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Submission No. 872
(Inq into better support for carers)

BETTER CARE FOR OUR CARERS

SUBMISSION FOR NEW PARLIAMENTARY INQUIRY

by Sharon and Stuart

EXECUTIVE SUMMARY

We are the parents of Jessie who was featured in the Four Corners program 'In Our Shoes'. Our submission will provide (1) a history of Jessie's case and the battle we have encountered to get support (2) an analysis of what happened (3) what we consider to be the most practical measures required to support carers looking after children with intellectual disabilities (4) concluding remarks.

History

Our daughter Jessie has a mild to moderate hearing loss, autism, moderate to severe global developmental delay, and the rare and fatal illness, Sanfilippo Syndrome. Sanfilippo Syndrome attacks the brain progressively. It is characterized by sleeplessness and major behavioural problems. She will die about the age of 12.

We made hundreds of phone calls seeking respite and assistance and were able to source nothing of use. In the end DADHC said our only option was to be reported to DoCS.

By early December 2007 we were totally exhausted mentally and physically. After being reported twice to DoCS to no effect, a summit meeting involving DADHC and related NGOs confirmed that no meaningful support was available. The only thing on offer was one night of in-house respite a month.

As we couldn't continue on this basis we refused to pick Jessie up from hospital to force a conversation with DoCS.

Our daughter was placed in 'crisis' accommodation in Newcastle over two hours' drive from her family by DoCS. Access was limited to two out of every three weekends and our rights were ignored. Jessie was dangerously over-medicated for three weeks after discharge from hospital and DoCS ignored our pleas for help. Eventually we intervened with our own GP and had the dose reduced, averting possible tragedy. DoCS shut us out of decision making but bumbled themselves; taking five weeks to register her in school and stuffing up medical appointments leaving the child languishing in an isolated environment.

Appeals to politicians for help were ignored for months. When answers came they were useless as they were drafted by those who were responsible for the appalling treatment of both Jessie and us. Only the shadow minister for DADHC in NSW, Andrew Constance, recognised the injustice of our situation and offered help and support.

We turned to the media. Two newspaper articles were followed by radio interviews. Finally 'Four Corners' included our case in its program on the plight of carers, 'In Our Shoes'. Our story was featured at a Public Forum of the Wood Commission into Child Protection in NSW which drew some of the media interest. The Ombudsman's Office also took an interest in our case.

DADHC finally came to the party and DoCS closed their file shortly after attention from the media and the Ombudsman's Office. DADHC now fund Jessie's out-of-home placement in Newcastle. They say they are committed to bringing her back to Sydney and have stepped up efforts in this regard. Only time will tell. Our rights as parents have been restored.

Analysis

Two bitter ironies: According to DADHC children need to be 12 before they qualify for out-of-home-care. Jessie may die before she qualifies. When confronted with this what do DADHC do? They recommend that they report you to DoCS to facilitate out-of-home placement.

Money is not the problem. The cost to the taxpayer of Jessie's placement in Newcastle is an incredible $11,000 a week.

Is a foster family the appropriate option for Jessie? Will it last or will an appropriate family even be found? It is likely that she will languish in Newcastle indefinitely if a family can't be found. It is also likely that if a family is found the relationship will break down as her condition degenerates. Then what happens? Why isn't small-scale, out-of-home, residential care even considered as a possible option in this case?

The placement of Jessie in Newcastle, away from other children, was not just an inconvenience, it was a tragedy. She was isolated for the first ten weeks and went immediately downhill. She was also thereby denied placement in the most appropriate school. The most important social issues for Jessie's ongoing mental stability were criminally ignored by this placement.

Jessie's education and development was sorely neglected in DoCS' hands. Incredibly she missed the first five weeks of school and more recently spent three months without hearing aids simply because DoCS couldn't get its act together. There was also an ongoing refusal to allow experts who knew Jessie well to become involved.

It is an endurance test to know Jessie could be in Newcastle for years. There is still nowhere to turn.

Practical Measures

DADHC offers respite and services which are fleeting, brief and short term but above all what is desperately needed is long-term respite. In our case and that of many others, out-of-home respite is essential. This service simply doesn't exist.

The stigma attached to institutional care must be looked at critically. It is simply stupid to claim that all institutional care is harmful simply because it was done so poorly in the past. Small-scale residential care may be the perfect solution in many cases.

The inflexibility of policies in organisations such as DoCS and DADHC requires a critical eye. Much more emphasis needs to be placed on the specific needs of individual cases rather than falling back on a 'one size fits all' approach. What is the main driver anyway, philosophy or cost?

Planning for the full range of circumstances facing carers needs to begin. In our case $286,000 has been spent on Jessie in six months simply because no other options were available and the placement was in a provincial city 180kms away. How ludicrous.

Medical advances will see the current population of disabled people explode. Future planning needs to be cognisant of this.

Politicians and bureaucrats, the decision makers for people with disabilities and their carers, need to get in the field so they have some idea about what it's like. If they looked after a child with a major disability for just two weeks huge changes to existing practice would surely follow.

There is a need to actively seek people out. Most carers are too exhausted and time deprived to make a submission to this inquiry. Get in the field and find out what's really happening. Go to them, don't ask them to come to you, they're out on their feet. For every submission you receive there are hundreds more that just couldn't be made.

Conclusion

The divorce rate of parents in our situation is somewhere between 80% and 90%. Parenting a disabled child is an all-consuming task that often causes loss of income, self-esteem, marriage partner, dysfunctional family life and poverty.

Women are particularly hard hit but all normal, healthy familial interactions breakdown as carers endure a Chinese water torture that in the end literally splits their minds and souls in two.

Neglect of families who include children with disabilities is of course directly neglecting the children themselves and their siblings. Adequate support very clearly doesn't exist and families more often than not implode. But only when there are bodies on the ground, irreparably harmed, will government departments act.

Any dispassionate viewing of Jessie's case can immediately see the inappropriateness of a foster family model. Our family needs out-of-home, small-scale residential support for Jessie. And Jessie needs us in a healthy state to see her short life through to the end.

None of the government bodies involved can think outside their own ideological fundamentalism and the well-worn paths they've already trod. Or to put it another way, they can only think from the general to the particular. In DADHC's case ***all children*** of Jessie's age can never receive assistance outside the home.

In the meantime Jessie languishes in inappropriate schooling and costly, isolated, crisis one-to-one care in another city indefinitely. It is an approach which is light years away from being in the best interests of the child and irreparable harm is being done, not by her parents, but by the very government bodies whose sworn duty of care has been abandoned through an inability to adapt to a particular circumstance.

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HISTORY

Jessie and the Prognosis

We adopted Jessie in 2004 when she was 20 months old. We learned over successive years that Jessie was hearing impaired then later, autistic with moderate to severe global developmental delay. In May 2007 we were informed she had a rare genetic condition called Sanfilippo Syndrome. This devastating condition is caused by an enzyme missing in the brain. This enzyme breaks down sugars. As the sugars are unable to be broken down they build up in the brain and eventually the brain is destroyed. Symptoms of this condition are extreme hyperactivity, inability to sleep (whereby the person may not sleep at all) and severe behavioural problems. Drugs can assist but tolerance to drugs builds quickly; eventually drugs don't work at all. We were also told that Jessie would die probably around the age of 12 but before that happened she would lose all cognition and acquired skills; she would become incontinent and possibly suffer acute bouts of diarrhoea and constipation. She would lose all language. Mobility is the last faculty to go which makes the condition extremely hard to care for, however, eventually we were told, Jessie would be in a wheel-chair. She would be so brain damaged that she would not know whether to choke or swallow her own saliva.

She has one year left to learn at most and then all ability to learn will cease and she will commence a slow downhill slide.

The Initial Search for Help

We realised after discussing the situation with the geneticist that we would need respite if we were to cope with this situation. In grief and suffering from shock we set about trying to find such help for the future. We had to phone up respite organisation after respite organisation, repeating ad nauseam our devastating situation, only to be channelled elsewhere or told there was nothing on offer.

It took hundreds of phone calls to be either told that no services are available or that we could be put on a waiting list but that this would probably take years to bear fruit. Commonly our calls weren't returned.

We endured this for six months – and got nowhere. We understand that DADCH had the responsibility to help but they failed terribly. The only assistance we got was a leaflet in the post.

It also became abundantly clear that respite is very limited. Any respite – should you get it - is short term. Our situation was not short term. It was going to get progressively worse. We were horrified to discover that there is nothing available of any consequence for families such as us who are simply left to cope on their own.

Everything came to a head in early September 2007. Jessie was barely sleeping at all and showing clear signs of increasing dementia. The family was in crisis. Occasional in-home respite was no help at all. We needed sleep. We felt like we were in a 'war zone' most of the time: going to work exhausted, coming home exhausted to face another night of sleeplessness – not to mention the behavioural issues our little girl was now exhibiting.

Two desperate crisis calls to DADHC (one on a Monday the next on the Wednesday) went unanswered. A crisis call to Carers' Respite garnered 'two hours respite that Thursday and Friday'. On checking with Carers' Respite we were told the person who arranged it 'has gone on holidays. Nothing is in place. Have you phoned DADHC?'

In the end Carers' Respite urged DADHC to respond to our calls. They finally rang: *Did we not understand there is no out of home care for Jessie to give us respite as she was under seven? She could report us to DoCS to get out-of-home care; that was all she could offer.*

It was a shocking experience. We love our daughter. We simply needed a break. We needed a long-term plan that could so we could cope with the demands her condition was now exhibiting. Yet we were told all that was available was to be reported to DoCS as a danger to the child. Desperate and in despair, we agreed to this.

So DADHC reported us to DoCS. This resulted in a banal phone call from a DoCS worker who made it clear she was not interested in meeting with us to discuss our situation.

By early December 2007 – having been ignored by both DoCS and DADHC - we were totally exhausted, mentally and physically. Jessie was in hospital for a sleep/medication study 'as much to provide respite for us' the specialist confided.

'You have to hold these agencies accountable,' the hospital social worker told us. 'I'm a fan of summit meetings.'

A summit meeting of DADHC officers and related agencies, hospital staff and DoCS was convened. (DoCS declined to attend or respond even though we'd been reported to them a second time as being unable to look after our child.) Many had tears in their eyes as they listened to our story and confessed that ***no substantial help was available*** – their hands were tied either because no service was available or because Jessie was too young to qualify.

Finally it was once again suggested that DoCS was the only option as out-of-home care was the only real solution. As we'd been reported to DoCS twice already and essentially ignored we wondered how we could pursue this. In the end we refused to pick up our child from hospital in order to force DoCS to have a conversation with us.

DADHC fundamentally failed us either because they had no services of consequence to offer or they had services and chose to withhold them. Their systemic problems and poor communication skills were abundantly evident. That's why it took many months just to reach the simple conclusion that nothing in reality was available.

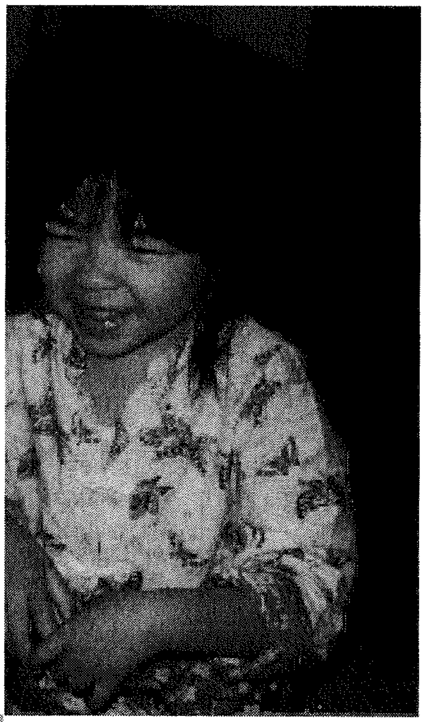
We battled with DADHC and its funded agencies for six months and hit a brick wall at every turn. If a child with Jessie's range of disabilities can't be helped then who can be helped?

DoCS' Care

Thus our daughter was placed in DoCS' care, in 'crisis' accommodation in Newcastle. It was in Newcastle because apparently there is nothing in Sydney! Sydney is the most populated city in Australia yet nothing was available and Newcastle was the only option. Imagine: a small child with an intellectual disability removed from her parents, from all that is familiar and placed two hours away with a group of rotating strangers. We were told by DoCS we could see Jessie 2 out of every 3 weekends. Our rights were ignored. Jessie was sent to a school (eventually) which is inappropriate. She has one year at the most to learn yet the choice of school was made due to its 'relationship' with the NGO. These are but a few examples of the needless tragedy that unfolded.

In short, our experience with DoCS was a nightmare. We outlined our concerns to the Wood Inquiry. For the purpose of this submission we will not go in to detail. However it should be noted that we considered her to be more in danger in DoCS care than she ever could have been in ours. As 'Four Corners' featured, she was left over-medicated for three weeks on a controversial anti-psychotic drug, Risperidone, despite our desperate please to DoCS. This entire episode was scandalous. We wrote emails, we screamed down the phone; eventually, in desperation we took her to our local GP who agreed she was 'excessively sedated'. Our daughter was dribbling from the mouth, shaking, could not walk straight, could not lift her head; she was crying, unable to stay awake and had the decrepitude of a 90-year-old. She looked like she'd had a stroke. This drug we later learned causes strokes if not monitored properly. Without our intervention we are sure Jessie would have remained over-medicated. The NGO had no knowledge of her off the drug and simply called her 'lethargic'. DoCS would not listen and we wonder, had we not been around, if Jessie would have been yet one more case of a child dying due to DoCS inaction?

(SEE PHOTOS – BEFORE AND AFTER – Jessie in October 2007 and then on Christmas Day 2007)



Our Options

This was a horrific experience. We wanted desperately to take our daughter back but we knew we couldn't cope. The grief and guilt is hard to imagine.

People have called us 'brave' – we are brave because we've faced up to the pain of having to give up our little girl in order to keep our family together.

No parent and no child should ever be put in such a parlous situation.

Only the Media Helped

We knew that as Jessie was in DoCS' care under a six month temporary agreement we would eventually be faced with going to court and face the possibility of losing our parental rights indefinitely. This was unimaginable. We chose to fight. We first contacted politicians and then resorted to the media.

Politicians

In December 2007 we sought help through our local MP, Paul Pearce. Mr Pearce wrote to NSW Ministers Kevin Greene and Kristina Keneally saying we were a 'family in crisis' and the out-of-home policy needed to be addressed. There was no reply. Mr Pearce wrote another 'crisis' letter. Again, there was no reply from either minister, not even a holding letter.

On advice, we met with the Shadow Minister for DADHC, Andrew Constance. A late afternoon phone call from Mr Constance to both NSW Ministers resulted in an immediate response the next day, with faxed letters arriving in Paul Pearce's office.

The replies were a 'washover'. It was clear that neither Kevin Greene nor Kristina Keneally were interested.

When you have Ministers in power who are so disinterested in their portfolio and their constituents it is shameful. In the light of this, we felt it pointless writing to Premier Morris Iemma. We thus wrote to Bill Shorten begging for some assistance. That email was sent five months ago. To date there has been no reply.

The politicians approached couldn't even summon up the energy to give us the run-around so we took our situation to the media.

The Media

An article in the *Daily Telegraph* and then in the *Sydney Morning Herald* started the ball rolling. We were also a featured case in the Wood Inquiry as our case highlighted many similar cases and this was reported on ABC Radio News. A successive radio interview on Simon Marnie's ABC morning show caught the interest of 'Four Corners'.

Our case also came to the attention of the Ombudsman's Office which, after a conciliation meeting with ourselves, DoCS and DADHC, has chosen to remain involved in our case for the next 12 months.

Back in DADHC'S Care

Due to media attention, pressure from Andrew Constance and being featured in the Wood Inquiry, DADHC suddenly accepted responsibility of our situation. They took over the cost of Jessie's placement in Newcastle and our rights were restored.

However, WHY did it take a media campaign to bring us back to the starting point? Jessie is currently in out of home care – still in Newcastle. But if DADHC has an inflexible policy that says no child under 12 can *ever* be in out-of-home care, how are they funding Jessie, who has now entered her seventh month in isolated out-of-home care, in Newcastle? This 'crisis' care may continue indefinitely.

ANALYSIS

A Need to Revise Policy

We are told there is no long-term out of home care available for children under the age of 12. Ironically, our daughter may well be dead by the time she 'qualifies' according to that rule. Surely a policy like this needs to addressed. The irony that DADHC don't offer out of home care to children under 12 yet will suggest they report you to DoCS as unfit parents to get such assistance is inescapable.

We understand that it is preferable to keep a young child in the family unit. In our case it wasn't possible. We needed breaks to cope. We did not want her removed from our care. It is probably the same in many cases. Yet our child was removed from our care and placed in Newcastle two hours drive away. How can this be in the best interests of a child with a disability who has loving parents? Parents who need some respite to cope?

Forced into DoCS System – 'Our Case Was Unusual'.

We did not fit under the DoCS umbrella yet we were forced in to its system due to the lack of out-of-home care resources and inflexible DADHC policy.

We were told by DoCS and DADHC that our case is 'unusual'. However, according to Justice Wood in the Wood Inquiry, our case is not unusual. It typified many cases he had seen.

Ten years ago Kevin J. Bain (former Board Member of Victorian Intellectual disability advocacy bodies) wrote in his report: 'Children with severe disabilities: options for residential care' wrote:

...the game playing to access accommodation services may also involve giving up the child to the State as a ward, manufacturing a situation of homelessness, or following the child protection route (i.e. abuse or threatened abuse of the child).

This was written ten years ago ***yet nothing has been done to address the situation***. Our case is unusual – no. It is a systemic problem which has been ignored over many years.

The Ridiculous Cost to the State

Jessie is still in Newcastle. We see her every weekend. She travels down with the NGO and we take her back.

The cost of this placement per week is $11,000.00!

What a ridiculous waste of tax payers' money. Imagine what a family could organise with just a fraction of that money on a weekly basis.

Current Push for a Foster Family

DADHC has now acknowledged that Jessie needs out of home care. Their only solution, however, is to find a foster family. We are currently talking with two groups regarding this. We believe that a foster family is not suitable but in order to get our daughter back to Sydney we will go with anything that is suggested.

Foster families appear to be the only type of care that DADHC see as a solution. They appear unable to consider that some children may not be suited by this environment. At the Wood Inquiry it was made clear by many professionals that out-of-home care models other than foster families need to be considered.

Clearly fostering is the right avenue for many children. We understand the theory: building the attachment necessary for a stable later life. However, children with moderate/severe intellectual disabilities and sleep disorders are very challenging. It is even more absurd when you talk about building attachment with autistic children; not all but many autistic children are unable to form attachment.

Again, some comments by Kevin J Baine written 10 years ago:

'*Is the current enthusiasm for foster care evidence-based or cost-based?...In practice, foster family care may be distorted to resemble a rostered staff situation to maintain the placement, with a large number of volunteer carers and parenting shared between different families and different sites...*

The view of many parents, advocacy groups, academics, foster agencies and child welfare practitioners is that the pendulum has swung too far in reducing access to other options, such as group homes.

A group home with rostered staff is an attractive option (to many parents). It has the potential to provide long-term security, trained staff, and greater authority to birth parents to influence decisions about the child's welfare than does foster care. Rostered staff carers can resist "burnout", and often develop a familiarity and attachment to the child, even when it is not strongly returned (particularly in the case of autistic children).

Permanency planning in Australia needs to drop slogans appropriate to different times (i.e. institutional care*) and accommodate subtlety, an openness to evolution and changing values and preferences.'*

We are concerned that a foster family could easily break down due to the Jessie's progressive deterioration. However, DADHC are uninterested. Jessie's geneticist has said:

I agree it will be a challenge finding a carer who can take on the very considerable challenge this would entail. Very detailed and explicit discussions with the carer about what to expect would be essential, and if this is the way things went I would of course be keen to have a chance to meet with the prospective carer to go over things before they made a commitment. I definitely agree with you that a minimum of changes of environment will be best for Jessie in the long run.

Sanfilippo Syndrome attacks the brain. Apart from the gradual disintegration described above, the child eventually builds a tolerance to medication and eventually medication does not work at all. Thus, while Jessie is sleeping better at the moment she is likely to face a situation whereby no level of sedation will be effective.

As the geneticist has pointed out, Jessie needs a secure environment and we fear – as is often the case with a fostering model – that she will endure several placements as the demands of her condition worsen.

She needs stability from the outset and regular ongoing contact with her parents. It has been stated by DoCS that: '*foster care is the best option for Jessie while she remains physically robust.*'

Does this mean that when Jessie is at her most vulnerable — that is, in the last two or three years of her life, when she is no longer 'physically robust', when she cannot walk, cannot speak, cannot see — they will remove her from all that is familiar? This shows a terrible lack of understanding regarding a child's needs.

The other common argument for a preference for a foster family is that the child needs to develop strong attachments. Once again DoCS and DADHC are ignorant or uninterested. According to , Genetics Counsellor at Sydney Children's Hospital, 'Jessie lacks attachment to primary caregivers and has a very short attention span. This is a phase of her illness and no intervention can improve this.' When you add this to the fact that Jessie has only a handful of years left before she dies, and perhaps only a couple of any quality, concerns about how lack of attachment may affect the child in later life are simply ludicrous.

On the other hand, the chronic shortage of foster families could see Jessie in Newcastle indefinitely. So how long will our child be in Newcastle while they search for a suitable carer – IF they ever find one? Jessie has already been in Newcastle for over 6 months. This is meant to be 'crisis' care; our definition of crisis is 'very short term' i.e. a few days, a week at most. How has a situation developed where this costly care has become an indefinite placement? Why, further, are there no such places available in Sydney which is the most populated city in our country?

We have to travel up to Newcastle for doctors' appointments, for case conferences and to return Jessie every Sunday. We cannot get there easily or quickly should Jessie become ill.

Jessie currently has a one-on-one carer situation. She does not need one-one-one care. She needs to be in a small group home with professional carers and with other children. Yes, she needs constant supervision but not on a one-to-one basis. Furthermore the carers looking after Jessie are young girls. We cannot believe this incredible waste of money.

The Effect of Placing Jessie in Newcastle

I urge the Inquiry to read the accounts below to see the devastating effects that resulted from relinquishing our child to DoCS as being the only option available to us:

, Jessie's special education pre-school teacher from Waterford Pre-school, Waverley:

'I saw DOCS take control – remove a child who has a developmental delay and a disturbing background to an isolated environment – two hours' car travel from her family, extended family and all the support services that were in place for her.

For a child who took so long to attach and experience being loved and wanted, this was a tragedy. Jessie has changed – spending most of her time with "carers" who are not her family or the familiar people she attached to.

She doesn't respond to the people she showed great delight in seeing in the same way. She now moves past them and has become more remote, less animated and withdrawn.

Jessie needs to be near children and make contact with them. The disturbing information that the "group home" she's in has one other child (two residents do not make a group!) who has socially inappropriate behaviours was discussed with ... (DADHC). When asked what social interactions Jessie had, I was told she was taken to the park. These "quick" interactions are casual and not reintroduced on a daily basis.'

The most important social issues for Jessie's ongoing mental stability were ignored by this placement. In the case of access to other children she has none of any consequence at all except when with us or with one little boy at school. And our own access in turn has been severely limited by the tyranny of distance.

Jessie's Education/Vital Development was Jeopardised

It was relayed to us in May 2007 by Sydney Children's Hospital geneticist that Jessie had around *'one to two years left to develop and learn skills'*.

He wrote: '*I emphasised the value of early intervention, as improved understanding and response to disciplinary measures at this age, is likely to be associated with easier management at later stages of the condition... Jessie already has all the services I would recommend at this stage for a child with MPS-III. In particular, she is already receiving early intervention.*'

At that stage, Jessie was receiving intervention from:

- The Shepherd Centre (one hour per week)
- Matilda Rose (2 mornings per week)
- Attending Waterford Pre-School 2 days per week
- Attending a day care centre 1 day per week

We had also organised for her to attend 'the best school in the State', according to the intervention specialists who knew Jessie. It is the *only school* that encompasses her needs: hearing impairment, developmental delay, discipline - and, importantly for us, provides a Catholic education.

She was to commence at St Gabriel's in February, 2008.

Jessie has been at Allambi in Newcastle since 24 December 2007. She didn't attend school for the first 5 weeks due to DoCS' bumbling and has been without hearing aids for the LAST THREE MONTHS. This again was due to DoCS' lack of action and their decision to shut us out of any educational/medical decisions. As we have recently been able to make appointments after our rights were restored this situation should not recur. However, the school which has an ongoing relationship with the NGO is completely inappropriate. Only one of the six children is verbal. Above all, Jessie needs to be in a verbal environment so that she can build her language skills.

Two key figures in Jessie's educational world who wished to provide feedback on Jessie's specific needs to carers and teachers in Newcastle were also shut out. See both emails below:

, Jessie's special education pre-school teacher:

'I have not been asked for input in to what would be the best setting for Jessie – I worked with Jessie for two years but I had to ring up to beg to be included in the process and was told that an OT and speech pathologist who had been involved with Jessie for 6 weeks were going to Newcastle from Sydney for fortnightly visits. What a scandalous waste of money: one day – 2 therapists – 1 client – maybe for a 20-minute session. I am concerned that Jessie is still in NO EDUCATIONAL FACILITY – week 3 of term.'

On 15 February 2008 we received an email from (DoCS) denying the 'right' to visit Jessie in Newcastle. Contrary to the opening line, we had no knowledge that had made this contact:

'As you are aware, Ms contacted me this morning regarding arranging a visit to Jessie in her placement in Newcastle. After discussing this with casework manager, and manager client services, , it was agreed that due to a large amount of people already involved with Jessie in Newcastle it <u>would not be in her best interests</u> to have more people visit this location at this stage. The Department is focused on Jessie settling into her placement, becoming familiar with her routine and Allambi staff during the week. I am aware from my conversation that Ms sees Jessie on the weekends that she is in Sydney which is the most appropriate option. , DoCS Caseworker)

The reference to 'the large amount of people already involved with Jessie', was actually two DADHC workers who had no history of Jessie. Jessie saw no-one familiar in Newcastle and was denied access to whom she knows well and is fond of.

For some absurd reason the ability to pass on invaluable information to other educational professionals and carers was denied by DoCS. However, this diverts from the central problem – a shortage of suitable out-of-home care for young children in Sydney.

Impact on our Family

All we want is for our child to be happy and for us to have as much time with her as we can. We have been tempted many times to 'throw in the towel' and take Jessie back.

We can't because we can't cope without sleep. Jessie has been sleeping better recently but already she is showing signs of tolerance to her medication. We know that to take this on again full-time would endanger our health and endanger Jessie's due to our own inability to monitor her. Our other child would also suffer.

So we can't. It is hard to know Jessie will die, it is hard to cope with her symptoms and it is an endurance test to know that she could be in Newcastle for years.

There is nowhere left to turn.

3. PRACTICAL MEASURES TO BETTER SUPPORT OUR CARERS

Introduction

Looking after an intellectually disabled child/person is a full-time job. It is disheartening and exhausting with very little coming back from the energy it takes from you. There are a range of services on offer, so they announce in Government literature like DADHC's. In reality there is nothing. It is an hour here or an hour there, if you can get it. Early intervention services have waiting lists that span years, but once you access them, are for hopelessly short periods.

So respite and services are fleeting, brief and short term. Caring for a person or child with a disability (particularly intellectual) is a life-time job. It is not short term. The carer therefore, to be able to cope, needs a life-time plan. Such things do not exist.

Above all what is desperately needed is RESPITE. Often the carer has to continue in the role of speech pathologist or occupational therapist once that specialists' few visits are used up. We found that we were required to enhance Jessie's intervention by doing it at home with her. This is exhausting. In order to replenish energy the carer needs to have a rest. Not an hour, that is useless – a significant rest.

When we were provided with a weekend away, we slept for the entire weekend. On coming home, although we loved our child dearly, we felt a hopeless despair come over us. Here we were going back into the 'firing line'.

So please understand what respite means. It means a long-term plan with significant breaks worked out with the family.

So often the ideas put forth to provide respite to carers are ill- thought out. We were told there was no out-of-home care available for a child of Jessie's age. We were given (not by DADHC, of course) the opportunity of having someone come into the home to stay overnight. This could only be offered for one night a month, at the very most. One night a month! What about the other 30 days of no sleep? In our case it didn't work anyway as we could still hear Jessie running around, and as any parent knows, you wake up when you hear your child. However, as someone noted on the 'Four Corners' comment page, 'Having a stranger coming in to look after my child at night would create more stress than the situation itself.' For some it may be suitable. For us it was extremely invasive.

Out of Home Care Must Be Available

The dismantling of all institutions without replacing them has caused a massive shortage in suitable placements.

Institutions of the past were inhumane; we are all agreed on this. Indeed so much so that those considering this option feel guilty. Thus guilt has been imposed on society's psyche by the current batch of bureaucrats. It is further imprinted in the case of young children.

There needs to be a removal of the stigma attached to the word 'institution'. Group homes can be very beneficial (as currently seen around the world) to some children and provide a stability that a foster family cannot. Policies also need to be reviewed to be in line with current need and not with fundamentalist and outmoded ideology. If a family is in crisis and needs respite to cope and that respite is out-of-home care, it should not be denied. To deny it will see the family take desperate measures as we did or drown. It will see the child suffer. Siblings will suffer and parents will suffer. Our situation is a travesty. We love our child. We needed ongoing, out- of-home care to survive the demands. We needed a long-term plan so that we could meet the demands of Jessie's condition in the best possible way for everyone.

Dismantling Institutions was a Massive Cost Saver

A government report in the early 80s recommended that all existing institutions be dismantled. The report went on to recommend better, more humane institutions. This part of the report was ignored by the government in power. What a massive cost saver to adopt the first part only.

Dismantling such institutions and not replacing them with other models placed the onus of care firmly with parents and carers. If that was not enough, a great big dollop of guilt was embedded into the process.

Also, as Kevin Bain says in his report, the fervor everyone has for foster families is clearly a massive cost saver. Indeed, Kevin Rudd agreed when he commented in the 'Four Corners' program: "You save the government a bucket load of money." Without appropriate respite and services we also suffer a bucket load of pain.

Money Wasted without Planning or Foresight

A build-up over many years of not implementing proper alternatives to fostering has caused a massive crisis in out-of-home care. On top of this there is now a chronic shortage of foster families.

We recently heard a doctor at the Wood Inquiry say that medicine itself was creating part of this problem. More and more children with severe disabilities are being kept alive due to medical advances and this in itself needs to be considered in terms of the shortage of out-of-home care.

Thus, due to a lack of foresight and planning we have situations where one child is costing the State $11,000 per week. So far Jessie has been in Newcastle for 6 months at a cost of approximately $286,000!

How can that be justified and how many other such cases are there? What is the overall cost versus the cost of building proper group home facilities for younger children? Perhaps government bodies should consider giving that money to families instead. We, for instance, could rent a house in our suburb, accommodate a couple of children, keep our child close to us, oversee her care and hire trained carers for half that amount.

Work Experience for Politicians and Bureaucrats

It's apparent to us that very few politicians and government bodies – who decide what type of service to offer families – have any idea the demands a child with an intellectual disability places on a family.

Those who preside over the existing system and have the power to make changes should be forced to manage the needs of these children for just two weeks by themselves. We feel sure that changes would then be made pronto.

Too Exhausted to Write Submissions

Our child is currently in care through the week and at home with us on weekends. If she was at home full-time there is no way we would be able to write this submission. The families we have spoken to who were part of an intellectual disability playgroup for our daughter were in tears at the thought of having to write something. Two of them were single, their marriages having broken down, and the others clearly outlined marital problems. These mothers didn't know how to get the energy to write a submission – even a short letter. Thus, we strongly suspect that of the submissions the Inquiry receives it would be a good idea to multiply them by at least 100 in order to get some idea of the difficulties 'out here.'

CONCLUSION

The bulk of children with intellectual disabilities remain in the care of their families without meaningful support at extraordinary cost to all involved. It speaks volumes just to reiterate that the divorce rate in such families is estimated to be well over 80% and some estimates place it as high as 90%. Parenting a disabled child is an all-consuming task that often causes loss of income, self-esteem, marriage partner, dysfunctional family life and poverty.

Women are particularly hard hit as it is usually impossible for both parents to work and commonly the mother becomes the primary carer. They are often consigned to devoting their entire life to the care of their child or children with no other prospect on the horizon, sometimes not even a walk down the street. The needs of a child with a disability take over the household completely and siblings suffer greatly as parents battle exhaustion and incredible mental strain. All normal, healthy familial interactions breakdown as carers endure a Chinese water torture that in the end literally splits their minds and souls in two.

Yes, people may survive all this. They are resilient. They may survive concentration camps also — but should we ever ask them to when other options can be created?

Those who have the power to make changes need to open their hearts, minds and souls to listen and provide real support to not only our family but to thousands of others suffering the same fate.

Neglect of families who include children with disabilities is of course directly neglecting the children themselves and their siblings. But on these occasions the neglect is on the part of the state and its agencies who watch by mutely until the damage has been done. Presently there is no one to report on the damage apart from the damaged themselves and no one to report to apart from those whose neglect caused the harm in the first place. Only when there are bodies on the ground, irreparably harmed, will action occur.

Adequate support very clearly doesn't exist and families more often than not implode. Then what happens to the child? Not one affected family we've met, and these are many, believe that DADHC is able or willing to assist them in any meaningful way. Not one. Most have received no help at all and they were envious and astonished that we were able to receive the dribble from DADHC we received. Most believe that there is no government department in reality with a focus on people with a disability.

And we have to agree. It is for these reasons that we took the extraordinary steps we did. There was no assistance and we were going under. So we had ourselves reported to DoCS twice. When this didn't work we refused to pick up our child from hospital. Can anyone imagine how that felt to two deeply loving parents?

DoCS were simply a final, desperate option from a family trying to avoid implosion. Now we have DADHC desperate to foster Jessie out to a foster family because this is what they're used to doing even though any dispassionate viewing of her case can immediately see the inappropriateness of this, not to mention the scarcity of families who would be willing to take on Jessie if they were fully briefed on her condition.

Our family needs out-of-home, small-scale residential support for Jessie. And Jessie needs us in a healthy state to see her short life through to the end. How can it be so hard?

It is hard because there is no suitable 'out-of-home care' for young children. There is a policy that all children under 12 have to be with their family or a foster family. None of the government bodies involved can think outside their own ideological fundamentalism and the well-worn paths they've already trod. Or to put it another way, they can only think from the general to the particular. Unlike equilateral triangles people are different from each other in myriad ways and their needs can't be deduced from general principles. This is especially so if they suffer from a disability.

In DADHC's case all children of Jessie's age can never receive assistance outside the home. There are apparently no exceptions except for extreme cases such as those who are on life-support systems. Now their only option is to wait until she can be placed in a foster family full-time. Other options are considered a last resort.

In the meantime Jessie languishes in inappropriate schooling and costly, isolated, crisis one-to-one care in another city indefinitely. It is an approach which is light years away from being in the best interests of the child and irreparable harm is being done, not by her parents, but by the very government bodies whose sworn duty of care has been abandoned through an inability to adapt to a particular circumstance.

Sharon and Stuart (Jessie Neal's parents)