

The Six Factors of Employment Sustainability

Analysing the feedback from Seth's employers and his case managers, my observations and his observations and extensive reading and research on FASD presented me with a combination of factors which I believe are essential for a person with FASD to have success in maintaining satisfying employment in the long term.

Many people may already know about these factors, after all, FASD is not entirely alone in some of the behaviours and characteristics. It may well be that these factors are familiar to people who work in disability employment.

What I learned was that for an individual with FASD to have a chance at sustainable employment, the following factors must be present:

Factor One – The right job with the right employer

Identifying the 'right job' for any jobseeker regardless of barriers should be based on the interests, experience, transferable skills, ability and capacity of the individual as well as the local labour market.

Hobbies, sports, interests, enjoyable school subjects, courses that might have interested the individual, previous employment, work experience or school projects must all be gathered together, thrashed and analysed so that there are at least two appropriate occupational options. I have highlighted the pros and cons of several occupations later in this chapter.

If there is a particular job that is of interest to the individual and it is realistic by your reckoning, it would be wise to commence with that one initially. But what if it is unrealistic?

As a case manager years ago, I would suggest to jobseekers, who wanted jobs I believed were inappropriate, that they find and speak with people who were currently working in those jobs. I encouraged the jobseeker to ask the incumbent how the position was obtained. Was it directly through recruitment? Was a qualification required? Was a licence or certain experience or expertise needed? Was it through a promotion? Did they have to prepare selection criteria? Even if I knew it was unlikely that the occupation would be available within a reasonable geographical area, or that the particular qualifications required were within the jobseeker's ability, I still felt there was merit in undertaking the research as it allowed the client to own the result.

It wasn't that I wanted the jobseeker to fail in the quest for their dream job – it was more that I wanted the jobseeker to hear the reality of the job from someone else. It also served to show me the commitment of the jobseeker and the willingness to do what was necessary to get this job. I was willing to do whatever it took if I knew the jobseeker was also willing.

For people with FASD, it is important to try and keep challenges to a minimum as the individual will experience these just living from day to day. However, you will not have control over the number or type, as people with FASD will attract them like moths to a flame. While many of us thrive on challenges, for a person with FASD it is best to limit anything that might create disruptions in the routine of his or her life. If the ability of your client is appropriate and he or she needs grounding about the job chosen, it *may* be appropriate for you to send him or her to obtain this research. I would be cautious of over-extending individuals who are more compliant. It is extremely unlikely he or she will return to you with this information and this is something you should expect.

Seth's job at the newsagency was *not* a suitable one for someone who is impulsive, who didn't understand the meaning of 'property' and who was always in need of money. Had I known then what I know now I wouldn't have put Seth or his employer through this period in their lives – working with money wasn't right for him at that point in time. If a workplace assessment had been prepared for him, a FASD professional would have identified immediately the unsuitability of the inherent duties of the job just as an occupational therapist would find heavy lifting inappropriate for a person with a disk bulge.

To ensure a better fit, try analysing the types of tasks that he or she does well; any sports or hobbies, interests or anything that offers options for the type of work for which you can search.

There needs to be a mixture of repetition and change. Repetition so that the individual can learn the job over a period of time and change so that he or she doesn't get bored with the job, particularly if they have a normal IQ.

It is doubtful although not impossible that a young person with this condition will be able to cope with the demands of a traineeship, an apprenticeship or any other job that requires the completion of external

competency-based training as a requirement of the position. However if you have the right support and the job is right for the individual don't entirely rule it out.

It may also be prudent to consider fewer than full-time hours to avoid overwhelming the individual, as he or she will find it extremely difficult to maintain long hours under pressure. It may be best to start off with two or three hours per day, four or five days per week.

The individual is *not* going to change in the short term; they are not *capable* of changing. Yet just as a man with one arm may, in time, develop skills with his remaining hand and arm he could not imagine having when he could use both, it is possible that skills can be learned by people with learning disorders. However, friends, family, teachers and employers need to understand it must be *they* who make the change, whether it is changing perceptions, expectations or behaviour. They will need to have just as much resiliency as the individual.

Remember the saying – 'all behaviour is explainable'. To get to the bottom of any decision or action no matter how 'strange' or 'offbeat' it may seem at the time, 'be the person'. Try to understand how childhood history and experience have moulded them and how their disability affects them and then you will understand why that person chose that particular pathway. If you can't do that, then you can't make a judgement.

On the next few pages, using common semi-skilled occupations, I describe what jobs might be appropriate for someone with FASD. This serves to highlight the impact of the condition and the strengths of people with FASD.

Be alert to your impression of your affected client on days when they are operating at optimal capacity – 'on' days. Don't be misled by the seeming competency of your client. As I have mentioned, there will be 'on' days and 'off' days. As evidenced by the comment below from a caseworker in the United States who works with pre-release prisoners with FASD, it can be very difficult for people not accustomed to this condition to understand.

... I have recycled (a client) through one set of skills at least twenty times. He can go from being totally independent in the skill to totally dependent an hour, a day or a week later and we start all over again. When he is at the positive end he does exceptionally well and turns out a good product and gets lots of compliments. This of course builds the self-esteem and he is very proud of his accomplishment. Then he will loose parts of the skill or the sequential thinking part of the task and we have to backtrack. His ability to generalize can be very weak at times. Despite that we have made some incredible progress with him. The overall problem is the one where a person making assessment calls catches him on a good day or a good behaviour and then proceeds to tell you that he just proved he can do it so when he forgets or isn't doing as well then he obviously is putting on an act, being difficult, being disobedient or being non-compliant and should be set up to be 'disciplined'.

If an individual seems keen to offer his or her services as a small business operator to work without the pressures of a boss with definite starting and finishing times, try and encourage him or her back into the normal employer/employee roles. Without the structure and routine of a job where someone else sets the ground rules, it is likely that this venture will suffer complications and difficulties almost immediately. In a small business, the individual must respond to jobs without having any external motivators present, such as customers coming through the door or a boss or supervisor as a constant reminder of the next task on the list for the day. This venture could be compromised by the difficulty the individual might have in planning and organising schedules. Motivation may also be a drawback. In a business such as this, the individual must be self-motivated and must plan dates, times and locations to get the best out of each day. Even though there may be a partner, family or friends assisting, it could be more than the individual can sustain in the long term. Once the initial novelty of having a business wears off and the day-to-day tedium of getting out of bed without having a pre-set starting time, with no one who can manage, remind, supervise, explain or decide for the individual, the problems begin. It is difficult enough to plan and organise a day *off* so it will be almost impossible to be the sole organiser of a business that makes a regular living. This will be true of any small business enterprise.

The individual with FASD can only take so much in at a time and once they become overwhelmed with information, noise or activity they can often either shutdown or become agitated to the point of aggression or belligerence. An ideal situation is a job where there are regular hours and where the employer commences the new employee on basic tasks. By gradually increasing the level of responsibility, the employee can build up his or her skills gradually and have time to consolidate each new task.

An employer model that includes the provider, employer and possibly the client, can provide cohesion between the parties so that many of the difficulties likely to be experienced by the client can be potentially overcome through the foundational work put into developing the stakeholder relationships in the early stages of the job search.

Bringing the client in as a stakeholder is ideal in a perfect world, however for the most part a person with FASD will remain connected to most discussions for no longer than five minutes and then it may become very obvious that the client would prefer to be anywhere than in a discussion about his or her future employment.

For ease of transition into the workplace, meeting the employer on several occasions for a short-term low level discussion may help the client look forward to his or her first day with some comfort and enthusiasm rather than with nervousness and apprehension. This strategy while simple, can pave the way for a smooth transition into the workforce. It would also help to ascertain the level and type of skills training the employer may require over the first few months of the placement.

By skills and training, I don't mean theory but practical hands-on skills that can be learned by the client through doing the job. This is where apprenticeships and traineeships differ from what I am suggesting here. They involve the theory behind each skill or set of skills.

It might be appropriate to go through some of the theory of the skills in short bursts while the client is actually on the job learning the skill, as long as the discussion or training does not go on for longer than a few minutes; no more than five words should be spoken at a time; repetition is necessary – the individual needs to have the opportunity to practice over and over again; and partial competency is acknowledged as a substantial gain. On-the-job training should be concise and practical with plenty of breaks and structure.

There is the potential for an individual with FASD to learn skills otherwise they would not be in an employment program looking for work. However, the skills they do possess have likely been learned over a long period and the majority have probably been learned at a more protracted rate with lower emotional investment than is the norm.

Gardening

The duties of a gardener are varied but they can also be structured and relatively repetitive. For the most part, each job will be in a new location and this could create problems learning and remembering. If a task is learnt in one physical location, the individual may not easily generalise that learning to another location. Gardening duties range from mowing the lawn; whipper-snipping; laying pavers and potting plants; establishing gardens; digging and laying irrigation ditches and assembling and installing irrigation pipes.

In Australia, gardening and landscaping is usually busiest during the summer months that could be, depending on the region, hot and humid or hot and dry. As mentioned earlier, it may be difficult for a person with the condition to manage the hot summer months because in some cases impulsivity will override the determination to persist in the job.

In difficult or uncomfortable conditions the individual's impulsivity and the fact they live in the here and now will take over and the determination to endure through discomfort is impeded.

The individual lives in the moment, so if the day is hot and uncomfortable it will be difficult to see through the barriers of heat and humidity to the end of the day and a cold shower. Nevertheless, as we all know, wherever there is a rule, there is an exception. There may be some affected people who can cope with these conditions.

Delivery / courier driving

Delivery or courier driving is not as easy as it may first appear. Drivers can often make around one hundred stops each day, dropping off and picking up packages. The driver must plan a route and then arrange the loading of the truck so that the item for the closest address is readily found and the package for the final address is on the bottom of the heap. A delivery driver also must have good local knowledge and be physically fit to lift and carry heavy objects and get in and out of a car or truck all day. There will also be paperwork required.

Planning and organising along with working to deadlines, working under pressure and driving quickly but safely are all skills integral to performing this job to an appropriate standard.

For some people with FASD, driving safely even *without* the pressure of deadlines can be a challenge so this job must be thoroughly assessed prior to placement.

Veterinary assistant

Working with animals is a job to which affected people seem to be drawn. When I once asked Seth what it was that he liked about animals, his answer was unequivocal and immediate: he said they were his 'friends'.

From watching Seth's interaction with peers as a young boy and as a teenager where his human 'friends' loved him one day and hated him the next, his answer made complete sense to me. Seth and Hayley have four animals

– they are friends as well as pets. He knows his animals won't leave him in the way his other friends have. They wait for him to come home and they wag their tails when he walks through the door. They want to be with him all the time, they don't care if he behaves immaturely or says something inappropriate or doesn't shave; they love him. His animals represent the friends that he rarely had and couldn't keep while he was growing up.

Knowing this, it doesn't take long to fathom why people with FASD might enjoy working with animals. Perhaps being 'friends' isn't all that lures people to this type of work. Perhaps it's also because animals won't call them names or taunt them and in some cases, it may also be a reminder that there is something they *can* control. Whatever the reason, working with animals is likely to be an ideal job for a young person with FASD. The job, as with everything to do with FASD, must be structured. There must be a routine to follow which does not require the employee to perform other complex tasks such as invoicing or record keeping, until they have become familiar with the core duties and their ability to take on those additional tasks has been assessed.

It's possible that vocational skills can be improved to the point where affected individuals can undertake some of the more complex tasks as he or she becomes more confident. Remember, skills are the key.

Sales assistant

Many people with FASD have very good verbal language ability, which makes them suitable for short-term low-level interaction with the public. Unfortunately, the inherent tasks of a sales assistant often go hand in hand with cash register operation and cash handling. If we are truly to be the 'external brain' of the individual then we should not knowingly place people who have trouble with the concept of property and ownership in the way of temptation.

Because of this possibility, a workplace evaluation must incorporate a risk assessment for what we call 'theft'. Just as a workplace assessment for an individual with a back injury would ensure that the workplace and the tasks of the job would not exacerbate the individual's condition or injury, so a workplace assessment is just as important for the individual with FASD.

I believe that this predilection will decline as the individual grows older as long as this value is reinforced.

As far as sales, checkout or cash register operation, without electronic change calculation there may also be difficulties giving change quickly and accurately. It shouldn't be assumed that everyone with FASD will have these issues. There are always exceptions and it would be an additional burden on individuals already unreasonably burdened if negative assumptions without evidence were made about their ability to work with money.

Night-fill or day-fill

Many people believe this type of position to be a reasonable option for people who need a job that is without great pressure or responsibility. However, in most supermarkets night or day-fill involves physical activity, quick responses and absolute deadlines. The shelves must be stacked by a certain time, and the worker must also match the boxes to the item on the shelves and work quickly and accurately to fill them.

If it is possible to get a night-fill position without these deadlines and allow the worker to work at his or her own pace (within reasonable parameters), then this might be a suitable job. Working at a slower pace does not mean that structures and timelines are not in place. Structure and routine are essential in any job.

It will be important for individuals to know that this job isn't the end of the road for them. People with a higher IQ may feel capable of something more than menial jobs, or what *they* consider menial jobs, and may feel irrationally trapped by some occupations. Luke in my second book, *Alcohol and Pregnancy – No Shame No Blame* said in almost all the jobs he had, even though he was often desperate for work, that he was scared he would be 'trapped' in whatever 'dead-end' job he was in at the time. When I read this in his journal, I was surprised because, as I said, he was often desperate for work. I found it difficult to grasp how he could be so concerned about being trapped in the job when all he had to do was to find another one. After giving it some thought, I now believe it is another example of living in the present and not being able to make accurate and realistic predictions of the prospect of future employment based on variables which would include 'possibilities'.

Ideally, you can counsel your client before they start as well as many times while they are working to understand that if they want, any job can lead to something more substantial and more suitable for them.

Occupational health and safety is an important factor in any job. In day and night fill, correct lifting techniques, regular breaks and watching out for boxes or other items on the floor is what we do every day without thinking about it, yet it is important to be aware of these hazards. In general, people with disabilities are loyal and reliable

staff members; they build a strong workplace culture and lift team morale¹. They can often do the job as well as or better than an able-bodied person, given appropriate accommodations.

Summary

After having discussed the advantages and disadvantages in each of the preceding occupations, summarising what 'the right job' might mean to an individual with FASD or similar disability, I believe it would be one that:

- Is interesting to the individual
- Is not contingent upon training or other extraneous conditions apart from the usual on-the-job training that occurs
- Is somewhat repetitive yet has some variety
- Has flexible hours if needed (this could be a Catch-22 situation. As I have said, routine and structure are crucial and reducing hours can be valuable during times when the individual is not well or has forgotten to take medication, however a change like that after a period of consistency could also have the negative effect of losing the stability and constancy of structure and routine)
- Does not require the individual to work long hours or overtime unless it has been found to be suitable for the individual (in some cases working seven days a week might be more appropriate than having time off over the weekend reinforcing the structure and routine, but this would have to be assessed by a FASD specialist or a workplace assessor)
- Is within the employee's ability
- Takes into consideration the possible environmental needs of the individual such as:
 - Proximity to cash or goods that may be a temptation
 - Proximity to transport to get to the job without hindrance
 - Colleagues and supervisor/manager who understand the condition

The right workplace is:

- One that is not inherently stressful – (if there is such a thing)
- One with only a couple of close-knit, understanding, older co-workers
- Where the worker that the individual is likely to role model is an appropriate one – if there are peers in the workplace who are not appropriate role models, then the individual cannot be held responsible for adopting inappropriate behaviour and ultimately means that this job is not suitable for the employee unless more appropriate role modelling is available
- Where he or she can become an 'expert'

It is important to know the characteristics of the ideal job. No doubt 'trade-offs' will be required and they can be negotiated with both the individual and the employer. It is the employer who holds the key to negotiating the features of the job and the right employer is one who fully understands FASD in terms of its impact in the workplace; offers a supportive work environment; and has reasonable expectations of the individual. Additionally it would be even more helpful if the employer could:

- Use literal language—not idiom or abstracts
- Establish consistency and routine
- Provide ongoing *informal* on-the-job training
- Review job expectations frequently
- Pair the new employee with a buddy who is prepared to get to know the worker and advocate if and when appropriate
- Ensure the direct supervisor/manager of the individual understands how having a worker with FASD impacts on other staff
- Understand that workplace health and safety means psychological safety as well as physical safety, and
- Understand what it means to have 'on' days and 'off' days as described earlier

¹ *Improving Employment Opportunities for People with a Disability: Report of the Review of the Employer Incentives Strategy, Department of Family and Community Services, March 2003.*

Factor Two – The Right Case Manager

The term 'case manager' includes job support person, employment consultant, case manager, caseworker, client support or mentor or whatever other name there may be for the person who helps people with disabilities find and maintain a job.

With the changes in the employment services industry that have occurred from 1998, the average family could be forgiven for not knowing what employment or pre-employment programs are available in Australia, let alone what is the most appropriate program for a person with special needs.

The outline of suitable employment and pre-employment programs is explained in the chapter on 'the right program' – so for now, the 'right case manager' is someone who is delivering the 'right program'.

However, just being in the right program does not guarantee success for the individual or for the case manager. The right case manager will be prepared to find out about the disability and discuss options and strategies with the client's family. The right case manager will welcome new information and be willing to take on board the fact that there is something he or she may not know, some information that will make a positive difference to a number of clients on the caseload. And the right case manager will not be defensive or constrained by their ego or their certainty that if a person appears capable they are capable.

With FASD, there is a set of characteristics such as impulsivity, poor money handling skills, inability to link cause and effect, poor comprehension, and others outlined in later chapters. However the people who live with your client will know and understand the idiosyncrasies of those symptoms and characteristics better than anyone else.

They will be better informed and better able to predict how the individual will react and respond to a particular situation. Linking in with family, parents, carers and friends will be crucial for you to understand what influences your client will respond to. At the same time, through whatever environmental or genetic factors are present within the family, they too may be suffering from undisclosed or undiagnosed disabilities or disadvantages and the right case manager will take that possibility into consideration.²

There are possibly hundreds of thousands of people who have experience with FASD but who understand it by a different name such as ADHD, learning disorder, bipolar, Autism, Asperger's Syndrome or even 'lout'. We have a unique situation in Australia where parents and carers have become the information source for providers, professionals and practitioners rather than the other way around.

Even though your client may *not* have a diagnosis of FASD, having read this book, you may now have a few clients in mind who have been diagnosed with another disorder, syndrome or medical condition, who you think could benefit from the information contained in this book. The individual does not have to have FASD to benefit from an understanding and compassionate employer and a knowledgeable case manager. Using strategies that are FASD 'friendly' will *not* cause problems for a person who does *not* have FASD, yet *not* to use them when the individual *does* have this condition *will* cause a great deal of damage and hardship for everyone concerned. From my experience, the 'right' case manager will have the following features. He or she will be:

- Non-judgmental and accepting of the client in terms of 'all behaviour is explainable'. This means that no judgement can be made by the case manager because he or she is aware that any decisions or behaviour were the *only* decisions or behaviour that the client *could* have made given the background, experience, cognitive ability and general functioning of the client
- A person with 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 transition support
- A case manager who engages the client, who knows when to back off and when to confront, is committed and is an advocate and campaigner
- A case manager who never gives up but who will admit that when no progress is being made other options must be sought such as:
 - Case discussion with other case managers or consultants
 - A further assessment
 - Permanently or temporarily referring your client to another case manager or consultant, or

² Fifty percent of women who have children with FASD have FASD themselves.

- Referral to a different program
- A case manager who is prepared to take on other tasks such as assisting the client to buy groceries and pay bills, and being an 'alarm clock' and a taxi service

When instructing the client in the work ethic, the right case manager will teach how to:

- Appropriately request or negotiate for improved or different conditions
- Disagree without using anger or violence
- Accept criticism or negative feedback
- Get someone's attention in a positive way
- Give and take a compliment
- Start a conversation
- Say no to peer pressure

The characteristics of a client and the environment likely to result in durable employment³ are, of course, the six factors. If a client comes to you with the following characteristics, there may eventually be success stories for you both.

- An accurate diagnosis⁴, appropriate medication and an understanding doctor and/or allied health professional and the willingness to share that with the employer
- Stable accommodation or able to move into stable accommodation; supports in place to make regular rental or mortgage payments; has mature social supports, friends and/or family
- Social and emotional maturity are at optimal levels. It is difficult to make an assessment of these aspects of your client at the initial interview – you are likely to only see immaturity when the client is under stress or after they have become comfortable in your company

If this individual eventually obtains employment with an employer who is fair, consistent, aware of the client's condition and willing to make changes to his or her expectations; and you ...

- understand which behaviour can be controlled by the client and which behaviour cannot
- are consistent with your support
- are prepared to take on other roles until you have the appropriate services involved and then are prepared to train these services
- do not give up

... then it is likely you will have a successful outcome.

The case manager can play a crucial role in reducing if not eliminating the problems that often result from unrealistic expectations on the part of all involved. For example, giving directions one step at a time is usually more effective than giving complex instructions all at once. Many people with FASD will have difficulty telling time on an analogue watch. Having a digital watch with a work schedule posted nearby can be useful in keeping the client on task⁵.

Seth's case managers have always been willing to include me in their planning (with his permission of course), throughout his various jobs. That makes it easier for me to support Seth. They have also been willing to find out about FASD and accept what many people seem unwilling or unable to accept – that an invisible disability is still a disability. I suspect this conclusion was reached long before Seth and I came into their lives, as they are both very qualified and experienced people in the disability sector.

This is also a disability that finds even experts making mistakes about the best options and the most appropriate care. So trying a particular strategy and finding that it doesn't work even though it should, does not mean a failure. If, after everything has been done and it still doesn't work, it is important that no blame be apportioned, that the fallout is minimised and that the individual is supported throughout the recovery period.

³ Durable employment is considered in this context to be ongoing sustainable employment

⁴ At the moment if a child is diagnosed in Australia it would be almost certain that he or she will have very severe symptoms because of the lack of understanding by medical professionals, that full FAS is the top of the iceberg so may not be suitable for an employment program

⁵ Fetal Alcohol Syndrome A Training Manual to Aid in Vocational Rehabilitation and other non-medical Services 1999 La Due R.A. et al

This is where all the support that is available needs to *be* available. Unfortunately, as I have mentioned in all my books, the only FASD specific support for a parent, carer or sufferer of working age has been NOFASARD. There remains no disability-specific government support for adults.

The only services that can be utilised are those that already exist for other conditions and these are often not suitable because of the eligibility requirements. The eligibility for certain services is the level of intelligence. If a potential client has an IQ higher than, say, 70, the service will not provide assistance. However as I have said, the majority of people prenatally affected by alcohol will have normal intelligence but will still be significantly disabled. Obviously, this is quite a considerable problem because almost no one in these services will truly understand what it means to support a person with the condition. If the individual has a normal IQ, he or she is considered to be 'normal'. Individuals have to gain access to these services on the basis of their secondary disabilities.

Because people with FASD are impulsive and very easily influenced, goals will change regularly. While your client may wish to be a checkout operator today, that goal can very easily change to something different within the space of a week.

If your client does not seem capable, able or willing to work on a primary barrier such as a drug or alcohol problem, then turn your energy to a smaller goal or barrier and work on that. Successfully working on a smaller more achievable barrier will allow your client to get some runs on the board and show him or her that success is possible with the right conditions. Remember that any success you achieve with your client may well be the only success that he or she has ever experienced. You may also become their role model.

While it is vital to be flexible in your approach with your client and never expect things to be the same today as they were yesterday, keeping your client on a consistent track will have its rewards. No matter how good or how bad the situation is, things will change quickly. Keeping the client as stable, secure and calm as possible, and his or her environment as predictable and constant as possible will prove rewarding to both of you. Regrettably, constancy is not something you should expect or be distressed by if it doesn't happen. For case managers in a pre-employment program or a program where an employment outcome is not an imperative, it is absolutely vital that, in the time you have with your client, you link him or her with services in the community that can perform necessary tasks. It would be ideal if you could obtain a diagnosis for your client but the likelihood of that happening, particularly if the client is no longer a child, is negligible.

Another strategy to be considered is the need to be involved or linked in with all aspects of the individual's life, not just those aspects related to employment. For instance, if the individual lives alone, which is unlikely yet possible, their house, flat, caravan or unit is apt to be messy, perhaps even to the point of being unhealthy. There are likely to be problems with money and budgeting, and transportation. There may be no money for rent or food because it has been spent on alcohol or other non-essentials. If there is no fuel the individual is unlikely to problem-solve alternatives – he or she just won't go to work or attend appointments regardless of how important they are.

It will be difficult for the individual to manage his or her own affairs and even more difficult to find solutions or resolve some of the usual day-to-day issues, such as taking the bus to work because there is no fuel or taking an hour off instead of the whole day to go to the doctor. Services that would benefit your client include the following:

- If he or she is on an allowance with Centrelink, connect with Centrepay⁶ to pay rent or board
- Housing services, either state government housing or the private rental market with support from a bond service
- A bill paying service at a bank or credit union which divides up regular bills and sets a regular fortnightly or weekly amount to pay so that all bills are covered when they arrive
- A service which takes people shopping and helps the client to clean the house
- A pre-selected sum of money out of wages or allowance can go directly to food vouchers so you are sure your client is eating the right food and not spending it on drugs or alcohol
- The Public Trustee to look after finances
- A social worker or caseworker who can co-ordinate these services much as you are doing now but for an extended period

⁶ Centrepay is a service offered by Centrelink which provides for certain bills to be paid automatically out of a customer's allowance before it is placed into the customer's bank account

- Assist the client to access public transportation by going with him or her several times using the same route as would be taken to get to work

These are concerns I have mentioned before and they can only be successful if your client is willing to accept the assistance, but they *are* crucial to the satisfactory functioning of the individual when your support ceases⁷.

Under normal circumstances, a job capacity assessment and other current and valid reports might assist in gaining a basic understanding of the individual's strengths, barriers and any suggested interventions that might be considered necessary. For someone with suspected FASD, the information in the reports will be based on the secondary disabilities. Any recommendations, assessment or advice on the individual's ability is only as good as the knowledge and expertise of the person making the report and the accuracy and validity of the information available.

Because it is incumbent upon the individual to provide his or her medical records to the job capacity assessor, a person with FASD is unlikely to have appropriate insight into his or her needs and abilities and may very easily express the desire and competency to work at anything and everything. He or she is also unlikely to reveal information that may be pertinent to support needs.

Compounding this is the probability that any medical or allied health professional recommendation is unlikely to incorporate FASD into the appraisal and if they do, may not grasp the implications for employment. If an individual has been diagnosed with FASD by an Australian medical professional, it is likely that he or she suffers very severely and therefore *unlikely* they would be going through this process.

A neuro-psychological assessment was conducted on Seth by a qualified neuro-psychologist. While the raw scores of this assessment were sent to Dr Sterling Clarren, an expert on FASD in North America who concluded that Seth had full Fetal Alcohol Syndrome, the assessment from the neuro-psychologist was that Seth was simply unmotivated.

So while both people viewed the same neuro-psychological results, the accuracy of the interpretation was based on the experience of the medical professional/allied health professional making the assessment. The outcome progressed from 'lack of motivation' to a 'typical FAS scenario' based on that experience.

For jobseekers with limited or no recent employment history, it could be beneficial to arrange work experience or voluntary work to assist in determining future job choices. A work for the dole project *could* be an option here. Problems associated with voluntary work will include the individual not understanding the concept of working without getting paid. Because of the lack of understanding of cause and consequence, Seth could not get past the fact that the employer would be 'getting him to work for nothing'. To his mind, the employer was taking advantage of him. Even now at 23 years of age, he still cannot see the benefit to him.

Even if the individual is agreeable to undertaking work experience or work for the dole, it can still be problematic as the individual will need time to learn the job and get to know the employer and colleagues.

If the case manager does deem this appropriate then the process of exploration may also help determine whether the individual will work for full wages or be paid productivity-based 'sub-minimum' wages through the Supported Wage System. It can also, in the case of the current disability employment programs, assist with the Disability Pre-Employment Instrument⁸.

Case management interview techniques

Interviewing a client with FASD can be daunting if you receive one-word responses, long-winded responses or if he or she gives you answers that do not offer any real information. Alternatively, you could get the information but then find out later that it was confabulation as discussed in Part II. The goal of an initial case management interview is to gather information from which you can make an assessment. You will need to explore ambivalence, encourage clients to express their concerns, investigate good reasons for change and draw out information allowing you to prepare a plan.

A robust program for your client is one in which engagement is consistent throughout, from the initial interview to a 26-week outcome and beyond. Engagement means that the client is connected to the case manager and

⁷ The length of support is dependent on the type of program – for instance in the industry today the Personal Support Program length is two years; the Job Placement Education and Training program has no official length but is usually around six months – the length of assistance under the new model may be shorter still

⁸ The DPI is designed to measure the level of disability-related support that the service has to purchase or provide to help a job seeker/worker to reach and maintain an employment outcome.

vice versa. There are interview techniques that may gently extract information to assist with the assessment and engagement process however, extracting good, solid information from an individual with FASD will be more challenging.

The above case management model highlights the need for engagement at all levels at all times and for obtaining a comprehensive account from your client, including a history of your client's biological parents and whether the client has a history of accessing departmental and/or not-for-profit services such as the Salvation Army or St Vincent de Paul.

For subsequent interviews, case managers may consider looking at progressing the client through their barriers step by step, always keeping the client moving forward, engaged, motivated and enthusiastic with the case manager providing basic informal counselling and generally attempting to increase confidence and self-esteem.

The statements below are excellent tools to use even if you use only a few. You may find them useful adjuncts to your usual interview technique for all clients, not just those with FASD. I have also offered examples below why behaviour may be incongruent to stated goals particularly for clients with FASD.

Examples of Basic Statements:

Q: 'On the one hand you say you are terrified of going to prison, but you continue to (engage in the behaviour). I'm confused.'

Possible reason for dichotomy: Does not understand the link between doing something that is illegal and going to prison.

Q: 'It sounds like you are still struggling with your drinking (or drug use), but you *have* made some changes. How do you think you might reduce your drinking (or drug use) even further?'

Possible reason for dichotomy: The client may be able to give you examples such as 'not drink so much' or 'stop drinking', but there will not be many more examples – the individual will not be able to link the examples to the act of drinking and very unlikely be able to independently follow through on the suggestions.

Q: 'So on the one hand you are clear that you want to work in the mines, but you are also still using cannabis. You *know* that they will want a drug test. I don't understand. Can you explain it to me?'

Possible reason for dichotomy: Can tell you that a positive drug result will not get a prospective employee into the mines but cannot link that to what he or she is currently doing – because of damage to the corpus callosum, the individual can recite the rules but not put them into action.

Q: 'What do you think your life will be like in (xxx years) if you continue to use?'

Possible reason for dichotomy: Is unlikely to be able to articulate the answer to this question with the exception of saying, 'I don't know'. This is because he or she really doesn't know. It is usually impossible for an individual with FASD to think so far into the future as they are very much oriented to the present. The other alternative is that the individual may give you a detailed idea of his or her future which seems unrealistic given their current situation.

These questions are somewhat abstract and the answers you may get in response could just be 'I don't know', but they are worth trying. For an individual with FASD you will need to keep statements short and concrete without abstract or conceptual content. Even then, there is no guarantee that the response will provide you with the information you require. In fact, almost every strategy and intervention could produce a negative result in the 'wrong' circumstances. There is no merit in trying to *make* the individual change his or her mind. Neither is there any merit in trying to get your client to try something different. It is better to take the opportunity to mention now and then the changes you would like to see. Show your client information from the Internet or another 'credible' source. Keep coming back to the one thing that is important at the time. One of the following:

- If you want to have a happy life then you must ...
- If you want to be the best you can be then you must ...
- If you want to have money then you must ...
- If you want that particular job then you must ...

Resume preparation

Most individuals with FASD will be unable to prepare their own resume without support. Depending on history, age and experience you will need to choose between a skills-based resume and a chronological resume.

A skills-based resume is probably best given that there are likely to be long periods of unemployment in your client's employment history.

Supported job search

Due to limited confidence, esteem and cognitive issues, many individuals will need considerable encouragement and most will require direct assistance to job search.

For clients with FASD, the case manager should always make the initial contact with the employer after working through the process on the following pages. This paves the way by first discussing the benefits of employing your client, possible difficulties the client may encounter while working, strategies to overcome these difficulties and the service you and your organisation offers. If the employer, for whatever reason, is unable to employ your client at this point, it is preferable that *you* take the rejection rather than the client. Negotiate with the employer in the initial phase and then bring in your client in the latter stages when the employer has all but agreed to the placement.

Three of the best methods of identifying employment opportunities for jobseekers are:

- Linking with employers who you know from previous contact have a disability themselves or have a family member with a disability – it is possible they will be more receptive to an employee with a disability
- Using your database to identify employers who have previously employed your clients, so there is already a broad understanding of the words 'highly disadvantaged' and a familiarity with you, your organisation and the program you deliver
- Reverse marketing – matching the employer and the job directly to the jobseeker rather than the jobseeker to the employer. This is done by making contact with a suitable employer and negotiating with him or her for an interview for the client. This will involve quite a bit of preparation. The case manager should be confident that the occupation will suit; look at the skills, aptitudes and needs of the individual and then discuss the client and any incentives with the employer

If you are matching your client to vacancies, ensure that you do not try to fit the client into the job. It should always be the other way around for an individual who is highly disadvantaged with a disability like FASD. You *must* fit the job to the individual. This is why reverse marketing is so much better than job matching.

If you have decided to reverse market your client, the steps to a successful placement and subsequent outcomes are:

1. Identify the type of job that best suits the individual by discussing the particular aspects of previous jobs that were enjoyed, or hobbies or activities at school that were interesting
2. Identify the skills that the individual enjoys and at which he or she might be relatively good. For example, Seth is good at four-wheel driving so a job at the local council with the mosquito control section, requiring staff to drive off-road and on quad bikes, is a good match
3. Identify the types of businesses where the occupation and skills are likely to be found
4. Write a list of those businesses and then identify the ones within reasonable distance of the individual's home or on a bus route. Factor in any particular need that is important to your client
5. Discuss those businesses which remain on the list to ascertain if the jobseeker has previously had any experience with them
6. Keep the individual involved in the process as much as possible – this will not be easy as it is challenging to keep someone with FASD connected to what you are doing or saying if it goes on for longer than a couple of minutes. In fact you should be alert as to how long you keep your client waiting – to you it will be five minutes, to your client it will seem like five hours⁹
7. Match remaining businesses in terms of your organisation's connections or network
8. Ring the remaining employers and make an appointment to introduce your client to discuss how he or she can help fill the gaps in the employer's business needs

⁹ While this is something you should expect, it is not always possible to see your client immediately. Both parties need to be willing to make accommodations. Perhaps you could be more aware of the length of time your client may be waiting and your client should try to learn that sometimes, waiting is unavoidable

9. Do not oversell the individual. This is what has been happening all his or her life – the expectations have been far greater than his or her ability. Conversely, don't completely undersell your client either – be positive about his or her ability but also be realistic
10. Use the persuasive powers of an employer incentive¹⁰ if appropriate

You should have been successful in obtaining an interview with an employer from this process. If not, repeat until you do. The interview can be easy or difficult depending on the IQ of the client. I am assuming that all other factors are in place.

Employers will want to know that your client:

- Will help make the employer's business more successful
- Has the right attitude and the right work ethic
- Will be punctual, attend regularly and work hard
- They *may* want to know that your client:
 - Has the right skills for his or her business or is prepared to acquire them
 - Doesn't cause any trouble, and
 - Will stay for the remainder of their working lives in the business if they have all the above, or leave very quickly if they don't

Most employers in this current labour market understand that this wish list is no longer valid. Reassure your employer by advising him or her that while you cannot guarantee your jobseeker, you *can* guarantee that he or she will have all available support needed, from you and your organisation, for the duration of the employment along with any additional training he or she may need to do the job.

You can also advise your employer that should he or she not be happy with the client's work or interaction with co-workers, you can be contacted to discuss the problems directly and develop strategies to ameliorate the situation, or you can look for another more suitable employee. That way the employer is not required to spend time counselling or re-recruiting – that is *your* job and while you are focussed on ensuring that your client obtains and maintains the job your goal is also to retain the employer-provider relationship.

Some employers, especially those in small business, may have once been tradespeople who generated sufficient business to slowly but surely expand into a small business. Some of these business owners are excellent tradespeople but may lack the finer management and recruitment skills required to develop a growing business. They do not always have the skills or the willingness to resolve conflict or solve problems related to their staff. If you sell yourself as the person who can solve these problems by guaranteeing your pre- and post-placement service, then even if the job doesn't work out for the client, your relationship with the employer will remain positive.

Even though the Rudd government has increased permanent migration levels and is considering the expansion of temporary working visas - including the controversial Class 457 visa, there has never been a better time for a person with a disability to find opportunities in the workplace. With the unemployment rate so low, employers have reconsidered their priorities and change the profile of their 'perfect' employee.

This is the benefit of having an unemployment rate of less than five percent. It provides more opportunities for disadvantaged people who need skills training and experience in the workplace.

The interview

If you are going to practise interview techniques, try to help your client learn in different locations and in different ways. It could be that he or she might learn the interview techniques and job search skills well when you are both in *your* office but be unable to remember what has been learned in the *employer's* office because of the inability to generalise learning.

When a lesson is taught, never assume that your client will automatically know how to generalise information to new situations. Point out other situations and get them to think actively about them such as, 'At what other times would you do this? Do you think it would work here? How is that situation similar to this one?'¹¹

Even though it is possible that the individual will have good verbal competency, it is an essential element of the reverse marketing process for this particular disability that you contact the employer to discuss the individual's

¹⁰ Wage subsidy

¹¹ Fetal Alcohol Syndrome A Training Manual to Aid in Vocational Rehabilitation and Other non-medical Services 1999, La Due R.A. et al

needs before they attend the interview. It is quite possible that the individual if left alone at the interview will say what they think the employer *wants* to hear. This *may* include some confabulation or it may be that the client will tell the complete and inappropriate truth such as, 'I don't really want to be a gardener but my case manager made me come to this interview.'

The other benefit of having you as advocacy support at the job interview is to ensure that as the case manager, you fully understand the job requirements and the key factors of the particular business.

As I mentioned earlier, for FASD in particular it is advisable to disclose up front that the individual is affected and outline his or her strengths along with major needs. The employer *must* understand before your client commences work exactly which behaviour is within the control of the worker and which is not – in other words, which behaviour is non-compliance and which is 'non-competence'¹². This is where the offer of a wage subsidy may pave the way. Most of us who have been in the employment services industry for any length of time have been told always to highlight the individual's strengths and minimise the weaknesses. In this instance, it is far better for the individual *not* to get an unsuitable job than to get one where the employer's expectations exceed the employee's capabilities.

When the individual begins the job, it is *not* the end of the support. In fact, from this time onwards for the duration of the employment, appropriate support is absolutely critical. It can range from irregular to almost daily and may include training, advocacy, counselling, negotiation and education. There will be many times when nothing you do will make a difference.

What if my client finds his or her own employment?

Any intervention will depend on whether your client wishes you to intervene or not. For those jobseekers with a higher IQ, it may be considered an issue of 'shame' to have a third party become involved in employment that was obtained without your assistance. If you can't convince your client that he or she might need your help, then you will only be able to sit on the edges of the employment until eventually there is an agreement for you to become involved. This is another reason why it is important for you to be the proactive partner in the relationship and in fact, it is the contractual requirement in the current (until 2010) Australian Government's Disability Employment Network contract.

If your client is older, he or she may have experienced problems with employment in the past. If so, there *may* be an understanding at some level that employment is not something that can be done alone.

If your client is young and immature and has a normal IQ, he or she will be like every other teenager alive – ten foot tall and bulletproof. This will make it very difficult for you and ultimately your client. But without permission, you can only watch and wait.

Buddy or mentor training

Ideally, colleagues, supervisors or managers will benefit from training on FASD, which should include, even if it is only very basic:

- The impact of prenatal alcohol exposure on employment sustainability, with the particular aim of avoiding misunderstandings and assumptions on the job. Misunderstandings can include the assumption of competence and non-compliance
- Any necessary modifications or equipment to reduce the impact of physical or sensory impairment
- Ensuring the individual has a clear understanding of the requirements of the position and any associated responsibilities
- Strategies to deal with unacceptable workplace behaviour
- How to deal with safety concerns in the workplace
- The necessity of a strict medication regimen
- The concept of 'on days' and 'off days'
- Encouragement through relevant and immediate praise
- Progress through relevant and immediate intervention

A family member may not be the best person to advise the employer about FASD. He or she may be too close to the subject and be unable to be objective. In fact, it's possible it could be more of a negative than a positive. Try

¹² Jan Lutke

to find someone who is educated about FASD and who understands the relationship between FASD and employment.

One on one – case manager/client training

It may seem like extra work but it could save time and effort later if you prepare:

- A task analysis and task component breakdown¹³ for each aspect of the job to assist the individual in understanding the requirements of the job – this could also be utilised for any training required
- Along with training in the work ethic in previous pages, training needs to be provided on rights and responsibilities in the workplace to assist the individual with inclusion and competence in the social aspects of the work environment. Any training provided to the individual should utilise the techniques mentioned earlier in this book and should cover:
 - The timing of breaks and the general pace of the workplace
 - What is and isn't acceptable as 'horseplay'
 - Acceptable dress and grooming
 - What the employer is allowed to ask of the employee
 - What it means to work under an award
 - Cliques, sub-groups and role models and what they mean to the individual and the employer
 - Taking time off – sick leave, annual leave
 - How much work is enough in a day
 - Workplace safety in all situations including psychological safety

Training should be offered to your client in small 'packages' at each appointment. If you are an employment services provider, you can also use this coaching as a progression through the individual's barriers on their intervention plan, goal sheet, activity agreement, or, on what appears to be the next iteration of the agreement between provider and jobseeker – the Employment Pathway Plan.

If you are supporting the individual through on-the-job training and assistance, every person, even if they have the same disability, will be unique and have their own capabilities, limitations and unique learning styles but there are also similarities in the way you support your clients:

- Teach new tasks step by step or task by task (use the task analysis if necessary) to define the elements of each task to be undertaken
- Demonstrate how to correctly perform the task and then ask the individual to perform it, explaining and correcting any mistakes as he or she goes through the task
- Be flexible as long as the end result is correct
- Provide positive feedback immediately where it is merited and – do not allow mistakes to occur without ensuring that they are gently corrected
- Avoid too much variety until the tasks are consistently learned – ensure that the individual has not just learned the task for one or two days but has achieved consistent accuracy over weeks or months ('on days' and 'off days')
- Avoid complex instructions or too much information too soon

Post-placement and transition support

I recommend a step-by-step approach to providing post placement and transition support (PPTS). I have outlined the steps below:

- | | | |
|---------------|---|--|
| Step 1 | – | Prepare a risk assessment - begin preparing it from the first interview with your client |
| Step 2 | – | Prepare a support plan and risk analysis |
| Step 3 | – | Begin PPTS |
| Step 4 | – | Reassess strategy at termination ¹⁴ |

Step 1- The Risk Assessment

¹³ See previous chapters

¹⁴ It is not my intention to pre-empt a 'failure' but when a termination occurs it is important to look at the factors related to the termination to try and avoid similar pitfalls in the future

Begin preparations for PPTS when you conduct your first interview with your client by advising him or her of the benefits of being supported in the workplace. Post-placement and transition support can be presented as a value-adding service to both employer and client. As an incentive for the employer, you could suggest you will undertake any induction necessary. This will save the employer time and money and may prove to be the 'value-add' for which you are looking.

It is important to understand Centrelink notification requirements and the date that your client is to lodge their SU19¹⁵ to obtain their allowance, so you can be sure that they are declaring income. It is unlikely that a client with FASD will think to notify Centrelink of any income earned, because they don't link the consequences of having to pay back large amounts when they are discovered.

It is not usually because they are trying to 'get away' with anything in particular; it's because notifying Centrelink is never the priority of the moment. Therefore, declaring income is something you should take responsibility for as it will ensure two things – firstly, Centrelink will actually *be* notified, and secondly you have the appropriate evidence when the outcome dates come around.

Key components of an efficient post-placement and transition support strategy include conducting a risk assessment based on your experience with the client, preparing an individualised post-placement and transition support plan and engaging stakeholders in implementing strategies to support retention. Stakeholders can include family, friends, Public Trustee, social worker or caseworker and other community organisations to which the individual is linked.

The risk assessment on the next page uses Diane Malbin's task component breakdown outlined in Part II as a method of assessing the level of support an individual may require post placement along with identifying the individual issues that could cause problems. Once the level of risk to the placement is understood, the level of support needed to alleviate the risk can be planned and put into place. Many experienced case managers understand a client's needs without undertaking a formal assessment. However, actually identifying potential individual risks to the placement can be of benefit should another person become involved who isn't as familiar with your client as you are or if your organisation has a centralised PPTS process.

No matter how well you prepare, things can change quickly. The risk assessment and support plan can easily be thrown out the window and you might need to conduct the post-placement and transition support by the seat of your pants when something unexpected occurs.

Ideally the relationship you develop with your employer over this time will show him or her that you and your organisation:

- Provide better support services than other organisations
- Are attempting to dispel the myths about employing people with disabilities
- Are providing a safety net not just for the employee but also for the employer

Step 2 – Prepare a Support Plan and Risk Analysis

Once the risk assessment has been prepared through developing the task analysis and the task component breakdown for each task, a support plan is prepared which will take the issues identified in the risk assessment into consideration and identify both needs and potential accommodations.

¹⁵ The purpose of the SU19 is to access a job seeker's entitlement to payment for the fortnightly period as stated on the form. It is also used to determine the rate of payment to be made.

Post Placement and Transition Support – Risk Analysis Example

Requirements: Environment, Institution or Setting	<i>Requirements of this job</i>	To be able to drive quickly but safely
Cognitive or Developmental Requirements for Success	<i>What is needed to succeed at this job</i>	Behave maturely when driving Self-control Knowledge of road rules Ability to translate rules into action
Primary Characteristic FASD	<i>The characteristics that will pose problems</i>	Inability to predict outcomes or understand consequences Inconsistent performance Impulsivity, distractibility and disorganisation
Secondary Behaviour FASD	<i>What will happen if client can't do this job</i>	Avoidance Unsafe driving Possible accident
Strengths of the Individual	<i>Strengths of the individual</i>	Can respond well to routine and structure Determined and persistent
Accommodation	<i>How to help client focus on strengths to get the same result and how the employer can adapt the environment, the task or the situation to get the required results</i>	Provide structure Provide mentor Thoroughly assess driving ability of client

The original task component breakdown is actually a risk analysis, which once again provides the case manager with the opportunity to isolate accommodations to the potential risks revealed in the risk assessment.

The support plan isolates the potential risks to the placement by identifying the accommodations and secondary behaviours in the task component breakdown against each task. For instance, in the model above the secondary behaviours are avoidance, unsafe driving and possible accidents and the accommodations are workplace structure, a buddy or mentor and the thorough assessment of the driving ability of the client.

Sensibly, in this case, an assessment of the individual's ability to drive safely under pressure would be the first action to take. If the client is assessed as competent, then work on other secondary behaviours and accommodations such as mentoring and structure.

Step 3 – Begin Post-Placement and Transition Support

Post-placement and transition support for people with FASD will be confusing. They may, for instance, be perfect employees for weeks or sometimes even months before you need to leap into action. Other clients will have problems intermittently and still others will require continual support from the first day until the last.

When you speak to your client during a PPTS contact, you usually ask questions of him or her to enable you to assess the situation.

For an employee with FASD the questions for the jobseeker should be framed differently, but no matter how the questions are framed, the answers you get will most probably be based on what has happened *today* even though you might ask questions about the week.

The questions below may make it possible for you to obtain the most relevant answers:

Client questions:

- Tell me what you did this afternoon.
- What do you like best about the job?
- What have you learned today?
- What is the best thing that happened today?
- What is the worst thing that happened today?

- By circling the most appropriate face, tell me how you feel about the job¹⁶.



It will depend on the client as to which of these methods will provide you with the best and most relevant answers.

Step 4 – Reassess on Termination

I cannot stress how critical both proactive and immediate reactive post-placement and transition support is to the sustainability of employment for someone who has FASD or a similar disability.

There are many experienced and efficient case managers and employment consultants in the employment industry. Nevertheless, even the best case manager or consultant will miss things or be too busy to respond quickly, and a placement will be lost.

When this happens and if you feel it is necessary, in-house or external counselling is the best method of managing the hammering that a client's confidence and self-esteem may take on losing a job. Because you have already prepared the employer for this eventuality, as soon as it happens, talk to him or her about slotting another of your clients into the position. Your immediate and professional follow-up and not the client's job loss will inform the employer's future business with you and your organisation, thus saving prospective vacancies.

At this stage, a reassessment of the level of support that was provided should be undertaken. Was the placement lost because the support itself was inappropriate, not strategic enough, too complex? Did you miss some crucial issue such as the mentor or role model? Did he or she role model inappropriate behaviour? Would you have done anything differently in hindsight? Perhaps the client was not ready for employment. Did your client lose his job because he or she was overwhelmed and stressed? Maybe there was nothing you could have done to prevent this and this job loss is just part of the employment/unemployment cycle described earlier.

These are all questions that need to be asked on termination, whether it is resignation or dismissal. There is always room for continuous improvement in this process even though in many ways the support provided is idiosyncratic, based on the individual's profile and risk assessment.

Many individuals with FASD have the ability to shift the blame from themselves to another person. This is due to the lack of insight into cause and consequence, so even though the individual might be at the heart of the problem that ultimately causes the dismissal, it will be difficult for your client to see that what he or she did several days ago resulted today in dismissal or discipline from the boss.

They are more able to make a connection between something a co-worker did and the loss of their job. This is *still* likely to cause distress, in that your client will feel cheated because of the (supposed) actions of the co-worker which, in the client's mind at least, are to blame for the problems. Do not try to *make* your client see what he or she did was 'wrong'; you will merely alienate your client from you. This lack of insight is not something that is within his or her control. It *is* something that can be used as a gentle demonstration to the individual of the impact of their actions. Do not dwell on this point for too long, as the worker is apt to become frustrated if they are unable to make the paradigm shift in thinking. It may come to them weeks or even months later – or not at all. To maximise the efficiency of your post placement support consider the dot points below:

- Prepare the risk assessment and the support plan from Part II focussing on maximising workplace productivity and sustainability
- Learn as much as possible about the condition and take on board information gleaned from talking with family and friends, from the Internet or from my two other books, which to date are the only books written for the Australian situation: *Alcohol and Pregnancy – A Mother's Responsible Disturbance* and *Alcohol and Pregnancy – No Shame No Blame*¹⁷
- Ensure that each family member has a role to play in supporting the individual maintain his or her employment

¹⁶ It is unlikely that you will get a good answer without the visual representation. It will be very difficult to get an idea as to how he or she feels about the job in general. It is likely that you will only get how he or she feels about the job *right now*.

¹⁷ Zeus Publications 2005 and 2007 – www.elizabethrussell.com.au

- Co-opt the following services if necessary:
 - The Public Trustee – finances and budgeting are important facets of the individual’s quality of life. Without the Public Trustee, the individual is unlikely to manage money effectively and so not factor in fuel, rent, food, bus fares or any other non-negotiable bills
 - Life skills support or a life coach for shopping, cleaning house or flat, relationships, transportation, assistance with parenting if necessary, how to answer mail, pay bills
 - If family and friends are not in the immediate area or not available to the individual for other reasons, and the individual does not live in supported accommodation then you should consider the intermittent services of someone who can fix things around the house or flat or help with cleaning
 - Appropriate health services and medical support and assistance to ascertain when it is appropriate to seek medical services
 - Drug and alcohol services and support
 - Housing and tenancy advice or advocacy
 - Someone on the job who can act as mentor, role model or ‘buddy’ to the worker to help make any decisions he or she needs to make in the workplace – essentially the client’s ‘external brain’ at work, but also to role model appropriate workplace behaviour
 - It may even be appropriate in some locations for certain jobseekers to have a full time mentor who provides post-placement and transition support for the jobseeker by spending every day on the job with them *indefinitely* an expensive process but one that might be what is needed for some jobseekers to successfully remain in the workforce

If you recognise that the placement is in jeopardy, you will need to act quickly to implement a retrieval strategy to resolve issues that have emerged. The following are possible strategies and interventions that could be considered:

- 1 Alter perceptions – it will be very difficult and it is not recommended in the short term to try to change the client’s perception of what happened in the job. This can be done slowly over time but must be tackled one point at a time and when the client is not stressed. I don’t have much luck doing this in the short term, but I see changes in perception occurring over the medium to long term. I have found on the odd occasion, and probably more often than I realise, things which were once indisputable to Seth make a turnaround over months and years. We know that with FASD, the first solution to a problem is usually seen as the only solution to a problem, even when it clearly does not work¹⁸ ... so once the perception of an event has been established (which is usually at the time of the incident) it becomes all but irreversible
- 2 Offer skills training, certificates, tickets, anything that might be needed to assist the employee become more valuable to the employer
- 3 Financial assistance such as a wage subsidy, mentoring, workplace modifications
- 4 Look at finding another job for your client (it may be possible to do this but my experience is that if the job gets to this stage, a recovery period is needed where the client is able to rest and de-stress for a period of time)
- 5 Apart from salvaging the client’s confidence and self-esteem it is important to ensure that the case manager/employer/client relationships remains sound

Care of the case manager

So far I have spoken about the care of the client and how best to help with the achievement of sustainable employment. There is another integral factor in helping a client obtain employment and that is the physical and mental health of the case manager.

Therefore, the right case manager is one who works in an organisation that provides appropriate de-briefing and professional supervision on a regular basis. Group supervision, case discussions, peer to peer supports, mentoring and professional development are all vital to enable the case manager to function optimally in the pursuit of durable employment or an improvement in the social situation of the client.

¹⁸ Neuro-behaviour in Adolescents and Adults (with FASD)

In summary, the right case manager will learn as much as possible about FASD or the particular disability from which his or her client suffers.

There is a fine balance between learning about the condition and focusing on the condition to the detriment of the employment prospects of the individual. In fact, I have heard said that the name of the condition is not important; it is the impact of the symptoms on the ability of the individual that counts.

I personally believe that in order to make an informed decision about what is best for your client, you need to be informed. Part of being informed is to understand the disability, medical condition or disease from which your client suffers and not just the symptoms that affect the job. That is to be truly informed because to some case managers, unless they are aware of the name of the condition, they may consider that certain behaviours exhibited by the client can be changed by the client, when in fact they cannot. Once again, this is what has probably been happening for the entire life of the individual where the expectations are such that they can never be met.

Learn from mistakes but be sure the individual is supported through any reactive depression. Sometimes the individual can't get back into job search for months. Knowing when to push and when to let the client rest up is also important. Learning about the condition in a book is one thing but learning about the condition from your client and his or her family and friends is quite another. It will give you the most pertinent and idiosyncratic information about the client and how the symptoms, characteristics and behaviour written down as part of this condition is actually represented in your client as an individual.

The right case manager will be consistent, non-judgemental and will *always come back* (within the parameters of the program they are delivering).

Factor Three – The Right Employment Program

Instead of describing employment and pre-employment programs in terms of what is available now, I will describe the *features* of the most appropriate programs for individuals with FASD. The structure of employment services changes under each government so the description of existing programs is likely to be quickly outdated.

There are two types of programs that I will describe because only these two types will be suitable for a person with FASD, depending on whether the individual is job ready or not. Most programs currently fall into these two categories – employment programs and pre-employment programs. In the future the model may include streams for 0-12 month unemployed; 13-36 month unemployed; 37-60 month unemployed and highly disadvantaged clients along with maintaining the Disability Employment Network capped and uncapped until 2010.

Pre-employment programs

The best program for people who have the following issues is one with a minimum life of two years and that offers personal one-on-one individual case management support for issues relating to:

- Drug and/or alcohol abuse
- Victim or perpetrator of bullying or violence
- Homeless or at risk of being homeless
- Victim of domestic violence/anger issues
- Mental health issues and social isolation
- Trouble with police or legal issues
- Psychological or psychiatric problems
- Sexual, physical or psychological abuse
- Ex-offender issues
- Relationship breakdown
- Lack of confidence or self esteem
- Limited employment history and literacy numeracy

Currently there is no additional funding for items such as the gathering of suitable identification, provision of motivational or self-confidence classes, neuro-psych assessments, training, counselling or the purchase of any other item or course that can assist the client overcome the issues they face. However in the future it seems as though what is now called the Jobseeker Account will be available as the Employment Pathway Fund to all jobseekers regardless of the program.

Participants of this program have lives that have unravelled. The individual alone is not able to put it back together again, even with the help of friends or family, should they be willing and able to do so. With the help of case managers in these programs, a stable platform may emerge from which to regain some control over their lives. This is also the program to which people with FASD will find themselves referred *because* of the above issues.

They will come with the secondary disabilities diagnosed as primary disabilities and barriers and may successfully progress through their barriers until the support is withdrawn when the program is completed. Case managers may see that over the two years as a participant of this program, some progress has been made. Unfortunately, without knowing that the client has a brain injury, they may expect the participant to independently maintain the advancement that has been made. For people with FASD, this maintenance is unlikely to occur unless lifelong services are put into place during the time on this program.

If that doesn't or cannot happen on conclusion of their time in the program because of the eligibility criteria of these services, (eligibility to many of them is based on IQ and as we know in FASD, an affected person can have a normal IQ but still be significantly disabled) the participant's situation will more than likely take a retrograde step and follow the line of least resistance back to the status quo of two years ago.

Employment programs for people with a disability

For an individual with FASD who can work in supported open employment, the best program is one:

- Which allows participants to work in open employment
- Where participants with a disability can work for full award wages

- Where an employer incentive is available (wage subsidy) while the individual becomes acquainted with the duties of the job. This wage subsidy can be utilised again during periods of ‘employment – dysfunctional’¹⁹ to offset wages where optimal productivity is not achieved
- Where support is provided for the remainder of the participant’s working life on an intermittent basis – if required
- In which the same case manager looks after the participant on a consistent, long-term basis

All employment programs funded by the Federal Government have service guarantees and codes of conduct to which providers are contractually required to adhere. Service providers who work with people with disabilities are additionally required to be quality assured under the Disability Service Standards, which comprise twelve standards set out on the next page.

Factor Four – The Right Stage of Social and Emotional Maturity

Socialisation is the process by which children and adults mature and learn from others and accumulate cultural, emotional and social awareness. We begin learning from others as babies, and most people continue their social learning all through life (unless a mental or physical disability slows or stops the learning process)²⁰. From experience, I have found that this process can be reshaped by the differing processing styles of children with FASD.

There is very little that any of us can do to mature sooner and while most of us (when we were young at least) wanted to be older than we were, none of us could make the years pass more quickly. Likewise very few of us can consciously hurry up the maturation process; it takes its own time. For some young people with FASD, not only can it take longer, but also because maturity is usually quite a long way behind chronological age, individuals are not age appropriate. Damage can be done to the individual’s credibility, relationships and opportunities because people are not aware that there is a physical disability behind the behaviour.

Even *childhood* relationships rely on children conducting themselves in age appropriate ways at appropriate times. If that doesn’t occur, the child is ostracised by peers and is eventually drawn to younger people who tend to make fewer judgements.

When young people, still without a diagnosis, get older and expectations of them are greater, their credibility can be undermined, often alienating the very people needed to set them on the path of employment – employers.

The misunderstanding based on Seth’s capacity, confidence and expressive language created untenable situations in each of his jobs which he could not cope with. The misunderstanding was the belief that Seth could do what he *said* he could do and cope with the requirements of the job because he *said* he could. In other words, the employer believed that because he could ‘talk the talk’ he could also ‘walk the walk’.

He was *expected* to behave in an age appropriate manner, properly communicate and carry on relationships in the socially acceptable manner. These expectations were completely appropriate for people Seth’s age – *if* they did *not* have a brain injury. Consequently in each job after the ‘honeymoon’ period, Seth’s credibility amongst employers and colleagues transformed from mutual respect into mutual disrespect when they found he was unable to ‘walk the talk’. He is able to cope for a certain period, sometimes as long as two to three months, and then the pressure becomes too much for him and he shuts down. At that point, he has to leave the job or continue to cope with problems that have in the past led to his dismissal. In almost every case, Seth really had no other option but to leave. There was never going to be any other result for him. It would have been so much healthier for him if he had never gone through those experiences in the first place. However, without them, he would not have the skills he has now.

There was no appreciable difference to this pattern until he reached the age of twenty-two. He still was not able to remain in a job longer than six months, yet his standard of work was relatively consistent and, with high support, he maintained the proper level of punctuality, attendance, productivity and behaviour.

At 23 years of age, his support needs remain high and I don’t expect that to change in the short to medium term; nevertheless, he is receiving more approval from bosses for his work than ever before.

¹⁹ Previously described in the chapter – Cycle of Employment

²⁰ <http://www.soc.ucsb.edu/faculty/baldwin/classes/soc142/scznDEF.html>

Controlled forays into short-term work experience, work training or temporary positions may be of benefit to ascertain whether your client is able to cope with the social and emotional demands of the workplace. This can also assist in identifying the impact of the client's personal and social life on the job. Unfortunately, the decision to go down this path must be balanced by the disruption caused to the client by having to learn new tasks, becoming accustomed to new environments and establishing and re-establishing relationships ... the common experience in short term temporary positions.

Before I found Seth had FASD, I could see that his maturity left something to be desired, yet on the other hand as an intelligent young man, I expected that he would 'put his best foot forward' and do what was required of him once the tasks and standards of the job were established.

That was an idealistic position and one that should never have been a part of my expectations of him. It was similar to expecting a blind person to read, simply because he was intelligent and reading was a requirement of the job.

When people don't behave as we expect, or they aren't able to perform as we think they should, instead of *our* expectations being considered wrong, the person with the disability is labelled according to our mistaken and invalid expectations.

That's the way people are judged all the time. It's rarely that we admit our perceptions might have been wrong or exclusive of the facts; it is usually the other person who is not behaving as we think they should.

On the occasions Seth *does* behave in a manner less mature than his chronological age, even though it is for similar reasons as it has been in the past, he can sometimes recognise that behaviour and reduce the impact of it on his friends and family. I say sometimes because I tend to think that in the majority of cases where he modifies his behaviour, it is because our family understands what needs to happen in his environment to reduce the likelihood of this behaviour occurring. Those times that he can't control his behaviour or the people around him aren't able to provide him with the environment he needs, it has a significant effect on the people who love him.

If an understanding mentor or a 'buddy' can be found in the workplace, then ideally they will be able to do two things: alert the individual to any inappropriate behaviour, or provide the necessary changes to the environment which includes changes in the behaviour of workmates. The latter is the most likely to succeed.

Eventually the consistent and repetitive reminders may do their job. Any mentor would have to be patient and prepared to learn as much as possible about the disability, and must also be trustworthy so the individual knows that he or she will not, in their own frustration, turn support into condemnation or criticism. The mentor must be there primarily for the individual, have the individual's best interests at heart and be able to gently turn inappropriate social behaviour into more functional conduct.

For family, friends, case managers and other support staff it will be difficult to know exactly when the 'right stage of social and emotional maturity' is – it will not be a certainty. If you prepare the individual, prepare the employer, prepare his or her colleagues, and all understand the reasons behind the worker's potential behaviour and not expect perfection, then all those involved will be in a better position to help the individual maintain meaningful employment. Nothing is certain with FASD. It is possible to have every factor in place, every strategy and intervention prepared, and the most experienced and professional of all case managers, and still have a gruelling post-placement period to manage with the end result of unemployment.

The only thing that *is* certain is that the right stage of social and emotional maturity is when you can look back and say in hindsight, 'That was the right time!'

Factor Five -The Right Living Environment and Social Supports

While medication is vital, reliable social supports underpin the entire cornerstone of care. Unconditional support structures and social networks or multi-systemic supports are needed not only to act as reminders for medication, appointments, responding to mail and behaviour but also to serve as external brains²¹. An external brain is someone trustworthy who can help the individual make decisions and clarify issues. The external brain concept is highlighted through an extract from my second book, *Alcohol and Pregnancy – No Blame No Shame*. A woman who has no doubt she has Fetal Alcohol Spectrum Disorder said, '... I can't think clearly and I need to

²¹ The external brain concept was coined by Dr Sterling Clarren who said that a person with FASD will always need an external brain –the key words were 'always' and 'external'

talk to other people about it. It's like it's not my own brain that puts things into perspective – I need someone else's brain so that I can understand things ...'

If there is an advocacy organisation in your location, they may be able to give advice on how to access support if you do not have family or friends who can take on this integral role. This is where I have found problems though. As I have noted in the past the eligibility criteria for services such as these seem to exclude people with a normal IQ. I have tried very hard over the last few years to obtain appropriate support for Seth. However, the services I have endeavoured to access reject him on the basis of his IQ and Seth does not have sufficient insight or inclination to have his independence constrained by service providers; so he refuses this very necessary support.

It is far better to first access this assistance while the individual is still young and the young person does not assume it to be an intrusion into his or her independence. Seth is twenty-three years old, married, and for all intents and purposes, an adult. To try to convince him that he needs services now has been almost impossible.

There is also the problem of budgeting which has been discussed earlier – another vital component for optimal management of this condition and maintenance of durable employment. For instance, without Seth's caseworker at the Public Trustee Office looking after his finances, he would not have sufficient money for fuel to get to work each day. Hayley, who has been his partner for four years and has recently become his wife, tries to help him yet in the area of finances, it is difficult for her. The impulsivity he experiences often outweighs Hayley's logic. He cannot link a surplus of one thing today with a shortage of that thing tomorrow so he is likely to spend money today without understanding the consequences – not being able to purchase the item that is in short supply tomorrow.

Perseveration is another behaviour that will influence the durability of employment. Recently Seth left another job. He wasn't getting his delivery runs completed on time and even with his employer telling him it didn't matter, Seth left because at the beginning he had been told he was to finish his run and that was what he had to do. At the time he was told this, it was a different run, shorter and more manageable – but to Seth, that didn't matter. He perseverated; he couldn't change his mind to accommodate new information – the fact that this was a longer and more complex run. With perseveration, the first choice is the only choice. The individual identifies a 'solution' to a problem (often self-defeating), and regardless whether it becomes obvious that the decision is counter-productive to the needs and desires of the individual or whether something else occurs to prove the original decision impractical or unrealistic, it doesn't matter. None of it makes any difference – the first choice is the only choice.

It seems there only needs to be a slight change in the pattern of thinking, a very slight decrease in interest in the job, and the pattern is set – therefore, the more positive inculcation, the better.

Everything must be seen from the perspective of 'all behaviour is explainable'. While most of us know that we have the choice about how we feel, it is a disciplined person who can do this when an onslaught occurs from several different sources with the added problem of not being able to see cause and effect.

Perhaps as individuals grow older, some may be able to function more readily on their own without supports if they have not become addicted to drugs or alcohol. They may still not be able to sustain employment long term. Yet in the current labour market, it is possible that they can move from job to job in such industries as construction, rural and farm work, harvest work and many of the semi-skilled and unskilled positions available around Australia at present, as long as they are able to manage psychologically and emotionally.

Individuals with FASD who wish to work will need a high level of social support and a stable living environment. From my experience, if the individual is living independently, they will require the following:

EMPLOYMENT

- A case manager who can provide all manner of employment-related support including negotiation, mediation and advocacy, coaching and post-placement and transition support

FINANCIAL

- Someone who provides budget coaching, personal development and life skills training (preferably informally)
- The Public Trustee who can ensure that money for rent and groceries is taken out of the individual's Centrelink allowance

PRACTICAL

- Transportation – people with FASD will have significant problems dealing with public transport²²
- Someone who is able to help the individual manage his or her home life, including cleaning and attending to and responding to mail, which is a crucial downfall for people with this condition
- A person (not a peer unless they are very mature and consistent) who can act as an external brain when the individual needs to ‘check in’ about something that has occurred during the day
- Someone to help the individual purchase groceries and other necessities

HEALTH

- A health provider who understands both the condition and the individual, who has the appropriate authorisation and a willingness to speak to the case manager or employment consultant about his or her patient

ACCOMMODATION

- A stable living environment where the rent is automatically paid out of Centrelink allowance (Centrepay)²³ or wages or through the Public Trustee
- Someone to mediate between the individual and the landlord
- A service to assist with structuring cleaning and yard work if the client is independently renting a unit, flat or house

SOCIAL

- Social supports for friends and family who are supporting the individual, as it can be a very stressful, demanding and challenging job

Factor Six – The Right Medication and Health Supports

There is a close relationship between health and employment. If your client is not healthy, then sustainable employment will be more difficult to achieve. For a person with FASD, there could be many associated problems given that in some cases, along with the behavioural and other characteristics of the condition, organs including heart and kidneys can be affected.

General health can also be compromised by a penchant for ‘junk food’. This ‘preference’ seems to be part of the sensory disorders related to FASD. If possible, ensure that your client is in relatively good health.

Individuals may have a high pain threshold but at the same time may be overly concerned about minor problems, such as a stubbed toe or an ulcer in the mouth. Years ago, Seth remained at a party for hours ignoring his hand and fingers that had been cut to the bone when he swung on a street sign. His fingers eventually required multiple stitches. He accidentally cut his wrist within a millimetre of an artery, severing his tendon, and he barely registered it. Conversely, I have seen him in a panic to get to the hospital because of a splinter in his finger.

He would not have made it this far in his life’s journey without the aid of medication. He started out on Dexamphetamine for Attention Deficit Hyperactivity Disorder when he was first diagnosed with this condition. He only remained on this medication for several months because of its negative side effects and the fact that it did nothing to alleviate the primary disability of brain injury.

After a few months without any medication and because of his suicidal tendencies and ideation, he was placed on anti-anxiety medication and a mood stabiliser. This settled him down well during an incredibly difficult few months. Then when he became paranoid, he was placed on an antipsychotic drug.

One of the most important elements of having a person with FASD on medication is also having a general practitioner who not only understands mental health needs, but who also recognises the dynamics between family members and any other stressors in the individual’s life.

In addition, a normal medication regimen may not work. While it is true that mental illness stemming from lifetime neuro-chemical imbalance can be part of FASD, there is nothing clinically that changes the usual psychiatric approach, except that patients may respond atypically to drugs that would usually be given. They

²² Fetal Alcohol Syndrome A Training Manual to Aid in Vocational Rehabilitation and Other non-medical Services 1999, La Due R.A. et al

²³ Centrepay is a free direct bill paying service available to customers who receive a Centrelink payment – www.centrelink.gov.au

might do fine, but they might need smaller or larger dosages or not respond in the end to typical interventions and so require 'creative' therapy²⁴.

An individual with FASD who is working, particularly if they are working with other people, would benefit from an outlet where all the problems and occurrences of the day can be discussed in a safe forum but it needs to be part of a regular routine. The counsellor, psychiatrist or psychologist would need to be aware of the non-competence and non-compliance issues. If not, they do not understand the condition in terms of accepting responsibility and working independently, they may in fact make matters worse by expecting their clients to do things of which they are not capable or encourage the use of natural justice as a form of discipline. I have never been able to get Seth to a counsellor. He refuses to go and I think this is because he was diagnosed relatively late in life. With a normal IQ, the combination is not conducive to having his 'independence' jeopardised by having to regularly attend a counsellor or therapist. The reality is that he is not independent but doesn't realise that having these additional services would increase rather than decrease his independence.

I am sure there are a number of lucky people who do not require medication in order to operate on a day-to-day basis. There will also be individuals currently un-medicated who, while they are doing well enough some of the time, could do much better on appropriate medication. There will no doubt be many people who are medicated inappropriately because of inaccurate diagnosis.

In my second book *Alcohol and Pregnancy – No Shame No Blame*, an adoptive mother described her son's medication regimen. She reported that as a medical professional, she was concerned about *over*-medicating her son. In hindsight and after some very difficult times with him, she realised that medication *was* a crucial component of his day-to-day management.

One of the problems I had before Hayley came on the scene was how to ensure Seth took his medication regularly when Don and I were not around. He and other exposed individuals need social supports to act as reminders for medication on a daily basis. During the periods I was away, as I travel quite a bit in my job, I would ring and remind him but I quickly found that just reminding him was not enough. There must be someone who can actually ensure he *takes* the medication. Obviously the case manager is unlikely to have the resources or the time to do this so it must fall to family members, friends or significant others.

The type of medication that is apt to be taken by an individual with FASD usually needs to be taken on a regular basis for optimal performance, so there should be someone amongst the individual's social supports who will take on the task of ensuring that medication is taken consistently. There is very little else in the individual's life that is consistent and there will *certainly* be no consistency should the medication not be taken. This is another aspect of personal care that should be a component of the individual's transition *before* he or she exits any pre-employment program and should be stable and consistent (as far as possible) in an employment program.

Medication has been crucial yet not the only factor to Seth's remaining out of prison and alive. It has also been vital in maintaining his relationship with Hayley and his family and friends. Anecdotally from carers this seems to be true for a number of affected people and it is the finding of evidence-based research conducted by several Australian researchers.

From my experience, positive social interaction, therefore employment would be very difficult or even impossible for a person with FASD without appropriate and regular mediation.

As mentioned, in Australia there is great difficulty in finding a medical practitioner, psychiatrist, psychologist or allied health professional who truly understands what it is to have FASD or to have a loved one with the condition and is prepared to support both the affected individual and the carer. Therefore, it is going to be difficult but with luck, not impossible, to find the right medication and health supports.

Determination and persistence are amongst the qualities one needs to obtain the most appropriate medical support. Attempting to secure this support for a person with FASD, or even acknowledgement that the signs and symptoms you are explaining to your general practitioner might be related to FASD, is challenging and also requires a great deal of persistence. More important than persistence is luck in finding the right doctor in the right place at the right time.

²⁴ Sterling K. Clarren, MD, FAAP CEO and Scientific Director, Canada NW FASD Research Network Clinical Professor of Paediatrics, University of British Columbia Clinical Professor of Pediatrics, University of Washington in an email to the author