

Submission No. 500  
(Inq into better support for carers)  
A.O.C. 7/7/08

**Submission to the**

**House Standing Committee on Family, Community,  
Housing and Youth: Inquiry into better support for  
Carers**

**Prepared on 26<sup>th</sup> June 2008**

## **Introduction**

### ***1.1 Prologue***

Understanding the role & contribution of carers in society involves the basic premise of gaining insight into the journey of both the carer and the care recipient. Our family's experience has shown it is not enough to simply look at where the carer is at a given moment in time but to understand the journey he/she has taken reaching that point in time. Future outcomes are explicitly related to not only the position a family finds itself in at different points in time but to the level of and quality of support they have experienced throughout their journey. The quality and amount of support received along with interventions at key transition stages are important determinants to developing high levels of resilience, coping and good emotional & physical wellbeing in the primary carer. These factors impact on a carers capacity to participate both socially and economically.

When reading our family's journey do not simply read. Please give meaning and respect to our story. Do this by stopping and putting yourself in our family's shoes. Do this each time you read the journey of a family who has taken the time to provide a submission. Ask yourself honestly, if this is me or my family how will I cope, what will I need to cope more effectively? What services and support programs will I need to access? How will I find these services? How much will these services and programs cost? Ask honestly, how will these needs impact on my family unit and me as an individual? How will I juggle appointments with my work commitments. How will these issues impact on our families finances. How will I juggle my work – family – caring life balance. Who can I call on to assist us? How often can I realistically call on my informal support systems? What if I have ageing parents and/or other children to care for in addition to my child with a disability? How will my relationship with my partner fair? We believe that it is through asking and answering these questions realistically and honestly that the

picture will emerge of how the role and contribution of carers in society should be recognised.

## **1.2 Acknowledgement**

Before proceeding with my submission our family wishes to formally acknowledge the important step the Australian Government has taken by convening this House of Representatives Inquiry. Our family accepts that this is not only a means for Government to gain insight and understanding of the needs of carers but recognises Government has taken the first step in acknowledging that carers do have an important role and make significant contributions not just for the care recipient but for the broader Australian society. Whilst there is a long way to go, our family recognises and acknowledges that a door has been opened providing our family with the opportunity to be heard. We thank the committee for this opportunity. Like most people I want not just to be listened to but to be heard and understood. My approach to this submission is to be transparent about our family's circumstances but to be solutions focussed where I am able.

## **1.3 The care provided, family and personal background**

My name is Lisa . I am the mother and primary carer of our 13 year old son, , who has a diagnosis of Aspergers Syndrome. has complex care needs. Caring is not perhaps the best way of describing what I provide for is at home full time as we have been unable to enrol him in a school – based setting. A great part of my day involves teaching . Whilst has a program from the Distance Education Centre – he has significant language decoding difficulties. This involves me reading through his work, modifying his work and then explaining to this is what you will be doing and this is how you are going to do it. It is necessary to go through this process for every task has been set by the Distance Education Centre. I must negotiate with individual teachers, either directly or indirectly through his tutor, for any modification to work. I have some relief from a home based tutor. However, much of this responsibility falls on my shoulders. may present as

an articulate young man and his difficulties are not always obvious on face value. can be quite personable and has average to above average intelligence.

has difficulty both recognising that he is stuck and expressing what that difficulty is. This can be in any area of his life, not just his education program. It may be a week or two after an event before we discover what the root cause of a problem was. Because of this I have to be constantly on alert, having high level observation skills in order to predict what may be causing him difficulties. As you may imagine, this can be exhausting.

Part of the care I provide involves managing challenging behaviour. Many of self strategising mechanisms have been removed from him. When in early years primary school would hide under tables (fright response) he was punished by teachers for this behaviour. Similarly, would run (flight response) once again he was punished for this behaviour. Whilst it is totally acceptable to modify and remove inappropriate behavioural responses it is a standard and well recognised approach to managing autism spectrum behavioural issues to provide the individual with an alternative mechanism for coping and reducing anxiety. This was not done.

was simply punished for what was deemed as age inappropriate behaviour but given no other alternative age appropriate coping strategies. This left with the 'fight' response. His only means of coping during a panic attack. As the primary carer I am now left to manage these complex behaviours as best as I can and trying to remove these behaviours in a much older child. is the size of a small man, so when needs to be restrained I am at risk of physical injury. When curls up on the floor or ground in a foetal position because he has gone into shut down I sit with him, calming him. This may take hours.

Our experience has found that an Education professional's inability to act appropriately to behavioural responses in children with special needs stem from a lack of knowledge of the needs of those with a disability and/or attitudinal beliefs. Attitudinal beliefs are very difficult to shift. Western Autism School in

Victoria provides professional development training for teachers and information sessions for families on a State wide basis. Discussions held with representatives from Western Autism have revealed that one of the biggest issues they face when providing training to a school is that of attitudinal beliefs.

Dealing with challenging behaviours in anyone is very stressful. There have been periods where I have had ongoing bouts of stress related illness. Stress related illness impacts on a persons ability to focus on tasks, on productivity and absenteeism.

also suffers from stress related illness. During these periods his care needs are intensified. Whilst I was working I was constantly juggling my work days not just round school exclusions but during times of ill health. level of wellbeing could be directly correlated to how well he was being supported in the school environment.

During his first term in year 7 was given a high level of support; settling in periods for Year 7 students are facilitated by reduced work loads and revision of work completed in grade 6. At the start of term 2 expectations for work produced and the difficulty of task content is increased. Allowances for students having difficulty organising themselves are removed. Students with ASD need life long support in these areas. Organisation skills are governed by executive function of the brain. People with ASD have significant deficits in respect to executive function – as a result of brain wiring difficulties. When these support systems were removed was unable to cope. He was reprimanded constantly for being unorganised. I sat through a parent teacher interview session with each of his teachers, each complained that needed to be more organised. No accommodation appeared to be made for his inability to actually organise himself without support. Those with ASD do not have imagination. I listened to his English teacher express her utter disappointment that could not write an imaginative piece of text. had an integration aide, yet we were still confronted with issues such as this. As a result of unrealistic expectations there

was an increase both challenging behaviour and stress related illness in . It became quite disheartening to constantly be confronted by people working with our child who just did not get it – despite us providing information in full version, point form version, summary version, we even produced a power point presentation in an effort to support the teachers working with our child. Our power point was refused. I know of only one staff member who actually read our sons file from start to finish. We made offers of support from his specialist team at our families expense – these were declined. After one major meltdown the school did hold a professional development session where staff could view a DVD by Richard Eisenmajer on Aspergers Syndrome. It was by now all too late.

eats from a limited range of foods due to sensory issues. This means preparing distinctly separate meals for on a daily basis. Sound dietary health practices mean we must attempt to expand diet. This involves behaviour management strategies where is desensitised to the texture and smell of foods that cannot tolerate. Individuals with ASD do not refuse food because they don't like the taste, the refusal stems from sensory issues or poor oral motor development issues. To do this we must introduce foods one at a time. The new food must not mix with other foods we have successfully introduced to . For example, may need to have more green vegetables in his diet. We may choose peas. A dietician with expertise in ASD has advised that we need to place 3 to 4 peas on plate. We must allow to touch the peas and smell the peas. If they feel safe to touch he may put them in his mouth. He may only put them to his lips. When placing the peas on his plate we must tell that we would like him to try **one** of the peas on the plate. This process will need to be repeated for a few weeks on a daily basis before may accept the food. This process will need to be repeated for each individual food. becomes quite unwell to the point of vomiting from the smells in his environment. Noises and large crowds also send him into sensory overload. Because suffers panic attacks, he is unable to travel independently on public transport. This means that when needs to get somewhere we have to drive him or accompany him.

I spend a great part of my day either addressing sensory issues. Desensitising to things in his environment. This is the work of a specialist Occupational or Behaviour Therapist. I assist with executive function tasks (organising, planning skills) as has significant impairment in this area of functioning. will not remember to eat if he is not cued. will not remember to shower or clean his teeth if he is not cued. will not recognise that he may have to take a warm jacket if he goes out in the middle of the day. He is unable to predict. It may be sunny outside as he is leaving but cannot imagine that it will be colder later. I approach these issues on an adhoc basis; putting out spot fires and overcoming road blocks. We do not know all of the stress triggers or the likely triggers in environment. Our approaches to management stem in part from his late diagnosis but mainly because we have difficulty finding an OT who can work with children over 10 years of age. We are also unable to fund ongoing life long allied health services without some financial relief through Medicare or another appropriate funding package.

When is not coping and starts to spiral into depression I provide counselling. I provide speech therapy by teaching the nuances of language, interpreting things for him. has a severe impairment of his pragmatic language skills. I may highlight to , that person is annoyed, distressed, excited etc. cannot read body language or facial expressions. He understands the most basic emotions, anger, sadness, happiness but not much in-between. I may have to make picture cue charts, remember to do this today charts etc. I provide social skills training for . This may be through the provision of social stories. learning to cope socially will be one of the key factors in him living and working independently as an adult. Somewhere in amongst the multitude of roles I must fulfil as carer (counsellor, occupational therapist, private chef, speech therapist, teacher, behaviour therapist, social skills coordinator and advocate) I am meant to be mother. Quite often my role of mother is lost amongst the numerous other positions that I must fulfil. I feel that my caring responsibilities have changed the fundamental mother child relationship. It is a very rare occasion where I can wake in the

morning know that today I am just [redacted] mother and I have no other obligations to meet in respect to his care needs.

My husband and I are also parents of our 15 year old daughter, [redacted]. I have a qualification in Community Development Work. My caring role has severely impacted on my both my social and economic participation. In the role as secondary carers both my husband & daughter's social and/or economic participation have also been affected. In the main my ability to participate in the workforce has been affected by systemic issues.

## **Background & Diagnosis**

Whilst on one level [redacted] was a happy baby he was also extremely difficult to manage. He was easily startled, difficult to settle, wean and toilet train. He did not cope with change. He had delays in communication. He was frequently unwell and took longer to pass through developmental stages. He was a very clingy baby and child. Our GP had difficulties identifying why [redacted] would go through periods of high pitched screaming. All she could offer was her home phone number in case he worsened in the night. With hindsight there were key indicators of ASD throughout his early years – however most professionals (Doctors, Audiologists, Maternal & Child Health Services etc) put his difficulties down to ear infections or that this was just his nature. At other times we were labelled over anxious parents who worried about too many things. [redacted] had some difficulties at Pre School but again these were overlooked and dismissed.

Once at primary school [redacted] was unable to cope. He was significantly bullied both inside and outside of the classroom, He found it difficult to maintain social interactions and friendships. He displayed behaviours which included hiding under classroom tables, isolating himself to the back of the classroom and running off in panic. Once again we raised our concerns about his inability to read social cues and his inability to cope. Again our concerns were dismissed. However, it was at this point that aspersions were made about our parenting. We



were blamed for our sons anxiety. We were desperate as        was becoming more and more difficult to manage. At the age of 7 he was regressing at home and had started bedwetting. There was a total lack of willingness for his first primary school to look at any other reasons for        behaviour other than our parenting. Our family had fallen into conflict with the school with both our family and members of the school staff becoming quite angry with each other. Children were bullying        in front of staff yet nothing was done. Parents were calling us at home because their own child had returned home distressed after witnessing incidents where        was physically hurt by others yet nothing was done. We were left with no choice but to move our children to another Primary School.

This was difficult as we needed to find a school where we thought        would cope, by this stage he was extremely fragile. We placed him in a new school at the end of his Grade 2 year. It took a year of working with        to help him overcome issues related to bullying. However, by this stage he was quite traumatised. He had suicidal thoughts and was becoming more and more withdrawn. He could not settle at night. We would lay with him for hours until he dropped off to sleep. There are simply no words which describe what you feel as a parent when your 10 year old child tells you that he would rather die than have the life he is living. Part way through his Grade 4 year staff at his new school had also formed the belief that        had significant underlying issues and referred him for assessment. We were unable to access the public system quickly there was a waiting list of over 12 months. We opted to go through the Private system. Even in the private sector we were faced with wait lists. We found a Psychologist but he had closed his books. We were placed on a cancellation list. Fortunately by the end of 2004 a client cancelled and we received their appointment time.

      was diagnosed with Aspergers (high functioning autism) the first thing        psychologist told us was "your boy does not read social cues." Whilst we now had a diagnosis; determining what services would best support        and finding practitioners who could work with a child who was already 10 ½ years was challenging. We have only just been able to source an occupational

therapist who will work with an older child. is now 13, he will be 14 in August. In the meantime we have worked at putting out spot fires. Doing the best we can. move into adolescence has been challenging. All in our family have dealt with grief and loss issues, even though we expected the diagnosis, we still went through the process. This has been extremely difficult for my husband. He has had to adjust from years of being told we had a badly behaved child and that we lacked skills as parents to our son has a disability and that his behaviour is not a reflection of parenting. As the primary carer I have been the main support person in the family.

During early years we had multiple caring roles. Both my mother and father in law had high care needs. My mother in law died in 1998 after many weeks in hospital. My husband and I spent huge periods of time finding an appropriate low level aged care home for my father in law as in 1997 he had been diagnosed with dementia. During this same year our daughter was diagnosed as having a rare form of glandular fever. She missed 6 months of her 4 year old Pre School year. She had symptoms which included anaemia, an enlarged spleen, loss of appetite, extreme tiredness and her liver was barely functioning. We were told in no uncertain terms that should sustain a knock or fall that her spleen was at risk of rupturing and if this happened she would die. It took 4 years for to fully recover. My husband would take time off out of his annual leave to accompany our daughter on excursions or sporting events as she was too frail to walk long distances.

In 2000 my father in law suffered a heart attack, he died after a month in a coma. We have juggled the care needs of multiple family members plus those of our sons with limited support. It is not surprising that I have issues with blood pressure, that at times I am exhausted. I don't remember what it is like to not be tired. Perhaps this gives you insight into why I place emphasis on understanding the journey a family has travelled in their caring role. No family should have to follow the same path as ours. No child should have to suffer as our son has. It is

for this reason that I am willing to disclose in a public forum what we have experienced. I do believe that things can be done better and hope that this is a step forward in creating better pathways for both carers and care recipients. I would however request that the names of our children be protected from public display. They are entitled to an element of privacy and as a parent I do not feel it is appropriate for me to decide on their behalf if they be named publically.

## **2 The role and contribution of carers in society and how this should be recognised**

An important element of recognising the role and contribution of carers is to understand that families are different. We have our own unique circumstances. Our care recipients disability may not be the same as that of another families. Even when a disability is the same as another's, it may present in the individual differently and impact on the carer in distinct ways. This is often forgotten in the recognition process. Often supports and services are based on a one size fits all approach. There is a lack of flexibility in the systems put in place to support those in need. For example, as a carer I recognise that support and interventions are not only formal community sector services and programs but may include support from family and friends. In our case we do not have any extended family network to offer us support or any level of respite. We are fortunate to have the support of some close friends but there is a limit to which one can impose on the generosity of friends. Often the system and society assume that we all have a wide informal support network to call upon in times of need. Such assumptions are often far removed from reality.

We are unable to access respite support or therapy based programs in Victoria because our son does not have an intellectual disability component to his ASD, yet his care needs are complex and his difficulties are as challenging to manage. This is an anomaly of the State – Commonwealth system. Our son is recognised as having a disability at Commonwealth level. At State level he is recognised as having a disability within the Education Department but within the Department of

Human Services, the main funding body for community based programs he is not recognised as having a disability and therefore ineligible for program support.

It is important to know that at 13 years of age our son is at home full time. We have been unable to find a school that will accept our son's enrolment. He has been at home full time since mid August 2007. Leading up to August 2007 he was at home sporadically either due to school refusal stemming from his anxiety or school exclusion at the request of his then school. These school exclusions did not always result from discipline measures, at times we were simply asked to keep him at home because he was stressed or tired or perhaps a programme that day(s) would not be suitable for him. being at home has resulted in me withdrawing from the paid workforce. I am unable to predict when I may be likely to return. Fundamentally, is at home due to systemic issues. In short the system has failed and continues to fail our son. In short I am unable to participate in paid work because of systemic issues. My husband uses his annual leave and works from home when he can to give me small periods of respite or to fulfil caring responsibilities on occasions when I am unwell or have other commitments..

Given our family's circumstances the type of respite needed is perhaps very different to that needed by others. For example, anxiety levels and the nature of his disability make it very difficult to send him on overnight respite. This approach to respite provision would perhaps be more of a detriment than a support. **As a carer I need our family's individuality recognised one way of doing this is through a flexible funding package enabling us to access mainstream community based activity programs around an interest of our son (and specialised programs when needed).** This approach gives our family some respite and provides with social inclusion opportunities and affords him an avenue in which to develop his social skills; a core functioning impairment of his. Such programs could be accessed at Community Centres, Neighbourhood Houses, local sports and recreation groups. For these programs need to be universal programs open to all members of the community.

As a parent I hold equally the hopes and aspirations for the future of both of my children. I aim to provide opportunities for my children by nurturing their strengths and helping them overcome or manage their weaknesses. I know that has the ability to be independent, to achieve and to make contributions to society himself. However, I accept that he will require more support and that it may take longer for him to achieve this than his sister who does not have a disability. At times I feel that this is not recognised. **The system and society assume that we are willing to accept second best or the bare minimum. This is not the case, I want the best possible outcomes for both of my children. As a carer I need this to be recognised through the provision of appropriate supports and programs.** My ability to have full social and economic participation is closely linked to the provision of these supports. Our experience of having limited supports available to us has produced the outcome of reducing my ability to fully participate socially and totally removed access to paid employment.

Our son's autism results in him externalising his behaviour. His challenging behaviour generally stems from sensory overload and difficulties in communication. He may hit out and has trouble controlling his emotions. His hitting out may at times be aggressive and violent. Other's with autism may internalise their behaviour, hiding and withdrawing. Both presentations are as equally difficult to manage but the system does not necessarily recognise this nor that both examples result in a carer providing the same high levels of care, More often than not society and the system does not see challenging behaviour as a symptom of our son's disability. We are often judged as having poor parenting skills, our son judged as a badly behaved child. We have even been accused through innuendo and inferences by school staff of abusing our son, despite him having a formal diagnosis of an ASD. Our son's diagnosis has been undermined by school staff where they spent enormous amounts of energy trying to prove that he was both psychotic and paranoid. Our entire family was sent for re assessment – this was not just an ordeal but done at great expense to the State. This was done despite our family and our son's medical team outlining in full the needs of our son and the strategies that would best support him to prevent panic

based behaviours. Despite the fact that we were referred for assessment by Bryn's then Primary School and that he was diagnosed by a Psychologist both recommended by the primary school and who is highly respected in the field of ASD. These judgements are often made by those who should know better. Perhaps it is their own inability to cope; but at the end of the day it is the care recipient, their primary carer and their wider family unit who wears the consequences of others in a position of power not coping. These are individuals to whom we entrust the care and wellbeing of our children for a large part of the day. If those who should know better are judgemental and/or not coping how do can we ask wider society to act differently?

Often these responses stem from the insecurities of those who make them. Perhaps they do not know what to do or even in some cases, do not want to manage a our son. However these responses have resulted in not just our son being bullied and harassed by his peers but our daughter as well. A number of our son's friends were also bullied and threatened because they chose to associate with him. Our son suffered a panic attack in 2007 resulting in an aggressive episode. Subsequently, our daughter was encircled by up to a dozen boys. These boys would not allow her to leave the circle. They then proceeded to make threats against our son's life – describing in detail what they would do to him. Our daughter was 14 at the time. As adults can we honestly blame other 14 year olds for such inappropriate behaviour? Should we not look at the adults in their school and home life. What examples did they provide to students of inclusive practices around those with differences? **I need it recognised that carers and the care recipient face many prejudices and value judgements on a daily basis and that there will only be a fundamental shift from this through ongoing funded and targeted community education campaigns.**

Quite often there is legislation in place to protect carers and the care recipient. However, the process that must be taken to ensure compliance, e.g. schools to be compliant with legislation such as the Disability Standards for Education is daunting and can come at great emotional cost to the family unit and result in

further social isolation. Families are often faced with the burden of having costs awarded against them should they be unsuccessfully in an action putting in jeopardy their financial security. Our family had to fight to get some of the most basis adjustments made to our son's program, despite there being legislation in place which compels schools to make such reasonable adjustments. Having a child with a disability at school is quite often a daily battle. These battles are exhausting. These battles are time consuming. These battles arise over each modification that is needed. Quite often these modifications attracted no cost, just some flexibility yet we still had to battle quite often with a refusal as a response. **I need it recognised that the systems put in place to protect the rights of those with a disability and/or their carers fail from the outset due to the enormous risks faced by users, safeguards need to be put in place to make these systems of protection accessible.**

What was in our opinion a lack of willingness by our son's secondary school to act upon his needs (despite him receiving integration funding) has not only impacted on my ability to participate socially and economically but has impacted on our daughter's ability to participate socially. At time it impacts on her ability to concentrate on her studies. She may have conflicting feelings, shame, guilt, love, embarrassment. She has been bullied and intimidated by others. She has been let down by the adults in her life on many occasions. Our daughter approached a teacher to offer assistance. The teacher demanded to know if this was how our son behaved at home. It rested upon the shoulders of a 14 year old girl to explain to a staff member that her brother had a disability and that he was in the midst of a panic attack which was probably triggered by a sensory issue and/or a communication difficulty. This teacher was totally surprised to discover that our son has a disability. We had formally requested in writing and verbally that the school both inform and educate all staff about our sons diagnosis and appropriate management strategies. How as a parent does one try to excuse inexcusable oversights. How do you ask your daughter who achieves high grades, is a school leader involved fully in all extra curricular aspects of her school to trust that her school will do the "right thing" when you know that they

have overwhelmingly failed, especially in light of her experiences? Despite what others may think, when at school siblings of a child with a disability are quite often a safety net and are carers in their own right. This caring role is often something that is thrust upon them.                also faces disruptions at home. When                is going through a bad stage the whole family goes through that stage with him. Sometimes it is only his sister who can get him to come out of his room. Whilst                may feel proud of her ability to engage with her brother it is also stressful and an enormous responsibility. These impacts are unpredictable. Continued disruption to her studies can jeopardise her future outcomes. **I need it recognised that siblings of a child with a disability have a significant caring role which carries high levels of stress. This caring role is not something they take on by choice. Siblings need support and understanding.**

### ***2.1 The barriers to social and economic participation for carers***

Leading up to August 2007 I was engaged as a project officer by

..... My employer was very understanding of my caring role and the need for flexible work hours. Of my 24 hour week I generally worked from home for 2 days of the 3 day week. On days when I needed to work from the office I was able to drive my children to school and then go to work. I was able to leave at 2:00pm in order to pick my children up at the end of the school day. I had flexibility to juggle the days I worked in order to fit in medical appointments. On my part when I could I provided flexibility for my employer. My employer placed emphasis on the work I produced as opposed to the hours in the day I worked. They had belief in me to do the job. The project I oversaw was a research project into the needs of those who juggled paid employment with informal caring responsibilities. I recognise and my own research showed that some employers support carers within their employ well. Others have a willingness to try but more often than not most do not.

The lack of appropriate community based support systems is what lead to my withdrawal from the paid work force. My inability to work is not from a lack of work available to me. I have been asked to take on many roles since August



2007, but have had to decline. Some of the barriers to my social and economic participation include:

- The unrealistic and intrusive requirement of schools for a parent to be available on demand. I have lost count of the number of times I had dropped my children to school to only receive a phone call at 9:30am (after driving some 45 to 60 minutes to my workplace) to collect my son from school as he was stressed and perhaps he should be kept home for two or three days. During such periods he was formerly registered as being at school. Despite this he still had an official recording of 21 days absence in one semester. On one occasion I refused to keep our son at home unless proper protocols were followed. I was not being difficult, just needing one day to get things organised.  
Background to my refusal.

*There had been an incident the day before where our son had behaved inappropriately. We expected that he would face a school exclusion. I was asked that day to collect our son early from school as a result of the incident. I cancelled appointments for that afternoon and started to make preparations for a school exclusion. My husband did the same. The school failed to follow proper protocols. When I collected our son we **were not** told then that he could not return to school the following day. We **were not** telephoned prior to the end of the day or prior to the start of the following day. There was ample opportunity to issue a suspension notice or to advise us verbally. School exclusions do not always commence immediately. Sometimes staff meet to discuss the issue before making a decision. We were not given a written notice. In Victoria a school must provide written notice and give a start and finishing date for a period of exclusion along with the reasons. This was not done. Schools are required to allow parents time to organise themselves, this is especially so in respect to a student with special needs. As we both had to rearrange a weeks appointments we needed this day to finalise matters. We had set in place sanctions at home for ... and explained to him that the school would also be setting consequences. That the school would speak to mum and dad about these, prior to them starting. ... was sent to school the following day in absence of any direction from the school. When ... arrived at school my husband was telephoned – he explained that we expected the exclusion but it was inappropriate to ring at 9:00am and expect us to accommodate the exclusion at such short notice. By this stage ... had been at school for ½ hour. We certainly would accommodate the exclusion*

starting the following day for the period set by the school. This was accepted. Then another staff member phoned and received the same explanation, this was accepted. In between calls phoned me to explain that would be excluded from tomorrow. Another staff member phoned during this series of phone calls. However this staff member could not get through because my husband was already on the phone to one of her colleagues. I was outside when this staff member made a call to my mobile, missing her call. I was loading my car about to head to my office. She left a message on my voicemail. I still have this message. She went on to state, I know you don't want to talk to me. is extremely agitated and twitching and in no fit state to be at school. is not taking my calls. If you don't call back or collect I am going to start ringing your emergency contacts.

When I picked up our son I found him to be calm but a little bewildered. I asked if anything had upset him. He said no. I asked what happened when he arrived at school. He responded by stating that he wasn't allowed to go into form assembly and join his class. That a teacher had put him in a room with one of the Aides. He himself wanted to know if he had done something wrong. was anxious because he had been taken out of his normal routine. He had been placed in a room and did not understand why. He thought he had done something wrong and was trying to work out what. I defy any reader to state that they would not feel stressed if faced with these circumstances. If neuro typical individuals would feel stressed under such circumstances imagine how a child with ASD would be feeling. never returned to school after this incident. We never received a suspension notice. was given an open ended suspension. When I enquired as to returning we were told not until both my husband and I had completed the interview. We were summonsed for the same late morning on a Thursday. We had both been juggling work and caring for . We explained we could not attend until the Monday and after 4:00pm. An appointment was made. On the Sunday, our son sustained a serious sporting injury needing surgical intervention. I was sleeping at the hospital. My husband phoned the school to explain the situation – that he would come to the meeting but could not be left alone, so I would not be at the meeting. We started receiving phone calls as to where we were at 2:00pm by another staff member. We decided that would not return to the school with the backing of Alfred CAMHS. CAMHS assessed and worked with , and referred us to two other schools. The two Govt schools would not take , is now at home full time on the Distance Ed Program.

- The lack of willingness by some school staff to work with our family and our son's specialists team in order to provide adequate care for our son.

- An unwillingness to make reasonable adjustments to our sons learning program and learning environment in order for him to cope in a school setting and subsequently access an education.
- The lack of appropriate planning by schools around our son's needs lead to regression in his behaviour and displays of behaviour that we had never seen before.
- The refusal by schools to allow a specialist to visit the school in order to identify possible stress triggers in the school environment and to work with both our son and the school with strategies. This happened despite the existence of the Disability Standards for Education compelling schools to put in place measures which ensure access to an education for all children. Our family had offered to meet the financial cost of this service yet our requests were continually denied.
- The general lack of understanding of Autism Spectrum disorders particularly in school based staff. School staff include teachers, principals, integration coordinators and visiting specialists from regional offices. Quite often integration aides, those working directly with students with special needs have no training at all.
- The absence of an independent complaints body within the Victorian education system. Parents must complain through the school hierarchy and then they can take their complaint to the Regional Education Office. At the regional office parents often find that their complaint is being heard by staff (predominantly ex teachers or visiting specialists) who have worked along side the subject of the complaint. There have been times when it has

become clear that the person recording the complaint may have a social friendship with person of whom the complaint refers to. This is unacceptable and is not tolerated in other areas of the community. We have an independent complaints body for the disability services sector, privacy issues, telecommunications issues, justice issues but there is none at education department levels. The inability to resolve issues around our son's education needs has been the overriding contributing factor to my exclusion from social and economic participation.

- The lack of allied health care practitioners with Autism training.
- The lack of allied health care practitioner who are able to or willing to work with an ASD child over 12 years.
- The lack of Medicare rebate support for individuals with an ASD who are over 12 years of age. This impacts on a family to fund ongoing allied health programs. Our experience has found that many allied health care practitioners specialise in early years intervention programs or may extend their programs for children up to 10 years and sometimes 12 years. This is often stems from targeted funding to specific age cohorts. There are very few working with over 12's. Those that do are not always geographically accessible. Others close their books or have a fee schedule which is cost prohibitive.
- The lack of funded ASD programs for those with an ASD without the intellectual disability component. It is outrageous that our son can only access Behaviour Therapy programs in Victoria if he has an intellectual disability and/or if he is at risk of entering the Juvenile Justice System. If he falls within the later he is then

treated as a juvenile offender. This is totally inappropriate management approach for an individual with ASD. The longer it takes for our son to access support programs the longer it will take for him to pathway successfully to a mainstream school based setting. As he does not have an intellectual disability he is not eligible to attend a special school. Additionally, a special school setting would not be appropriate for our child. The longer it takes to pathway our son to a school the longer it takes for me to participate socially and economically.

- The absence of Autism specific schools, particularly at secondary school level and for those with ASD without the intellectual disability component. Indeed there are none in Victoria that we can find. Our son is enrolled in the Distance Education Centre of Victoria; a Victorian Government School, along with a number of other students unable to attend a school based setting on medical grounds (social emotional status). This is an inappropriate learning environment for our son. Parents are required to be at home to provide supervision and support. This in effect starts to change the relationship between the parent and child. It also assumes that a parent has the capacity to support the child and that the student has the capacity to undertake study by correspondence. The support systems in place are not suitable for those with ASD.
- The inability to transfer our sons \$17500 per annum integration funding package from his Government Secondary School setting to his Government Distance Education School. Our son needs significant support in order for him to complete his

studies. To receive some in home support it was necessary for our family to complain to the Victorian Minister for Education. We were then and only then advised that we could apply for funding under the Commonwealth Program for Students with Special Needs so severe they are unable to attend school. Upon applying for this funding we were granted a \$14,100.00 package, some \$5400 less than what we applied for and some \$3400 less than his school based funding. To support our son at home we need to purchase one on one services. We were funded for \$35 per hour for in home tutoring. We are mandated under the funding agreement to provide a minimum of 8 hours tutoring per week. Our enquiries found that the standard rates for tutors range from \$60 up to \$80 per hour. If we were to engage someone at \$60 per hour our family who has already lost a part time income of \$30,000,00 per annum would need to meet the shortfall of \$1000 per month but this shortfall could have effectively blown out to \$2000 per month. We have been fortunate to find a student teacher with the capacity to teach and provide pathway skills to a school setting (a requirement of the funding) who will accept \$35 per hour. When applying for our funding package we opted to carry some of the shortfall for Occupational Therapy and Speech Therapy Services. The funding application was completed by the Distance Education Centre in consultation with our family. We relied on the Distance Education Centre for appropriate fee scales for tutors as this is not an area of my expertise. The State is required by law to provide our son with an education – it is totally unreasonable to not only ask a family to take on the role of primary educator but to also expect them to make up the financial shortfall of providing the education supports that our son needs to access his learning program.

- My limited and disrupted earning capacity during some of my key working years will result in me retiring on reduced superannuation and savings, further impacting on my social and economic participation as I enter retirement and throughout my retirement years..
- The stress experienced by me as a carer and my risk of physical injury (when having to restrain or lift my son) is also a risk factor to my social and economic participation.

#### **4. Practical measures, key priorities for action & strategies to assist carers to access the same range of opportunities and choices as the wider community**

- As a carer I need our families individuality recognised. One way of doing this is through a flexible funding package enabling us to access mainstream community based activity programs around an interest of our son (and specialised programs when needed). Another is for Government based services/programs (e.g. Centre Link) to take into consideration a families broader circumstances, support systems etc as part of the eligibility process. There should be emphasis on the amount of care provided as opposed to an individual with a disability having to meet a medical based model of eligibility criteria. Our son for example can make himself a simple sandwich and get himself a drink. However, if there is not someone there to alert him to the fact that it is breakfast/lunch/dinner time he will not eat. He will not recognise that the feeling he has is one of hunger until someone cues him. Under the adult system for carers allowance

(which comes into affect at the age of 16) or disability support payment he would be deemed to have adequate self care skills.

- The system and society assume that we are willing to accept second best or the bare minimum. This is not the case, I want the best possible outcomes for both of my children. As a carer I need this to be recognised through the provision of appropriate supports and programs. When I am supported to meet the needs of my child with a disability I do well. When parents do well families do better. When families do better children do well, providing them with improved chances to lead an independent life and to contribute to society as adults. When I am supported I am able to address my son's needs more effectively and take that step to re enter the workforce.
- I need it recognised that carers and the care recipient face many prejudices and value judgements on a daily basis and that there will only be a fundamental shift from this through ongoing funded and targeted community education campaigns.
- I need it recognised that the systems put in place to protect the rights of those with a disability and/or their carers fail from the outset due to the enormous risks faced by users, safeguards need to be put in place to make these systems of protection accessible. In the case of the Education sector this may be addressed through the provision of an independent complaints commissioner within each State and Territory.
- When Carers endeavour to work with schools around the needs of their child they are often faced with education professionals who lack knowledge of disability related issues and/or hold attitudinal beliefs in respect to disability. Under such



circumstances the management of the student with a disability in a school setting often becomes untenable. The outcome is the Carer has the child with a disability at home during periods of school exclusion or school refusal. If the situation cannot be resolved circumstances can reach crisis point where the student is either withdrawn or expelled from a school. Carers may not be able to immediately place the child in an alternative school setting. This may be for a significant period of time or on a permanent basis. When on a permanent basis the carer is faced with administering an education program from the home environment. All scenarios directly impact on the carer's ability to maintain or retain employment. A mandatory and extensive professional development program for education professionals needs to be set in place for practicing teachers. State level peak bodies, e.g. the Association for Children with a Disability in Vic have the expertise to provide government funded professional development programs around the needs of children with a disability in schools. They are also well placed to provide guidance on the development of disability training packages for trainee teachers. A mandatory component on disability must be introduced to all teacher training programs complimented by trainee teachers undertaking a quota of their teaching rounds working with students with a disability in either a mainstream or special school setting. This enables the trainee teacher to relate theoretical based studies to practice.

- I need it recognised that siblings of a child with a disability have a significant caring role which carries high levels of stress. This caring role is not always take on by choice. Siblings need support and understanding. At times a sibling may also have the need for counselling services. Provision should be made by

Government to provide Medicare rebate able counselling services for siblings of a child with a disability.

- Taxation concessions for families or individuals with caring responsibilities. Especially for those who are forced to move out of the paid work force due to caring responsibilities. Tax concessions should be flexible. To be used to either offset the loss of income or to be paid into the carer's nominated superannuation fund in order to provide increased retirement income. Eligibility would be based on those who have passed the eligibility test for carers allowance and/or carer payment.
- Continued improvement of in the communication between the Commonwealth and States. With a more COAG based initiatives. The needs of carers covers a broad range of portfolios including DEWR, FAHCSIA, Education and Health and Ageing. It is important that support systems be as seamless as possible. With programs within and across the range of portfolios complimenting each other. As such issues pertaining to the needs of Carers and Care Recipients should be overseen by Office of the Prime Minister and Cabinet. This approach should be replicated at State and Territory level, through the Office of Premier and Cabinet or their equivalent. This will allow for an effective policy framework to be developed and provide links between the three levels of Government and other key stakeholders.
- The provision of funded training support packages and workplace mentors for carers returning to the workforce. Provision of a return to work allowance enabling carers to purchase appropriate workplace clothing and/or equipment.

- The provision of Medicare Rebate allied health services for all individuals with ASD within all age cohorts . Providing re bates in a limited range of age cohorts, whilst designed to support families has disadvantaged many others. We have faced enormous difficult just finding specialists to work with our son who is over 12 as specialists appear to shift their emphasis to where funding dollars are directed. For those who remain there are large waiting lists or their fee structure becomes cost prohibitive. . is ineligible for the new autism package because he is over 12 years of age. Even with finding an OT we will be unable to fund the ongoing intensive allied health services he needs. An individual with ASD has life long care and therapeutic needs. Some issues arise at key transition stages, early years, transition from early years to school, adolescence, transition from primary to secondary and transition from secondary to post secondary schooling/or adult pathway programmes.
- The right for all Carers to request and have flexible work hours. This has right has been legislated in the UK.
- Carers leave is inadequate. It could be extended to 10 days per annum and have more flexibility. Many carers use their annual and sick leave to fulfil caring responsibilities, leaving them vulnerable should they need this leave for their own health needs. Using annual leave for caring duties results in carers returning to work unrested, This impacts on productivity and contributes to poor health. Currently employees are required to provide a medical certificate in order to be eligible for carers leave. Carers are not always providing care which stems from a medical intervention. Often carers need leave to provide

supervision, in our case, school exclusion, or to attend appointments with service providers, e.g. schools or day programs. Carers leave could include a percentage of days without the need for a medical certificate. Eligibility for Carers leave could be managed by an employers HR division; where a carer discloses their caring responsibility; ensuring the carer privacy in respect to their caring role.

- Some large Australian companies have effective flexible workplace policies for carers within their employ. This includes initiatives such as sick leave and carers leave pooling. Companies such as the National Australia Bank and Malleon Solicitors are leaders in the field of the development of effective flexible work place policy models in addition to carer support programs and staff wellbeing programs. Many companies may want to support Carers within their employ but do not know how to go about it. Others need to be engaged. The development of online carer information kits to support employers would be a positive step. Many not for profit organisations e.g. Multiple Sclerosis Australia and Carers Australia, are well placed, with the support of appropriate funding, to provide training to employers in supporting Carers within their employ.
- Smaller to medium size businesses may need assistance to implement measures to support carers within their employ especially around the issue of closing the sick leave and carers leave gap. Where people have no opportunity to extend their paid leave through their employ but need time off and retain their job too, it is important to ensure there is no income support gap. Currently carers use their leave entitlements to fulfil caring responsibilities. A 2005 Access Economics report found 25% of

all primary carers have gross household income in the lowest quintile.

Supporting both the carer and the care recipient is fundamental to a carer being able to participate socially and economically. I thank you for accepting and considering my submission.

Lisa

26<sup>th</sup> June 2008