

Submission to Australian Parliamentary enquiry into FASD December 2011

Unfazed by FASD – A parents' perspective

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Signed:.....(please see separate scanned page)

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Unfazed by FASD – A parents’ perspective

From Paul Harper

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TERMS OF REFERENCE

Part I – Debbie’s story – seeks to mainly address the second term of reference: ‘**Intervention Needs** ...the early intervention therapies aimed at minimising the impact of FASD on affected individuals.’

Parts II and III seek to mainly address the third term of reference: “**Management Issues ...access** to appropriate community care and support services across education, health, community services.... for the communities, families and individuals affected by FASD.”

It should be recognised that there is considerable overlap of these terms of reference between the three parts of this submission, due to the nature of giving this account in a clear, sequential manner.

It should also be recognised that, as foster parents trying to put together this submission while still in the throes of significant health and education difficulties, the stresses of time constraints to get this completed by the due date have been substantial. Therefore some allowance needs to be made for the ‘roughness’ in some sections of this presentation.

I Debbie’s Story

This is not meant to be an exhaustive account, but just enough to let people into Debbie’s world in order to understand our observations and maybe take on board our suggestions regarding FASD.

WHAT ON EARTH IS GOING ON?

Debbie was born in the high-rise public housing estate in Flemington. Both of her birth parents were heavy drinkers. Both of them came from broken families of heavy drinkers. What my wife Kerry and I witnessed during our 5 years as church community workers in Carlton was an education in reality. The reality of our welfare classes is by and large a sad indictment on the attitudes of our society as a whole. Left without hope of a future, many families like Debbie’s are locked into such a savage cycle – not of poverty, because they have enough money – but rather a poverty of spirit. Brought up in pain, violence and neglect, life becomes an all-consuming quest for happiness in a sea of troubles. The four sources of consistent, reliable happiness for Debbie’s parents were cigarettes, alcohol, sex and gambling. These circumstances, habits and life-cycles ‘submerged’ their humanity, to a point where it became almost invisible. And yet, if you looked close enough, got alongside them in daily life, every now and then we got a glimpse of the lovely personalities, strengths and possibilities that lurked just below the surface. These people didn’t have to turn out like this. Somewhere along the line they had no choice but to step into the abyss, with no-one to pull them out. Debbie’s story is about just one person who, by the grace of God, was pulled out.

A STORY FROM HELL

We first heard about Debbie from some of our friends who lived on the estates. It was hard to believe the reports we were getting about this baby. And some of these people who themselves were alcoholics were shocked at what they were seeing, wanting us to do something about it! But what can you do when you hear of a 5 month old child, in a seedy pub, having brandy poured down

her throat to keep her quiet? Or the mother, while in the community coffee shop, making up the baby's formula with boiling water and then proceeding to feed the child straight away? And this is only when they are in public! The mixture of revulsion, anger and helplessness that welled up in us was like the effects of a computer freezing up from data overload. What on earth could we do? Fortunately for Debbie (and me) my wife has some ridiculous capacity to 'reboot' her emotions every morning. So she went and saw this child for herself and with the maternal instincts in overload accompanied the mother to an appointment at the children's hospital to see the paediatrician. And that was all it took. Seizing on the opportunity to get someone 'on the ground' involved, someone who was not part of the system, but could work independently, he begged Kerry to take Debbie for just a week, to see if she could put some weight on. This was because he was close to advising a feeding tube be inserted directly into her stomach, because she would not feed properly (no wonder). Debbie was still her birth weight. At this point Kerry 'invited' me to come and have a look for myself. My life was about to be irreversibly changed forever.....

ENCOUNTER THIS

We arrived at the flat about 11am. No-one answered the door. After some more knocking, 'Bob' answered. We were welcomed in and could straight away see they were still in bed. Kerry and I made a beeline for the cot, and what I saw I will never forget. I've skinned plenty of rabbits in my time, but nothing could have prepared me for the sight of a human being who looked so exactly like one. Listless, unresponsive, skinny as hell, Debbie had not been fed or changed that morning. I cried; I simply could not believe what I was seeing.

RESISTANCE IS USELESS

In the car, before going up to the flat, Kerry had related what the doctor had requested. My response was emphatic: "There is no way we can take this child long-term. The impact it would have on our lives and our ministry here would be simply unsustainable. So one week means one week; she goes back after that." After one week Kerry returned with mum and child to the doctor. Debbie had gained 210 grams. His response was one of jubilation. And... "Could you possibly take her for another week, just to put on a little more weight?" When Kerry came home with this wonderful news, the sense of becoming part of some bizarre TV reality program was growing... "Ok but she goes back after one more week – you know we can't possibly do any more." "Yes dear", she replied.

ONE INTELLIGENT HEART

Another week and 200 grams later, this amazingly bright doctor must have been barely able to contain himself, and so brazenly ventured a third 'offer'. My response to Kerry was the same, but must have been sounding pretty lame by now. At the end of the third week, Debbie did go back. And the scene in our kitchen is another branded onto my brain. Our two daughters, aged 10 and 14, protested "You can't let her go back!" We sobbed together uncontrollably. In just 3 weeks we had all become so attached to this precious little life. Even though we'd had virtually no sleep, with Debbie screaming every single hour. Debbie had shown us who she was and where she wanted to be, in no uncertain terms.

Debbie was a deeply sensitive person who wanted to thrive. Even though the brilliant paediatrician had declared, "She won't thrive; she'll just survive"; he was wrong. The only thing stopping Debbie

was an issue of trust. The reason Debbie wouldn't feed was because of what had been put down her throat. Our first job was to get her to trust someone in that regard. So at 5 months, we taught her how to drink from a bottle again, stroking from the chin to the throat while holding the bottle in the mouth, until she could see that nothing bad would happen. By the third week, she was taking in reasonable amounts with confidence. And her confidence in trusting someone suddenly opened up, latching onto Kerry for dear life, while 'tolerating' the other three of us as we used our rough-house play tactics to coax any normal baby response we could get out of her. And this meant dealing with something else that was completely new....

Debbie had developed a 'fascinating' defence mechanism to protect herself from any form of pain. She would hold her breath, stretch every muscle she could in her body, so her arms were straight out sideways, back arched backwards, until she knocked herself out cold, even turning blue in the lips. It was a scary sight and could be brought on by the milk being just one or two degrees too warm, or a slight knock as she was being moved around, or a pain in the stomach. And she would do it anywhere – on a tram, in bed at night, in the car or pram, totally unpredictable. But after 3 weeks with us, over the next 10 days that she was back with her parents, she started doing it whenever one of her parents picked her up. Despite all the damage done to her in her first 5 months, this child showed an extraordinary intelligence that defies belief. She had chosen her new mother.

PROTECTION DUTY

The next 10 days were interesting to say the least. Kerry was asked by Health and community services to visit the family daily as they did not have enough workers to allocate one, and on a few occasions I also attended. We could now appreciate the state of their day to day living. Kerry also hung around with the assigned social workers and officers from protective services. The big advantage we had was our independence from beauraucracy, where we could simply turn up unannounced. Making a daily journal of all we saw was very helpful for the authorities, to get an accurate picture of what was happening. During this time of course, Kerry and everyone else were trying their hardest to instruct the parents about the right way to bring up a child, but all to no effect. It was clear that these parents just could not do it, given the levels of addiction, poor living skills and general lack of motivation. As a result, we were left in no doubt that our allegiance lied with Debbie and what was best for her. It only took 10 days for the court to issue a 3 month custody order with us.

AUTHORITIES IN CRISIS

Mention should be made here of the extreme difficulties faced by our government bodies responsible for Debbie's welfare at the time (and it would seem from media reports that not much has changed in 15 years).. Foremost is the issue of personal rights. From the outset it was clear to us that the rights of the birth parents superseded the rights of the child. For the first three months Debbie's parents were given access to her three times a week at our house to enable them to see how to care for her in a family setting, because, naturally, they have rights. But more than that, the prevailing philosophy was that the only rightful place for Debbie was with her birth community, and this was the only proper place for her to somehow live out her 'authenticity' as a member in our society. "That's where she belongs"; "She'll fit in there best"; "We have no right to impose our wishes on how she might turn out" were the sorts of things we heard from social workers and agency staff continuously. The feeling was much similar to the feeling associated with the stolen

generations. But there is a huge difference – what happened to Debbie had nothing to do with ethnic background, tradition, identity or ties to a particular geography. It was purely and simply caused by a cycle of welfare in which the abuse of alcohol is widespread. Debbie's was not the only family we witnessed being damaged by alcohol – there were hundreds we were personally involved with. We can either choose to, as a society, "leave them where they fit in" (ie all of them) or we can start addressing the underlying causes and change our expectations to enable whole families like this to 'fit in' to the rest of society rather than being sidelined into a ghetto. Enabling involves healing, restoring, retraining, coaching, planning, discipline, resources and above all commitment to see it through. There is no plan, no process to enable people to exit welfare and build a productive life, because there's no hope, no vision.

It is into this environment that social workers and agency workers find themselves immersed. Added to that, most of them are young and inexperienced with the rigours of life in general. Faced with a case like Debbie's, they throw their hands up in the air in desperation and frustration, unable to effect change or even see a way through the maze. Their only guide seems to be the set of rules they have to follow, which are all about the parents' rights on one hand and the rights of the child on the other. In practice what this leads to is a situation where children are only removed when they are on the verge of death, and the only right place to send them back to is the family home, after a period of recuperation.

Every applicable department had been involved with Debbie's parents in the first 5 months. The royal women's hospital kept the mother and child in for a month after the birth due to concerns, the Queen Elizabeth centre where her mother had stayed with Debbie to teach her how to care for the baby. We were allowed so much access because the agencies were unable to provide any more assistance and funding was exhausted for this child'

The government department involved with Debbie persisted for 6 months to try and 'share' the parenting with us. But nothing could possibly improve while the parents' own lifestyle failed to improve. Continually trying to force the child back into her original home where nothing had changed only caused greater trauma to Debbie. It came to the point when the social workers were unwilling to take Debbie to her parents for access visits (they found it emotionally hard and distressing to distress Debbie by taking her somewhere she didn't want to be) and their manager was required to supervise one. The manager did not believe the workers or Kerry when told that Debbie was having 'breathtaking' fits when handed to the parents for access. When the manager finally did take Debbie on an access visit, Debbie screamed all the way over and all the way back, with several fits in between. The manager handed Debbie back with "Here- take the bitch!" at which point Debbie stopped screaming, turned to the manager and laughed. Debbie's loudest, most persistent advocate for removal was herself. How many other children are screaming out in different ways, but not being heard? How many children after years of this have lost the instinct to live, replacing such behaviours with destructive ones?

A FLOWER BLOSSOMS

These 6 months saw incredible change. We witnessed the resilience of a life that had become so utterly damaged. Debbie's ability to bounce back from death's door, with a determined desire to develop into a normal child was like a miracle unfolding before our eyes. All we did was the regular stuff we had done with our own children. We played with her, cuddled her, spoke to her,

manipulated her arms and legs to teach her how to crawl, comfort her when she fell or had a pain in the tummy, dressed her up, took her out, and so on (90% Kerry of course). What emerged was the most adorable, cheeky, fun-loving little imp you will ever meet. To experience her very first laugh at about 7 months of age was to receive a blessing of the highest order. And it was such a unique laugh, a half-giggle half catch-the-breath squeak. Then a few weeks later, while waiting around in the family court, we heard her mother laugh – and it was identical. Three months became another 12 month court order, at the end of which a magistrate expressed a very rare joy for him, in awarding us permanent custody, such was the transformation of this child. It was during these 12 months that Debbie gradually learned to trust our other 2 daughters and me almost the same as Kerry. The breath-holding fits became less and less, until one day when she hurt herself it finally gave way to a good old bellowing cry instead,(which was as joyful to hear as her first laugh).

A MEDICAL SUMMARY

Debbie's medical condition is one where the effects of FASD are amplified by a genetic disorder inherited from the birth father called Microcephaly (small skull). What this results in is an extreme form of FASD, because one of the possible symptoms of FASD by itself is microcephaly. Debbie has all the facial markers of FASD, but the underlying muscle structures in her whole body are of much greater concern. This is called Global Dyspraxia, where it is not only the intellectual capacities that have been compromised, but also the regular working of every single muscle in her body. It took much more time and practice for Debbie to crawl, walk, talk, bathe, brush, dress, write and so on. The muscle tone throughout her body is so low that each part requires much more practice to master and control. But she gets there. Once she is coached enough in a particular activity and sees the benefit produced for herself, her confidence grows and determination builds to go to the next level.

What we think is unique about Debbie is that these physical effects are linked to the intellectual effects in such a way that they become an outward manifestation of what is happening inside the brain. The way to get results intellectually is to use the same methods that work physically. Constant repetition, celebrating the incremental gains, then pushing onto the next level, creates in the child a momentum where they can see the gains and 'go for it'. But this requires lots of 1-to-1 support, helping the child to focus (and keep it interesting) for extended periods during the day and over the months, consistently building in a progressive way without letting up. So for example, even though Debbie has no depth of vision and poor balance, she can now throw a basketball through a hoop and ride a bike without running into anything. How is this possible? With enough practice the brain learns to 're-wire' itself. The trick is to think of the brain as just another muscle. Even though with FASD the membranes that separate the different parts of the brain have become thickened (this is the core neurological issue), preventing easy connections from one part of the brain to another, SOMEHOW the brain can compensate when forced to do so repeatedly. This method has been proven effective in people with Acquired Brain Injury, where intensive therapy can produce amazing results. The question is do we have the commitment to put similar time and resources into those who have acquired the injury not through an accident, but while in their mothers' uterus? And if such success can be achieved with the most extreme version of the disorder, then how much more can be done with those who are nowhere near this level of disability, but are nevertheless struggling terribly to cope?

II CHALLENGES ALONG THE WAY

FROM THEN TO NOW

Debbie has continued to develop steadily over the past 16 years. She has had 18 operations to fix physical defects in her body that could be improved, to enable a higher, more normal functioning. In every context we have found ourselves in, we have encouraged her integration. Whether it has been on the high-rise estates in Carlton, or among our various church communities in Mulgrave, Bacchus Marsh or Ballarat, most people have been drawn to Debbie's charming personality. Aside from all the operations and the regular activities of a growing child, the biggest challenges have been teaching Debbie to swim and to read. We focussed on these two things because from early on Debbie showed little glimpses of enjoyment that grew the more she was exposed to them.

Kerry had quite a struggle getting a swimming instructor to teach Debbie. From one place to another, one instructor to another, she eventually struck upon some who had enough confidence and diligence to keep it up. Now Debbie can swim better than either of us can, and has won medals in several Special Olympics State Games. Even though this is the most positive, successful activity Debbie can do, there are nevertheless times when her motivation is low (like any teenager) and we have to push. Debbie doesn't have the luxury of being able to drop one activity in favour of another, like regular kids do. If she was to drop swimming then only bike riding would be left for strong physical exertion, affecting her fitness and also social outlets. So a delicate balancing game between encouragement and discipline is what we play out. Sometimes we just have to let swimming practice go, because Debbie is too tired; sometimes a little 'reverse psychology' is all it takes to get her motivated; and more recently, discussing the different 'compartments' of her life with her and how exercise is important works too.

III EDUCATION – A MAJOR ISSUE

SCHOOLS THAT WORK

Our experience of schools has been varied. Only 2 have performed very well for Debbie: one a private school and one government. Bacchus Marsh Grammar went out of their way to provide whatever Debbie needed, generating not only a supportive environment among the staff but also the children. We are confident that if we could have stayed in the area Debbie would have done all her schooling there, despite the growing gap in abilities with her peers (which is now about 8 years).

But another school, which might be thought of as at the other end of the educational scale, a government specialist school, was also excellent. Ashwood School performed wonderfully in teaching Debbie to read and do everyday tasks like tie her laces. The energy and attitude in tailoring programs that actually work was obvious to see. They kept us on our toes, introducing new things on their own initiative and involving us in every aspect of curriculum development. They always had multiple staff at IEP meetings and always resolved issues by following them up promptly. This developed over 5 years into a truly collaborative approach to Debbie's learning.

SCHOOLS THAT DON'T

We have had long, personal conversations with other parents along the way. We are not the only ones struggling just to keep going with a disabled child – that's enough by itself – but also currently struggling with a school which is simply unwilling to listen to our concerns and make the necessary changes for our child to reach her true potential. Our observation is that this situation comes about in part because of the makeup of the school community in any given location. There are some government schools where the numbers of professional parents are sufficient to exert considerable influence on what happens at the school. But for the rest, there seems to be an assumption among parents that whatever limitations there are on the level of education at those schools, you simply have to accept it; it's no use protesting about perceived inadequacies. Many parents so implicitly trust their school, and it would never even enter their mind that perhaps things are not being done as well as they could, or should. And among those who do perceive something wrong, only a fraction would have the confidence, or time to even raise the issue, let alone follow it through to a substantial resolution. An institution such as a school is a formidable thing to tackle for many parents, if the first port-of-call, the teacher, is not equipped, willing, and supported to deal with issues adequately. So many parents, if an issue is not dealt with adequately by the teacher, will never take the issue any further. It seems to us that it is only in those contexts where the parent body has sufficient numbers of concerned parents who demand excellence that thorough, lasting change for the better occurs. For the rest, it would seem that an unacceptably large proportion of students are not benefitted the way our education policies intend them to be. As a result, our burgeoning problems of welfare dependence, alcohol abuse, domestic violence and further generations of the same continue to swell.

We have spent many a sleepless night over the past 3 years worrying about Debbie's future and wracking our brains trying to work out how to convince school authorities about the appropriate teaching methods that work. During this time our concerns have largely been ignored and not followed up. We have been met with patronising attitudes, where only teachers and principals have the professional training to make any comment on curriculum and teaching methods. We know nothing about teaching and can't imagine what it takes to teach children like these. And so a simple request like just 10 minutes per day reading Debbie's reader was taken as an unreasonable demand. For 2 whole years it could only be done twice a week, because "I've got 11 other students to attend to as well." But while it must be acknowledged that numbers are an issue, it is still not an excuse. Somewhere, sometime, someone has to do something to fix this deplorable situation, if FASD kids are going to do any good at all. The pressure this places on us as caring parents is almost unbearable, and in the end forces us, like many others, to back off and make other arrangements to see that our child gets what she needs.

AN ESSENTIAL ATTITUDE

We are soundly convinced that appropriate learning models can be implemented which are suitable for kids with FASD, because in at least 2 schools (even before a specific program was designed for FASD) they were able to intuitively deduce what was required and had the will to work hard at an individual program that worked in their context. Both of these schools were determined to demonstrate measurable outcomes and modify teaching methods to suit, while creatively weaving the particular emphasis for Debbie into a broader network that was beneficial for the other students in the class as well. Where the will and creativity are present, astounding results can occur.

The 7 key elements in effective service delivery in education, as we see it, are:

FOCUS

Appropriate class size and focus. If a specialist school tries to incorporate too wide a representation of disabilities in the one class, there will be a reduced capacity for beneficial outcomes for children like Debbie. **Focus** is the key word: employing a system that enables a sustained focus of attention allows the brain to reorganize or 're-wire' itself. Without focus, the information gathered remains scattered, leaving out the necessary connections for information to become embedded in long-term memory. Therefore too many distractions or disruptions during class time impede heavily on this. Our recommendation is that class size within a specialist school should be limited to 8 students with a full-time teacher and teacher's aid. Anything above this requires a second teacher, where the 2 teachers can work as a team, utilising the teacher's aid more effectively, A second teacher's aid instead of a second teacher would not be effective.

TIME

Appropriate 1-to-1 time and support throughout the school day. In a class with mixed disabilities , each child requires different things. Some within the class will be able to do schoolwork with less direct supervision than others. FASD kids need to be seen as top priority when it comes to step-by-step instruction, rather than letting them 'phase out' after receiving a list of instructions. There may be a problem with motivation or understanding the instructions, which compromises the child's confidence about proceeding with the task. Very often it's just a small detail that prevents them from going ahead with what has been asked of them. But with ongoing checking and clarification, a child like Debbie can pick up momentum, confidence and good results.

REPEATING

Regular (daily/weekly) reiterating, retesting, revisiting of key concepts is vital, because concepts and processes learned one day may not yet have made it to long-term memory by the next day or week. And it is completely unpredictable which things a child will pick up quickly and which things they won't. We are constantly surprised by the random things Debbie somehow picks up on the first time and never forgets; but this is not the norm and it should never be assumed that if she can do it once she can do it again. Constant repetition and retesting is required to assess what has and has not been remembered. It is also vital that educators do not give up on this process. Overall progress is incremental and slow, but 2 things remain constant: 1) the child's desire to do well and 2) the certainty that the child will become very frustrated and disheartened if **they** don't see real progress themselves.

Varying the **mode** of delivery while **maintaining** the obvious **focus** of a particular subject often gets the best results. A simple example is the retention of new vocabulary. If a student says it, reads it, writes it, spells it each day for a week, they may retain the word for a month. But if they do all those things just 3 times during the week (which is essential) but the teacher and family are aware of the new word, keeping that word in the back of their mind for the week, and utilising the word, (in a way that is obvious to the child), in as many natural settings as they can (general discussion, tv, radio, reader, emails, phone texts, etc) the child has a much greater chance of retaining the word forever (and being able to use it properly).

EXTENDING AT HOME

Proactively involving the family in the education of their child. Repetition is so critical, it must continue beyond the school walls. Getting the child to exercise the brain every day, rather than just school times requires a significant partnership between parents and teachers that goes way beyond anything normal. Trying to make this interaction enjoyable is the key, because otherwise it can become a grinding chore. So things like making a game of it, exchanging jokes, aiming for prizes, sharing success stories and the like go a long way to developing an open, free-flowing highway of information back and forth which conveys a consistent direction for the child to move along with enthusiasm. Without this complete consistency between home & school, the child develops a '2 worlds' view that is confusing and perplexing, often refusing to co-operate in one context because something different is required in the other.

LISTENING

Listening to parents who are passionate about contributing to the education of their child. It is obvious that we are all growing in terms of learning about FASD, the effects and what works to help. It is essential that the various insights from different sets of circumstances be given enough attention so as to incorporate and test new methods. So many unpredictable and strange outcomes emerge naturally within the family home, which can all contribute to a better understanding of the varied outcomes with different methods along the scale of this 'spectrum disorder'. So when a parent suggests to a teacher a particular method of teaching which has proven effective, then the school should do everything possible to incorporate it, test it, refine it and expand upon it. Unfortunately the school where Debbie is now has no such desire, but instead becomes offended at any suggestion of teaching methods, refusing to take these things on board. As a result we now have an unavoidably hostile relationship with the school, where we have had to remove Debbie one day a week for private tutoring and home schooling just to advance her basic numeracy and literacy. We have also had to engage a private Speech Therapist for the same reasons. Both of these cost us considerably in money, time and energy. And even after formal complaint to the Victorian Education Department, the issue remains unresolved, largely due to competing government policies that seem to leave such schools largely unaccountable when it comes to measurable results. So when a parent criticises their results the school feels no obligation to correct or even address them if they don't want to. And nothing short of a parent revolt will make them. This is a situation that is clearly unsatisfactory.

COACHING?

Coaching parent-to-parent may also be a worthy aim in such schools. We have experienced great encouragement while being part of a parent support group, in relation to general information about disabilities services. But we are wondering if a similar approach to extended learning in the home may be a way forward especially for FASD kids and their families. We can well imagine the different backgrounds where less than ideal circumstances are evident in the home. More able parents, especially once their child becomes older and more independent, can be a valuable source of 'life-mentoring' for other parents. It is our opinion that this needs to be investigated and trialled. A simple example is cooking. If an FASD kid never gains a real interest and confidence in cooking good food, then chances are they will spend most of their lives eating takeaway and gaining weight in front of a TV, with low health and energy. And if the family that child grows up in has low confidence

and drive to cook well, then nothing will change, bad habits will become ingrained. But in the current climate of excitement about cooking good food, even among children, now is a perfect opportunity to be doing in-home cooking classes for parent and child alike. It may be possible that 3 objectives can be achieved in the one activity: teaching a child how to cook; teaching a parent how to cook; and teaching a parent how to teach their child!

And to finish, a most important point:

INTELLIGENCE

The problem with these children is not underlying intelligence. These children could be described as slow, or disconnected, or confused, or lacking confidence, or stubborn, or even criminal in some instances, but they are **not** stupid. If educators focus on the limitations, what a child can't do rather than what they can do and have the potential to do, then those educators will fail. It is a constant exercise in 'can-do' mentality that is required.

Thank you
Paul & Kerryn Harper
December 2011