

Key Note for the Disability Employment Service Conference - Perth

Thank you for inviting me to provide the keynote for this conference.

I am honoured to be part of this conference. For a person with few formal qualifications who never expected to be of interest to anyone apart from my immediate family, standing up here is quite humbling.

I have been asked to give this address on Fetal Alcohol Spectrum Disorder and its importance to the employment industry in Australia.

I am sure there is a range of knowledge of FASD in the audience ranging from those people who have never heard the name to people who may be parenting or caring for a child who has or is suspected of having FASD.

Hands up those of you in the audience who have heard of FASD?

How many people have never heard of it before?

SLIDE 2

FASD is a spectrum of disorders caused when alcohol is consumed while pregnant. It can often be diagnosed or misdiagnosed as Autism, Asperger's, ADHD, a personality disorder such as antisocial personality disorder or some of the schizoaffective Disorders.

Alcohol is a teratogen which is a substance that causes birth defects.

SLIDE 3

It freely crosses the placenta and creates a blood alcohol level in the fetus the same or higher to that of the mother. Because the fetus has a small unformed liver, it takes longer to metabolise the alcohol so it remains with the baby longer.

One weekend binge drinking is sufficient to cause irreversible damage to the fetus which may not be picked up at birth. Very often it is not until the child reaches puberty that it becomes obvious there is something amiss.

SLIDE 4

The condition that is usually considered to be the most severe end of the spectrum is called Fetal Alcohol Syndrome. More people may have heard of this condition and perhaps associated it with alcoholic mothers. I would argue that this is the most severe end of the spectrum and I would also argue that the mothers of babies with FAS are typically alcoholic. Research has found that 96% of women who deliver babies with this condition are social drinkers.

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FAS which is the full syndrome with visible facial differences is caused when alcohol is consumed during a period of the pregnancy called gastrulation which often occurs on the 19th or 20th day of pregnancy. FAS has certain facial anomalies which can be fairly easy to recognise when you know what to look for.

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On this slide is the quintessential photograph of the brain differences between FAS and a child without FAS. It was taken very early in FAS research undertaken by the University of Washington. This was a very severe case and the baby did not live past birth.

Because the goal of this presentation is for you to be able to identify clients with FASD I will carefully go through the facial features with you but it's important to know that there is also a condition called Alcohol Related Neurodevelopmental Disorder or ARND where individuals will have a brain injury but will not have any outward signs.

SLIDE 7

In this photo you can see that the face of this child is a little different. This child has full Fetal Alcohol Syndrome or FAS. The differences are a flat philtrum, thin upper lip, flat midface, small head circumference, short palpebral features, low set ears and sometimes a small chin.

SLIDE 8

Where there are these facial features there is always a brain injury. On the other end of the spectrum is ARND which also comprises a brain injury but as I said, there are no outward signs of anything amiss. This slide has photographs of a child with FAS. He has full FAS however you would be hard put to find anything different in his face. To me, and I'm sure, to you, he is a beautiful little boy. However when you know what you are looking at, you can see the facial features of FAS – the thin upper lip, the flat philtrum and the lowset ears.

But FAS is just the tip of the iceberg in the spectrum of disorders that is FASD.

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To me, ARND is the most severe part of the spectrum because it is not immediately evident that there is a brain injury just by looking at the individual.

Now I **know** that in the disability employment sector there is a focus on 'ability' rather than 'disability', however with this condition, you **MUST** be aware of the disabilities and the inabilities of a client with FASD.

Firstly **because** there are no diagnostic clinics in Australia there has been no regular diagnosis of this condition, therefore many children and teenagers with FASD have been diagnosed with other conditions such as those I mentioned earlier. Not only has misdiagnosis often occurred, but through frustration and sadness from not living up to others' expectations when the primary condition of a brain injury is not accurately diagnosed, individuals have been incurring another set of problems, called secondary disabilities.

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Some people in the audience may know that a cognitive disability or intellectual disability is part of FASD. This is absolutely correct – in fact FAS is the most common cause of non-genetic mental retardation in the western world.

However just over 20% of people with FASD will have a low IQ. Because the majority of people (70 – 80 percent) living with FASD will have a normal IQ they will be expected to behave in the same way as other people of their age and maturity.

Because they will have a brain injury which compromises their executive functioning, they will not be able to use their IQ making the expectations on these people far too high to ever meet.

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This can and most often does..... cause secondary disabilities. These are the conditions that are sometimes diagnosed as the primary condition when no one is aware that the individual has a brain injury from prenatal exposure to alcohol. So while 'ability' and 'strengths' are still important, it is also crucial that the 'disability' side of this condition is acknowledged and understood by everyone the individual lives with, works with and loves.

SLIDE 12

In order to explain this condition and describe how to make a preliminary unofficial identification in your client when there are no outward signs, I need to go through the following.....

1. my background in employment and disability
2. my background in FASD
3. methods of working with people with FASD in employment

How many people remember the old CES days?

Hands up 😊

For those of you who don't know, the CES was the Commonwealth Employment Service and was the government's answer to employment for fifty years. The CES was closely linked to Social Security which is now Centrelink. In 1998, at the time of the name change, I was part of the CES. We thought that as we were going to be disbanded if Social Security was Centrelink then the CES would be the Missing Link! We hoped at least that that we were going to be missed.

In 1992 I was walking past the CES in Mackay – at that stage I had a job but wanted something different. I looked in the windows as I was talking by and such a wave of I guess you would call it *deja vu* for want of a better name, hit me. I stopped dead and had to think really hard whether I had actually worked in the CES before. It seemed as though this organisation and I were so closely bonded that I had maybe worked there in a previous life, or a different dimension. If you don't prescribe to the linear theory of time then my experience would have been based on the fact that another

me was already working in another CES in another Mackay. All jokes aside, the experience and my reaction was really extraordinary.

I'm sure you can guess what happened – 12 months later, I applied for a Trainee Employment Officer's job and against thousands of odds, I was successful and began work in the CES in Mackay in September 1993.

I completed my traineeship and ended up as a Case Manager in Employment Assistance Australia - the case management arm of the CES which worked with highly disadvantaged and long term unemployed people. I loved the job and apparently was quite good at it. But there **were** people I was case managing that I could **just** not figure out. Not having a degree in psychology, I invented my own syndromes and a very basic naming protocol and informally categorised those of my clients who I couldn't quite work out how to help.

The first syndrome I identified I called : "The Blame Others Syndrome"

The people in this cohort had three things in common.....

1. The reasons for leaving their previous job were because of someone else's bad behaviour even though their stories seemed to indicate that they had played some part in the behaviour which lead to dismissal
2. The tenure of their previous jobs was relatively short – six months at most and
3. They seemed to be excitable and angry with the world

The second syndrome I called the "Recalcitrants" which in my complete and utter ignorance, I believed was a term which described choices made by some of my clients. These were judgements made by an ignorant, uninformed Case Manager and one which I now regret because I really didn't help anyone in these groups. All I did was refer them to the next job or program and then breached them when they did not participate or cooperate.

In 30 March 1998, the government discontinued the CES and Employment National was formed.

So who remembers Employment National?

Again I worked as a Case Manager for long term unemployed and highly disadvantaged people. I was getting a reputation for being a good Case Manager especially with those people who had mental illness, drug and alcohol addition, homelessness, ex-offenders, and other at risk populations.

During that time I was diagnosed with depression and probably had been depressed for most of my life, so naturally I looked for depression in my clients – and found it. I sent many a client off to Community mental health for scripts and counselling. I got a name for being able to help very difficult clients but I knew I was still not doing anything for the people in my syndromes.

I wondered why those clients who were in my "recalcitrant" category didn't attend appointments with mental health providers when they admitted they needed the service. I also wondered why so many of them had addictions and were homeless.

I began taking them to their appointments – sometimes even waiting there while they went in. What I also couldn't understand was that often they would come out of their appointment with the psychiatrist with no script and no referral. I eventually got permission to in with some to these appointments to find out what was going on.

I discovered there were 3 possibilities ----- firstly they didn't want to talk to the psychiatrist even though they had told me they were desperate----- secondly, they didn't have insight into what their problems were and thirdly that they weren't able to articulate these problems to the psychiatrist. I had no idea which one of these was correct.

I never saw my own addictions and other mental health problems looming even though I was often at the pub next door for morning tea and lunch. I was never off work, never hung over; never censured and still, apparently, I did my job well.

After Employment National lost contracts all over Australia, I moved to CRS Australia where I worked for three years finding jobs for people with disability.

There I came across other groups I ended up categorising into syndromes. The main one was where a person may have had a physical injury but also had the "Blame Other Syndrome" or the "Recalcitrant Syndrome". I was interested and always trying to figure out these people but never could quite put my finger on the problem. In fact that was the name I gave that particular syndrome, the "I can't quite put my finger on the problem" syndrome! I realised even at the time that it was not appropriate to be categorising people however I found it helpful to be able to sort them into groups so I had a general idea of the services they would require.

I spent many hours discussing my clients and their motives with the psychologists at CRS. There were many different theories almost all related to mental illnesses or personality disorders ----- FASD was never mentioned.

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Now – my experience with FASD.

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"Mistakes are always forgivable, if one has the courage to admit them."

On this slide are the words which encouraged me to 'come out' so to speak.

I am the birth mother of two children with fetal alcohol spectrum disorder. I am a recovering alcoholic and in 1981 and then again 1984 when I was pregnant with my sons I used sufficient alcohol to change their potential for ever

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Learning about FASD has been an adventure and sharing this adventure with people for whom FASD is an uninvited and demanding guest has been a journey I would not trade.

Of course what I *would* trade, and what a considerable number of women around the world would no doubt trade, is having made this mistake in the first place.

Living with FASD is hell. No other word describes the trauma of parenting a child, teenager or adult with FASD, in fact even 'hell' doesn't do the situation justice.

These are photographs of my boys when they were young. You can't see any difference yet one has a significant disability and is unable to live independently, work without support or manage his money. The other can do all these things but has temporal lobe epilepsy and his stature is small for his genetic inheritance.

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While other disabilities 'enjoy' understanding, compassion and services, parents and carers of children and adults with FASD have no specific services to turn to for help. Each service has to be advocated for and educated. Not only that, but the superficial behaviours of young adults with FASD are delinquent and antisocial ----- behaviours that do not result in understanding and compassion, but judgment, both of the young adult and the parenting skills of the mother and father. Services often look at the IQ of the individual as being the factor that makes them eligible for programs. As I said earlier in my presentation, only 20-25 percent of people with FASD have a cognitive disability. My son has a normal IQ but is still significantly disabled. Where are the services and supports for him and others like him?

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There is also the other more personal side – when I know that my son is trying his hardest on days when everything goes wrong; when I know the great need he has to understand why friends do not endure; when he craves acceptance and respect and in return experiences contempt and rejection time and time again; when the pity and the grief are so intense they can hardly be endured, I doubt the ability of any parent to cope. My son may have avoided this life of heart-ache and rejection if I had known like you do now, that alcohol and pregnancy do not mix.

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Seth has begged me to 'let him go'. I think he wants me to stop caring about him so he can kill himself. I told him it will NEVER happen – so he had better get his act together. I'm sobbing on the inside when I say this but on the outside it sounds just fine – tough love. But how can you apply the 'tough love' concept to teenagers and adults who don't understand cause and effect and who cannot take responsibility for their actions or their lives because of a brain injury that occurred before they were born? – you can't!

Tough love and natural justice do not work and should not be used on people with FASD – and this is why it is so important to recognise this condition and provide programs which are FASD friendly – because if you don't, their experience will be a negative one – probably one of many.

My sons are both credits to themselves. They are fine, caring and compassionate individuals. Mick my eldest son the child not circled in this slide, will always be able to prove that to others but for Seth, there are only a few people who know what he is really like. Those are the people who live with him and who know the struggles he contends with daily. To everyone else he can either appear confident and happy or angry and immature but all he is doing is behaving in every way according to the symptoms and characteristics of his disability. His behaviour is a symptom, it's not who he is.

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It's hard and I would never want anyone else ever to go through it but in Australia they are. Most do not have the support my family does and are doing it tough on their own, not knowing why their children are behaving in the way they are; and their children not understanding why they are always in trouble and disappointing their parents, teachers, case managers, employers and friends.

I will never stop fighting for people with FASD ----- they are not to blame for their condition ----- no one is to blame ----- it should be a completely blame-free condition. While it may have a clear and unambiguous etiology and is considered to be 100 per cent preventable, I know that there are many reasons why alcohol is consumed when pregnant and it is only in the rarest of cases, deliberate.

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I used alcohol because I didn't know it could cause such problems and because in 1981 my doctor prescribed it as a tocolytic after an amniocentesis – maybe forgivable on my doctor's behalf at that time but not now. Tocolytics are medications used to suppress premature labor.

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Now the question is how to utilise my experience in both of these areas to help identify FASD in a caseload and then to help them obtain and maintain employment.

Even though the employment services industry has changed over the last 20 years, one thing that hasn't changed is the need for a robust assessment in order to accurately and thoroughly identify jobseekers' or participants' barriers. Apart from other obvious sources such as the Job Capacity Assessment, medical and psych reports there is the initial assessment.

The information needed to make an educated decision as to whether to use FASD-friendly strategies can be gathered from this assessment and subsequent contact with the client. If your client has a history that indicates prenatal alcohol exposure, then putting FASD-friendly strategies into place will do no harm if the client does **not** have the condition, but will make a **significant** difference to the client who does. Ideally, referring your client for neuropsychological testing and other relevant tests will add strength to your assessment. However if you do this, be sure that the assessors has been trained in understanding and interpreting the results of an assessment for people with FASD. Without fully understanding the condition, the raw scores can be incorrectly interpreted. In fact a neuro-psych assessment was conducted on Seth and the recommendation was that he was unmotivated. I sent the raw scores to Dr Sterling Clarren from the University of Washington and he said 'typical FAS'

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Not everyone has the same 'capacity' or 'ability'. People can have a high IQ but not be able to tie their shoelaces. If a person has been prenatally exposed to alcohol then their capacity to undertake training, employment or education without appropriate supports is severely compromised.

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Few people with FASD will have been diagnosed therefore they will not have the words Fetal Alcohol Spectrum Disorder on their JCA. We are likely to find that while the individual with FASD might seem, and may actually be capable while supports are in place, it is when the supports are taken away that everything can fail.

Any client who has a history of repeated upheaval – where there is something 'not quite right' and things never seem to improve – needs to have further investigation. I am sure that a good proportion of those clients in my 'blame others'; my 'recalcitrant' and my 'something is not quite right' categories would have had FASD.

As a case manager years ago, I tried every strategy I knew but for some of my clients nothing seemed to improve for them. They found jobs and lost them and I couldn't understand how I could have been so mistaken about their job readiness and capacity.

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While there are definite similarities in the FAS face and the behaviour of the individual, exposure to alcohol can affect people in different ways. If your client has a history of mental health problems; Alcohol or drug problems; Low education; Literacy/numeracy problems; Trouble with the police; aggressive or violent behaviour; low motivation; and often miss appointments, then I would conduct a comprehensive assessment because he sure has a history which could indicate prenatal alcohol exposure.

This group are very unlikely to ask for help unless it is related to money or bills. As far as their own personal issues go they seem to have very little insight.

SLIDE 25

Because of the primary brain injury, people with FASD may also have conditions or problems that don't seem to be related at all to FASD. This may be related to not knowing when to visit the doctor or their lack of understanding of cause and consequence which influences their ability to maintain their own safety.

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A person with FASD can have a good IQ; they can talk to you well and carry on a good conversation but still not have the 'capacity' to do a job.

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From anecdotal research, it is clear that many people with FASD cycle through employment and other services. The reason that people with FASD are often so difficult to identify and 'categorise' if you will, is because their expressive language is typically very good. Expressive language is the ability to speak well and sound convincing. However this is combined with limited receptive language ability which is ability to understand what is being said and then respond appropriately in relation to the conversation and their personal situation.

At the job interview, their verbal ability creates expectations in the employer's mind that they cannot fulfil. They get the job and all is okay until the employer and colleagues realise that they are not progressing beyond the 'new employee' stage. Usually they are terminated between 3 and 6 months for not learning; not carrying out the required duties; their behaviour towards colleagues; or their immaturity.

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Some of the services that the client may cycle through include....

- Housing
- Drug and alcohol
- Mental health
- JSA Providers
- Advocacy and
- Criminal Justice organisations

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From my experience and the experience of people who come through my organisation the Russell Family Fetal Alcohol Disorders Association, I believe there are typically four phases that jobseekers with FASD may experience. They are the four phases of employment.

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Phase 1 is the beginning of the job where many allowances are made for the new employee. This phase is usually a happy time. The individual realises he belongs to a group – the 'work group' and that makes him feel wanted. Unfortunately when he begins to feel comfortable with his colleagues is when his immature behaviour is likely to surface.

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After the 'honeymoon' period of a new job it is unlikely that the individual with FASD can achieve the expected productivity of an out of probation employee. A person with FASD who is 21 years of age is likely to only be able to operate at an 8 - 10 year-old level.

This is the phase where the expectations of the employer and colleagues are more than the individual is able to provide and it occurs usually at the 3-6 month period

Once the employer finds that the individual has not progressed past the knowledge expected to be gained in the first couple of weeks he becomes disenchanted.

The immature behaviour stems from trying to impress the people in his 'group' – his colleagues. He sees other people telling jokes and playing games and wants to do the same.

But because of the difficulty he has in making good decisions and his inability to link cause and consequence, his behaviour is often seen as 'inappropriate' or 'immature' and the exclusion and termination process begins.

The employee could also walk off the job because of an argument with a colleague or the boss. There are many scenarios but the end result is likely to be 'no job!'

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After he is terminated and as a result of the pain of the exclusion and rejection from those colleagues he thought were his 'friends', it takes a while for him to be able to work again.

Because almost 100% of people with FASD have a mental illness, this flares up again because of the rejection and surprise of resignation because.....he thought he was doing well. This causes a great sadness because this is yet another failure for him or her and why it is important to be cautious when referring to training or employment.

But now the only way he can integrate this experience into his psyche is to blame someone else. So he usually blames the boss or his colleagues for his job loss.

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Now that he has rationalised what has happened - that it is his boss or colleagues who have lost him his job, he is angry and upset with them.

Seth still cannot see the part he played in being dismissed from a job when he was 17 for stealing – he still blames the boss for discovering the theft. He can't understand cause and effect so he doesn't 'get' that it was his behaviour that resulted in losing his job which is why he has to blame someone else. This may be why we often find reported in the news that such and such hasn't shown remorse for his actions.

After he has recovered from the problems associated with the job which may take anything up to 6 months or longer, he is ready to start work again.

This last phase sees him back into jobseeking because of a lack of funds and boredom.

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We know it is unlikely clients will have a diagnosis but if they are living alone, they will also be unlikely to be medicated as well.

Why?

Because they are unlikely to fill repeat scripts even if they do manage to take the prescribed medication regularly for the first month!

They are unlikely to even visit the doctor unless someone else takes them.

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The results of the four phases model leads to identifying the six factors which need to be in place for anyone to maintain satisfying employment. We don't usually think of these factors being in place for us, we just unconsciously assume they are and because we do not have a brain injury, we can often operate effectively without all six being in place. However for a person with FASD they are all equally important.

So if we want to support those people we believe might have FASD, we need to ensure that these factors are in place before we then refer to employment or even training.

Two things need to be emphasised here before we go on to the six factors.....

1. Firstly, getting all these factors in place prior to referral to a job or training is what might happen in a perfect world where the wellbeing of the individual is the critical consideration rather than the duration of the employment. Unfortunately in this contract it is all about quantity that is, the number of individuals who can sustain 6 months or longer in a job or jobs ---- at least that's the case in Stream Services
2. Secondly unlike Autism there are no specific services for people with FASD, no specialists, no specific diagnostic teams and no clinics. Until then the person with FASD and his or her case manager are in a difficult situation. However there are things that can be done to help.

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People with FASD need to be medicated in order for them to live to their full potential – it could be medication for depression and anxiety or anti-psychotics for paranoia.

There is no medication for FASD as such but managing the symptoms can greatly improve the individual's life.

Remembering to take medication and to fill scripts is very difficult for a person with FASD so there needs to be a friend or family member who can take the role of 'external brain' – someone to support the individual to make the right decisions or remind him to do what needs to be done in his life.

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The second factor is the right case manager.

The right case manager for a person with FASD is one who is non-judgemental and accepting of the client

- Has high energy and a desire to succeed without compromising the health of the client and without cutting corners
- Of the understanding that outcomes are achieved through solid preparation, engagement and active post placement; and
- Someone who engages the client and doesn't give up easily

The right case manager will slowly teach the client how to disagree without using anger or violence; Accept criticism or negative feedback; Get someone's attention in a positive way; Behave appropriately in the workplace; Give and take a compliment; Start a conversation; Say no to peer pressure; Request or negotiate in an appropriate way for improved or different conditions.

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Factor 3 is the right employment program. Currently the right program would be either stream 4 in stream services, or in a disability employment service.

People with FASD should at the very least be in Stream 4 – you may be able to get them upgraded using their symptoms rather than a diagnosis if they are in a lower stream.

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Factor 4 is the right stage of social and emotional maturity.

Maturation takes longer for people with FASD.

While they can often have a precocious puberty, their social and emotional maturity is often a long way behind their physical maturity.

Unfortunately people make assessments of a person's ability by looking at their physical age.

Controlled forays into short term work experience, work training or temporary positions may help to identify problems before proper jobsearch begins.

Don't expect that the client will 'put his best foot forward' when he or she is given the opportunity of what might seem to be the right job for him.

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The right living environment and social support

Ideally the individual would live with family, caring friends or a spouse who is prepared to take care of them.

Reliable and caring social supports and relationships underpin the entire cornerstone of care for a person with FASD.

Support structures and social networks or multi-systemic supports are needed not only to act as reminders for medication, appointments, responding to mail and modifying behaviour but also to serve as 'external brains'.

The payment of rent should be through Centrepay or through the Public Trustee.

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The right job with the right employer

The working client with FASD will have 'on days and off days' where they can do the job perfectly one day but forget what they have learned the next.

The last thing and maybe the most important is to ensure that if the new employee is working in close quarters with others, that those people role model the behaviour that is appropriate in the workplace.

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As you may have gathered FASD is a complex problem. Usually the training that we deliver takes a full day at least. Clinically FASD can seem straightforward but dealing with it on a personal level either as a parent, carer or a support worker can be terribly frustrating and extraordinarily challenging.

It takes great patience, perseverance and love to care for a person with FASD. Some will require 24/7 care and others will require support to live independently and maintain employment.....but most important is that they will need someone to believe in them and care for them and you will be surprised and gratified at what they can achieve.

Thank you.