of agencies and the way that



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you are supposed to navigate through them (the LAC network) often doesn't work because the LAC's are too overloaded with people they are supporting.

The problem is that the system has changed and changed again so often that now it is a place where there is a lot of rhetoric and not much happening when it comes to best practice. A lot of the people working for the agencies are good people and that is the only reason it works as well as it does, when it does. It is not the system, it is the people. The LAC system is a good example, there are good people working in it but there are also examples of terrible LACs. So when the wrong person is in the job the job doesn't get done. It is not our system that is great it is the people in the system who care.

One of the biggest things I've found is conflict of interest and competition through funding. If you are managing someones money and providing a service which is the same type of service down the street are you going to refer that person down the street even if it is in their best interests? No of course you're not. There are too many conflicts of interest even in well meaning organisations.

This wouldn't happen to people with disability if they did not have a disability. Some people are just trapped.

## 89. Workers' Comp

'You realize the system is completely broken'

I broke my back in 2000 on a minesite when a truck ran into another truck that I was in. I heard it snap and I was awake through the whole experience.

When you get hurt for the first time, you think that everyone is on your side. When you get hurt in real life, everyone is nice to you. So the nice insurance man from the company who comes out, you trust. The same with the rehabilitation company and with the 'specialists' you get sent to see. You really think

they are interested in getting you back to work, not testifying against you when you go to court.

You don't have any idea that when you go to the psychiatrists office, you are being filmed. They tell you that they will record this interview and then they point to the tiny recorder on the desk. Later you find out that there is a film of you and you wonder what else they did without your permission.

During your first few months you have a hope that you will get better. Then the realization sinks in that you will not get better for a long time and that these people are NOT on your side, they are trying to save the company money. The specialists that you are sent to see are the 'company' specialists and you are confused and upset when you read one of the reports about your state of mind, which says that you are a malingerer. You go to see a lawyer and they tell you that you should get your own specialists. That costs you a lot of money and a lot of heartache.

It takes a long time to fight this fight. You are sick, you are tired and you are becoming paranoid. When the first man turns up at the front of your house with a video camera, you wonder what you've done to deserve this. You've never lied and you've always tried to minimize your injuries because that's the way you roll.

Eventually you tell your lawyer that if you are not going to get better you just want to settle to make it all go away. Suicidal thoughts are happening daily now and doing anything causes pain. Your pain is the type of pain that goes deep down. You are diagnosed with reactive depression and the doctor tells you that this is common, more common of victims of workers comp. The company agree to settle out of court. You take whatever they give you and run. Then you find out that you will have to live on that amount for the next eleven years at a rate of \$32,000 a year. You don't know how you will support your family on that, and it won't pay your \$400 a month medication bill. You sometimes use a wheelchair and now you have to buy one. You start to use drugs and alcohol more, because you realize the system is completely broken.

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## 90. Jake's Story

'We can only hope that they can imagine...'



Jan 2010 – Our own world was about to be turned totally upside down. With the devastating news that our only son Jacob (Jake) was diagnosed with a rare and incurable, life shortening condition called Friedreich Ataxia, which is a neuro-degenerative disease that affects a persons co-ordination, mobility, heart function and causes impaired hearing and vision, slurring of speech, difficulty in swallowing, extreme fatigue, diabetes, scoliosis of the spine and changes in sensations to heat and cold in hands and feet.

Jake was diagnosed when he was 13 years old and within a few months the falls were becoming more frequent each day and dangerous, it eventually got to the point where Jake was unable to have the strength to stand or walk unaided.

We live in a thriving Western Australian wheatbelt town being York where we have lived for 16 years, Jake has grown up in York. Upon the news that we received the whole town got together and the Castle Hotel had an Auction in Jakes Honour to raise money for any medical or financial needs, which was a total surprise to us. Also amongst this we received a wheelchair from an anonymous couple in town that wanted to help our son even before he

was ready for this change.

In essence had it not been for the Community of York in their generosity and this Special Couple our son Jake would have been unable to get around initially, even though this chair required someone to push Jake. This was certainly a blessing and given the fact that as we were all new to the situation did not realize it would take 9 months to get Jake his own specially designed wheelchair, which came through the hospital system and CAPE, it came from America and was designed specifically for our terrain, we live on a rural property and Jakes chair had to be conditioned to it.

Upon learning of Jakes condition within 6 months we started Fundraising for Research for a Cure and started a Support Crew for the WA being the WAFA Support Crew, we are under the Friedreich Ataxia Research Association in Melbourne and are actively contributing to research to help find a cure for our son and others.

During the last 18 months we, as a family have not only encountered being put into the wilderness of disability with not knowing what support is actually out there through government departments, we also tackle the ignorance of society and non-acceptance of people with disabilities. Along with National Legislation that dictates whether you are eligible to receive Carers Payments based on a "Points System" and not the actual situation that your family members are in nor the care you actually provide to them. It is a constant battle between Government Departments and Society as a whole...

Personally we have been lucky to have been surrounded by people that have shown compassion and the willingness to help, such as special friends and close family members as well as our local WIFSA (Wheatbelt Individual and Family Support Association) and their CEO Karen Miller and her staff.

The NDIS is a very much needed scheme that would be welcome with open arms by every Australian that have a disability and their family members/ carers.

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The Australian Government needs to really look at the BIG PICTURE and just for those Politicians that have the POWER, they should maybe try and imagine if THEY were in the Day of a Life of those such as ourselves and many others, How would they Feel watching their loved ones go through such frustration and hardship everyday of their lives....

"We Can Only Hope that they can Imagine"

Jules Brad & Jake Lampert - YORK WA

## 91. Changing Needs

'We need to make change and we need to do it now.'

To Whom It May Concern

I am writing to ask if you will please consider a National Disability Insurance Scheme for all Australians and especially Western Australians.

I have a degenerative disability and whilst my needs are not great at the moment, years of working in the disability system has made me despair of what will happen when my disability gets worse.

I do not want to be poor, I have worked all my life and paid my taxes. I do not want my adult children to have to care for me nor my husband. I do not want to have to cope with being in pain and having a disability and then also having to worry about whether I can get showered and get up in the morning because I don't have enough support.

I do not want to have to struggle just to get a wheelchair and to get my house modified and my care modified. And I do not want to die and leave my children nothing because all my hard earned money has been spent on having a disability. I earned it to live on and leave to my kids.

I have worked in the disability sector for many years and there are good people here but we are living in a BROKEN and fractured system. We need to make change and we need to do it now. Thank you.

Julie Butler

## 92. Abused in Care

'We need infrastructure that will protect their rights...'



My son Raymond hasn't been receiving any services for a few years now from WA government services.

I was lucky, because I could go to court for a medical malpractice suit. Raymond contracted meningitis at three months old and has a brain injury - he is now thirty.

We suffered greatly at the hands of state services. Everything was a struggle. Getting respite was a struggle. Every bit of occasional support was a struggle.

When he was seven, Raymond was finally accepted into care. He was only there for four weeks and he was abused for the first time. We were told that this was not a bad case of abuse and then the abuses went on.

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The place that Raymond was put in has been dismantled now, it was called Devonlea. Twenty eight people stayed there at the same time. Raymond has had five ministerial inquiries into the abuse in care for five separate incidents. These were not trivial incidents - in one, he was left by carers and abused by other people in the home. He had 28 bites to his body and no one seemed to know how that could happen. They didn't inform us that he had been bitten so badly and we had to take him to hospital and put him on antibiotics - it was another resident who had bitten him.

It was so hard. We tried so many group homes with DSC trying to find a safe facility. Raymond is not a violent person and he doesn't know how to discriminate between a safe person and non safe person.

How can a seven year old be placed in a home with a twenty one year old, who then abuses him?

There were different occasions where Raymond was abused in different ways. He accessed the open drug cabinets and overdosed on drugs after eating the residents medication. He ended up having burns treatment for major burns. When he took the drugs, they gave him ipecac but did not tell us the incident had occurred. We didn't know til taking him out and he collapsed on the beach at Fremantle within an hour of taking him out. Fremantle hospital transferred him to PMH.

There were so many occasions when abuse happened. When Raymond was fourteen, his father died of viral encephalitis. That week, he was assaulted in his group home with all the hair ripped out of his head by a co-resident. He was grieving for his father and he was very distressed.

His dad had become a social trainer with Nulsen Haven and we were trying to get away from the substandard care and it was only through the process of getting a lawyer for Raymond that we got anywhere. The lawyer decided to threaten the Commission with suing them for placing him with people known to be dangerous and told them that Raymond would take out restraining orders against individual clients. In the end they said that they would have to put him by himself and they transi-

tioned him to a private house and one on one care. A clinical psych report said that Raymond had suffered so much institutional abuse that he could never again be expected to live in a group home.

Raymond now wears a helmet to stop him banging his head. He has issues of self harm with post traumatic stress disorder. The litigation we pursued involved seven and a half years to settle but Raymond has now his own trust with the NAB trustee. All the care component is directed by myself and Raymond's stepdad is the service coordinator. He does all the training and development and makes sure that Raymond has the safest and best life - he will never suffer again.

It would be the most terrifying prospect for me to ever need any support from the government, again, ever.

We have basically had to pay our way to get out of it. It did us so much damage. He was moved 13 times, there was all the abuse.

When he was first molested there was a big meeting and they tried to explain to us that the behavior that had happened to Raymond was not that serious. My husband stood up and said 'if it is all right with you, I will do the same to you as what was done to Raymond' and they changed their perspective.

They placed him for 18 months with Activ Industries. There is no place for a child, no place or environment that they could put him in...for any child who was not able to protect themselves.

What is needed is a much more holistic approach for families who don't want to choose between giving their child up or being supported. We were treated as though we had given up and he was no longer ours, when we needed help.

When you're not coping support is not a luxury. It is essential to get some sleep. He didn't have adequate supervision because we were always so tired.

Even if you have money you are only as safe as your next days care. You need funding but you need infrastructure that protects your rights. - Jenneanne

# the OTHER 100 conversations

## 93. Priorities

'How do you decide which one isn't as important?'

What we've found is that, because there isn't enough therapy to go round, kids with Down Syndrome isn't a priority - there are kids with multiple disabilities who have greater needs. I understand that. But that doesn't mean my child doesn't also deserve what she needs. And you can only have one kind of therapy at once, too bad if you need speech AND OT. How do you decide which one isn't as important?

## 94. Not a Burden

'It isn't my child who is a burden. Its having to fight that is a burden.'

I get so angry when I hear people going on about it being hard for parents of kids with disabilities, that their kids are a burden, poor carers etc. It isn't my child who's a burden, it's the always having to fight for services that's the burden.

## 95. Just Parents

'Give my child the support she needs and we can just be her family, please.'

And, there shouldn't be a need for parents to be called 'carers'. we want to be her parents. We want our other kids to be brothers and sisters, not 'young carers'. If the system worked, we could be who we are. Is it not enough that our kids with disabilities get labelled? The rest of the family has to be labelled too? Give my child the support she needs and we can just be her family, please.

## 96. Second Class

'It would help him to be more independent...'

MY son left school at 18, and he was only just getting the idea about reading and writing. Another family told us that TAFE in Perth have literacy programs so we went along to find out about them. The lady told us our son needed to have a certain literacy level to begin with, and I said, but that's why we're here, for him to learn. But it was just pitched too high. There's nothing else available, and it's probably too late now. I don't know. I feel really sad about it as I think he'd get a lot more from life if he could read properly. He loves magazines. And it would help him be independent. There should be classes for people straight from school, to keep on teaching them the basics. Not everyone picks these things up as quickly. I think this is one of the things that saddens me most, you know. They leave school and that's it. No therapy, no chance to go to further education, and so hard to get a job. It never seems to end, the struggle to get the basics. Yes, I feel very sad at the unfairness, it's like he's a second class citizen

## 97. Asking for Help

'Thank God for my friends, other parents of kids with disability...'

I have two young children with disabilities, and another child, and I have health problems myself. I keep asking my LAC for help, but she never gets back to me. Thank God for my friends, other parents of kids with disabilities, for getting me through and helping me find information and services.

## 98. Failed to Develop

'My husband had a severe breakdown after eighteen months...'

I live in Kalgoorlie, I am a mother of three young children aged 8, 6, and 3. our eldest daughter of 8 was born normally, but failed to develop after 18 months, and continued to regress in all areas, including the ability to move, swallow and smile. After several years of investigation, she was diagnosed with a rare axonal degenerative disorder. Our

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daughter will die sometime between 10-15 years of age.

We require specialist equipment for tube feeding, catheterisation, wheelchairs, hoists, wheelchair lift in the car and so on. We do not have a large income, and have had to rely on current services. I must travel frequently to Perth for admissions to PMG, leaving my family behind.

Local Allied therapists here at the hospital are either graduates, or are here for brief periods of time. We cannot private therapists, so must rely on current services. Because our daughter's condition and needs are so intense and complex, we are given some degree of priority, but what is on offer is not the best at all.

My husband had a severe breakdown 18 months ago, after coming to the full realisation of what was happening with our daughter. We could not afford the private and exorbitant fees to access specialists in Perth and the clinics needed to restore my husband to some semblance of normal mental health. If not for the intervention of a generous family member he would be dead at his own hand now.

Our lives are difficult, about survival from day to day. My grief must be buried in the multitude of tasks required to keep my daughter in health and functionality. Your system has not saved us or my daughter, it is family, friends our own determination, and the fundraising efforts of our community which have assisted us. We need an NDIS, I do not invite you to walk in our shoes.....we are private people. But consider the people of WA who live a life like us, and there are many of them. Be very careful before you congratulate yourself on our system. I cannot stay here longer, my daughter needs await me.

## 99. Its So Difficult

'It isn't my child who is a burden. Its having to fight that is a burden.'

Mr Barnett, I live in a small wheatbelt town, where facilities are minimal and distances to travel are ob-

noxious. I have two children, one has an autism spectrum disorder. Katie is in Year Six, she has an exceptional IQ, but because of that we do not qualify for DSC assistance in any form, as we are ineligible for registration, due to the fact she has no intellectual disability associated with her autism.

We cannot get assistance from schools plus, because of this. Katie has changed from a happy and bright child, to one who avoids contact with others now, as she has lost confidence and self esteem. We are now considering psychiatric assessment for her, as we are concerned she is heading down the road of isolation, depression and anxiety.

Guess what, the fees for this are enormous, we do not have private cover, and have had to pay for everything that might help our child, by ourselves. This puts immense stress on our income, and our entire family. We need an NDIS, I believe, it is long overdue, and I don't think you are right that everything is OK in our state. We can't even access DSC, as stated, and where else do we go to help our child become the person they should be entitled to be??

While I know people in much worse situation than us, it's not the point, we are still struggling to give our child the help she needs for a full and productive future, and you are not helping us in our struggle, you are actually inflaming it. Can't put my name or contact details to this because we live in a small town as stated, and my child would be mortified if she ever heard of this. I am mortified that raising a child became this difficult.

## 100. The Final Word

The final word is a transcript from Lesley Murphy's Productivity Commission inquiry interview. They heard her voice - will you?

**MS MURPHY (MDAWA):** My name is Lesley Murphy. I'm here today representing the Muscular Dystrophy Association of Western Australia and I'm also here wearing the hat of the primary carer of my son Con-

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nor who has Duchenne muscular dystrophy. For those of you who don't know what that is, that is a severe degenerative neuromuscular condition, usually diagnosed between the ages of three and five, resulting in death at the age of about mid to late-twenties. It's a genetic condition so there's no treatment and no cure, as is the case for all muscular dystrophies of which there are about 60 different named types.

So my comments today will be based on my personal experiences as a carer but also on my experiences in dealing with the wider muscular dystrophy community. At present I do try to go into the office two days a week but I perform my role on an entirely voluntary basis and I have been doing that for about the last four years, basically since Connor finished school - and I'll comment on that in a minute. The first thing I would like to bring to the commission's notice - and again, this comment is based on - I think I know personally of the 50-odd people with Duchenne alive in WA today so these figures would very much be relevant to all of them and anyone else who has a child with a severe muscular or neurodegenerative condition.

Connor was diagnosed at the age of three in 1992. We had just moved into our dream home, a home which we then discovered was entirely unsuitable for an electric wheelchair. In fact, we asked the architect if we could modify the home and his comment was, "Well, you could, but you'd have to pull it down." So we were then faced with the prospect of rebuilding, a cost that we estimated to be in the vicinity of 500,000 to 600,000 thousand dollars. We did receive about \$6000 towards the cost of wider doorways and bathroom taps and so on through the CAEP program. We've also had to purchase two wheelchair-accessible vehicles over Connor's lifetime and we may need to purchase another, depending on how long he survives. These two vehicles between them have cost us around \$100,000 and we have received no financial assistance to purchase any of those.

Furthermore, since Connor finished school in 1996 I've had to leave paid work to care for him. This has

not only meant the loss of my income but it has impacted on our superannuation contributions and therefore our ability to finance our retirement - that is, assuming we live long enough to enjoy any retirement and, quite frankly, with the burden of care that we are undergoing at the moment there's much we might not actually need. To put that into further perspective, there are 168 hours in a week and we receive support for Connor for 38 hours. That means, roughly speaking, we provide something in the vicinity of \$150,000 of care for Connor a year for free.

That's not to mention the housing, the vehicle and so on and so on. I mean, obviously he's our son. You expect to have some burden of some costs with any 21-year-old son who's living at home; that's not counting that. In return for this we get \$50 a week - well, I get \$50 a week roughly, and the \$600 a year that the federal government gives me. I don't even want to think about what the costs of that would be compared to if our family situation breaks down to the point where he would have to go into institutional care - and don't even get me started on crisis intervention and all that.

So I just wanted to then go on to address some of the Part 3, 4, 5 and so on in the paper. Starting with part 3, I was quite surprised in my reading of it to see that in Australia we still don't actually know how many people have these conditions. We are in fact actually now a laughing stock in the world because we do not have a rare diseases registry. If we had a rare diseases registry we wouldn't have to say, "There are about this many people," "There are estimated that many people." I'm talking about things like muscular dystrophy, spinal muscular atrophy, osteogenesis imperfecta, motor neurone disease, Batten's disease, Huntington's disease - the list just goes on and on and on. These sorts of conditions are hugely debilitating and obviously extremely costly to provide care for. So surely to goodness for the cost of a small outlay - and I'm talking a minimal amount of money - to set up a rare diseases registry would massively help in the planning of the costing of those kind of costs - you know, down the track.

The next thing I'd like to comment on is part 4 and

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the need for people to have more control over the resources that they are allocated. At present we receive - or Connor receives about \$33,000 which we manage in a shared management arrangement and we use that to buy care and support for him so that he can attend university and have a life. However, this is the interesting fact: up until a few months ago this same amount of money through a different agency bought us 17 hours a week. Hello. Yes, so how can this be? Clearly it depends on which agency you choose to go to. Now, I'm sorry, but there's something severely wrong with that. That cannot be right.

Sorry, I'll just start - the \$33,000 a year buys the 25 hours of support for Connor. The other 13 hours are provided through other support agencies for personal care and respite, and I get a couple of hours a week for someone to help with some housework and stuff like that.

So that funding of \$33,000 a year buys him 25 hours of support to attend university, social events and whatnot and, like, I say, I did a bit of shopping around and discovered if I changed to a different agency that instead of getting 17 hours a week, for the same amount of money I'd get 25.

Better, dramatically better. I guess it's the case of larger is not better. Smaller agencies are able to provide more direct and more personalised care and support for what you need, whereas with larger agencies - you know, my two most hated words on the planet are "eligible" and "entitled". They're right up there with the F word, the E words; they're my two most-hated words - and the bigger the agency the more you hear you're not entitled and you're not eligible, which brings me onto the whole issue of self-management of funding. Now, I know that there's a lot of people who are not capable of managing their own funding but clearly there are many, many people who are.

I really believe if we had that \$33,000 to manage totally on our own we'd be able to even buy more hours because we wouldn't charge to manage that money. Anyway, I just think that there has got to be another way found for people to be able to self-

manage their own funding. Now, I know it has been abused in the past, I understand all that, but there has got to be a better way of giving people who are willing and able to manage their own funds the opportunity to do so. This brings me to another point in the issues paper, section 4, and this is about the inconsistent assessment methods for allocating services and funding.

In WA for all funding for respite, family support and so on we use a form called the Common Application Process. This form is heavily weighted in favour of people with intellectual disabilities and behaviour problems. For instance, in many of the sections people with disabilities but normal intellect and communication skills get no weighting at all from any of those sections. So it doesn't take much to work out that they are never going to get to the top of the heap when it comes to getting funding and I can attest to that. I have been in that pool waiting for some funding for extra help for three years.

The physically disabled applications are then assessed by the same criteria and in the same pool of applicants. Not surprisingly, we rarely, if ever, get funded by this method. Usually, and I am not exaggerating, what happens is that we have to actually threaten suicide or to harm our children before we get some funding. I illustrate this point by the fact that the Disability Services Commission themselves say they have three levels of services, and this was alluded to by the previous speakers. Level 2 is for people with profound or severe disabilities and level 3 is for people with intellectual disabilities, so in fact people who are intellectually disabled will qualify under level 2 and level 3, but people who are physically disabled would only qualify on level 2. Therefore, by definition, much, much more of their funding must be being directed towards people with intellectual disabilities. They would argue hotly that this is not the case but obviously, clearly it is. That's on page 3 of their CAP form. So the bottom line for me is that the physically disabled should not be assessed for care and support funding using the same assessment tools which have been largely developed for people with intellectual disabilities.

It is my belief from personal experience that the

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physically disabled are the most disadvantaged by the current care and support arrangements in the nation and particularly in WA. I'd like to highlight the plight of people who are in their 20s, 30s, 40s and 50s who are diagnosed with degenerative neuromuscular conditions. For these people, the support and funding networks are appallingly limited, if not non-existent. Many of these people have known all their lives that there was something not quite right. They have known that they were a bit weak, couldn't run, but didn't really know what the problem was, and they have soldiered on with their lives, studying, working, marrying and so on. Now they're faced with an almost certain premature death, drastically diminishing physical capabilities, limited employment options and so on. They need advice on how to perhaps retrain into a different job or career pathway. They need advice on equipment and housing options and they need counselling about the genetic consequences of their condition. What they get instead is waiting lists and not much else.

To give you an example of this, I know of many people with muscular dystrophy who are virtually housebound because they are not eligible for an electric wheelchair. Under the current CAEP guidelines in WA, you are not eligible for an electric wheelchair if you can still walk around inside your own home. If you have one of the many adult-onset types of muscular dystrophy, you can still walk around inside your home but you can't get out of your home. So these people who are usually quite capable of maintaining some kind of contribution to the community literally become prisoners in their own homes because they cannot get up and down their own front steps. I mean, I just think that's beyond belief really, but that's the rules.

To answer the question in section 6 about who should be eligible, obviously in my opinion, it should be to new cases of people who are disabled, but also to people who have existing diagnoses. In terms of reassessment, genetic and chromosomal conditions don't improve and they can't be cured, so what's the point of constantly having to reassess, except for the point of increasing needs. As their

physical capabilities diminish, their needs will increase.

I believe that some sort of funding should be available for people to have a one-off sum of funding to either rebuild a home or redevelop a home and to purchase some kind of wheelchair vehicle. In terms of ongoing funding and means testing for large amounts of ongoing funding, I am a bit ambivalent about that. I know of people who are multimillionaires and who receive every single dollar they can get from the state, because they're eligible, so I'm a bit sort of ambivalent about that one.

Section 7 touches on the issues of who makes decisions and again, I suggest that there are many people who are more than capable of managing the funds they're allocated and who are denied the opportunity to do so. Again I direct you to my example of the discrepancies between different care providers and how many hours can be purchased with the same funds. Primary carers should not in my opinion be allowed to pay themselves directly from a fund but they should be considered to be an employee, in the same way as any other support worker that comes into the house, so they should have the opportunity to have holiday pay, workers compensation insurance and so on.

I just want to check that I've got that right. If someone receives an individualised package, they would be able to have their primary carer, even if it's a family member, paid a salary?

Yes, they should be allowed to pay them a salary, but that person should be considered to be an employee in exactly the same way as any other support worker would be an employee that comes into the home, so they get the same benefits. Individualised funding could be monitored by many kinds of different acquittal processes. You know, it's not rocket science.

A national disability insurance scheme should provide people with the opportunity to buy vehicles, housing and so on. I've said that. The other thing that is sorely lacking for people who are in their 20s to 50s and diagnosed with degenerative conditions is access to therapy services. I've been told this di-

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rectly: that the funding is directed towards early intervention because that is where you get the best outcome. That's fine. However, people who have degenerative conditions also need access to physiotherapy, occupational therapy, and unless they can afford to pay for it themselves, they don't get it.

He's a client of Rocky Bay and he attends there twice a week for some physio and that's purely because in the end, I decided I was his mother, not his personal physiotherapist and there's a limit to what I can do for him, what I'm prepared to do for him. They have other clients in the Muscular Dystrophy Association who have different conditions who don't actually become clients of Rocky Bay because they're not eligible, who have no access to No. I have no confidence at all that we will get any because he can communicate, he can express his needs. He doesn't have behavioural issues. He's not intellectually disabled. Therefore we will never - unless I physically threaten to either abandon him or physically harm him myself or he becomes unsafe in our home situation, I very much doubt we will get any funding.

*Conor Murphy was funded after the Productivity Commission hearing and after years of struggling in the 'hideous race to the bottom' - competing against three hundred other families a year. He now lives independently and is living the life that other young men his age live. Lesley says that she cannot bear to think of the many other young men like Conor, who remain unfunded, unsupported and who fight daily through a broken and crisis driven system.*



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