

Starting a Business Using AAC

INTRODUCTION

Starting out in business for the first time is scary for anybody. When that person also uses AAC it just adds a whole new dimension of hurdles to be overcome. However, this person also has a whole different range of experiences, many of them very funny, from the average person in the street. The challenge, as I see it, is to turn that uniqueness to your advantage in developing a business. I hope to demonstrate, how one person, has created a successful business out of doing something that not many people could do.

In this paper, I describe:

- The background to my working life .
- The steps I took towards self-employment
- The 'Essentials'
- Why I chose self-employment
- How I prepared myself
- The AAC issues
- Pros and Cons
- My Business

I want to emphasise that what I am doing is no easy ride! I do not think that all people who use AAC or all people with a disability should feel that they must try to work for a living. But, what I and some others are doing is showing that it is possible, if you have the drive and ambition.

I hope to change attitudes, so that in future, no parent with a child who cannot walk or speak is told that they will never amount to much, and to not bother about getting a good education as the child will never have a job.

Some of you may have attended my presentation at a CM Symposium two years ago, when I described my efforts to find employment, and the impossible welfare benefits trap that I felt I was in. I'd been thinking about working for some years, and looked into it, but found that even in self-employment, it would be too risky to lose all my benefits, and too difficult to earn as much as I was receiving in income support. At that time, the regulations would have only allowed me to earn twenty pounds a week, without losing benefit.

Before I got my first communication aid (at 31!) the only job offers I'd had was to work voluntarily for 'parks and gardens' collecting litter with a pointed stick. I'd also tried to work with young people in the youth service, and attempted to get some qualifications, but been told that I wouldn't be able to do the written tests as they'd be too hard for me, and just to come along to youth clubs as a volunteer.

Once I got my first communication aid, I began leading an increasingly active and busy life. I'd often thought about trying working for a living. My presentation at CM2002 was written after visiting my Job Centre and being sent on a hopeless paper chase around the Job Brokers. I was very despondent about getting out of the trap I felt I was in, and some people said that my CM speech was extremely depressing. I'm pleased to be able to tell you now I am successfully self-employed, and hope that what I'm able to share with you now, will help others in the future.

Two years ago, I was so busy with unpaid work that I was working almost full time, and doing it for free. Sometimes, I gave presentations at events where the other speakers were getting hefty fees, while I had to refuse any offers of payment, or ask for it to be paid to a charity on my behalf. If I'd not done that I'd have been in trouble if found out, as I was getting welfare benefits. The situation was getting ridiculous, and I felt ready to try again at employment. I decided to set up my own business and work for myself.

I spoke to lots of people about trying to move into work. Although I felt that there was a change in attitudes over the past 5 years, I was still advised by people such as Scope workers, and people working in the voluntary sector, that it was too risky, and that I should stick with what I was doing. I felt that they didn't know as much

as I did about what was going on in the world of employment, because for years I'd followed every announcement and government statement about employment and disabled people. The announcement for example, that from April 2002, the Independent Living Fund (which pays for most of my personal assistance) no longer takes earned income into account when working out your payments. Many people still don't know this!

I read many articles, and heard in the media about policies towards disabled people and their rights to be able to work, if they wanted to, as part of the 'Agenda for Inclusion'. The final event that convinced me to 'go for it' was attending a conference at the Royal Academy of Dramatic Arts in London in January 2004, about employment and training for disabled performing artists. I rubbed shoulders with well-known actors and directors, who were all saying that people with disabilities must be included in all the arts, and doing so enriched and improved the world of the performing arts. I felt very excited returning home from London, and almost the next day, made an appointment at my local Job Centre with the Disability Employment Advisor, again!

This time, my interview with the DEA was quite different from 3 years ago. Last time, I'd felt that she didn't really believe that I was capable of earning a living, and was just 'going through the motions' because she had to. This time she sounded very interested, studied my business plan, told me all about Access to Work, and gave me various options to get started. There was a scheme where I could test trading for some months and keep my income support, as long as I saved all I'd earned. I decided to leave that, and just do it!

Some of the steps to self-employment will be the same for any person with or without a disability

My decision to give up all my welfare benefits and set up my own business and become self-employed was not easy. To begin earning money means you give up a large amount of security, which in the case of a person with a lifelong condition, this means lifelong security.

This suits me, in my own circumstances, but for others, doing some unpaid, voluntary work can be equally rewarding and valuable, so please don't misunderstand what I'm telling you.

I started trading on 1 March 2004. Before visiting the Job Centre, I wrote a business plan, which wasn't too difficult. I'd done a business course for disabled artists, and been shown how to do it. I needed this for the DEA, the access to work assessor, my bank business advisor and several others. Thinking about my original plan, its strength was its flexibility. I based my estimated number of engagements on, my years of voluntary work, and was not far wrong. Some jobs are just 'oneoffs', others will be repeated year after year. Looking back on my first business plan, things have changed a lot, but I have tried to be open to all requests as taking on fresh challenges is exciting and helps me develop my skills. I am always learning new things now. Pricing my service was not easy. I had to decide what people had offered me before I began my business, and what I thought people could afford.

Once the date to start was decided, I had to inform social security that I was stopping claiming benefits. This was not easy, and I'm still dealing with some resuming issues. The system is not really designed to make coming off benefits easy.

Also the funders of my personal assistants had to be informed what I was doing. The ILF and social services 'Direct Payments' were supportive, and my self-employment has, so far, not reduced my care payments.

I live in an area of quite high unemployment, and so there was a scheme in place which gave me a month's income support replacement, and also paid for a laptop computer. This was great, giving me a month's 'breathing space' while my fees began coming in.

My DEA arranged for an Access to Work assessor to visit me and make support recommendations. I had a list of equipment that I hoped would be recommended including another communication aid that would enable me to keep my work commitments, even if one aid was out of action, and a specially adapted power chair especially for dance.

I also had an idea what support I'd need from an assistant. The money for personal assistance can't be used for help with paid work, so having a support worker who was allowed to accompany me to work to drive me, and carry equipment, open doors and remember the butties and invoice, was essential. My support worker

does the things I'd do for myself if I was able to control all my muscles. He does not plan, or carry out my work. This is important to get across to Access to Work. My support worker could not do the job that I do. It is all dependent on myself.

I had to plan my personal and business spending carefully for the first few months. I did not need to get a loan to start my work, but put most of my own savings into it. After a few months I was able to repay myself.

I advertised myself through a web site, and by having brochures printed. Also I informed all my contacts from my years of voluntary work, that I was now self employed.

The Tax Credit scheme can help, and for people with disabilities, can make substantial payments while a person's net income is low. This was good news, and at first was a key factor in my survival.

The most important thing in the success of my business is my own good health. I am fitter now than I can ever remember, and this may partly be because I'm so pleased with what I've achieved.

Being a reasonable competent AAC user is important too. In my work I do communicate in a variety of ways, through dance, music, and movements, but my communication aid is vital for most things I do.

Having a clear idea of where you want to get to is essential. I like to say that I am very focused. People tell me that I must be, otherwise I'd not have achieved what I have. This does mean making some hard choices. I may have to choose between going out with friends, or preparing a speech on my device. I know that if people are paying me to work for them, I must have a professional attitude, and do my best to give them what is needed. I know that if I do not do this, then they won't ask me back again. My main motivation is the excellent feedback I always get after I've done a job. It's fantastic to get letters written by school children, or to hear from a teacher, that a child who had never really been interested in using his MC device, had, after meeting me, been using it well in lessons the same day.

It's great to hear that I have changed some people's ideas about disability or altered a parent's expectations for their child's future. Of course, the money is a big motivator, and the stark fact that if I do not earn, I will have to go without some things.

Without a true love for my work, I would not be able to put in the time required to make my business a success. I often work 7 days a week, for over 12 hours a day. This time is not all out doing jobs by any means, there is lots of administration, planning and preparation to do based at home in the office. The time I have to put into my work is long, because everything takes longer for me to do than it would if I wasn't a person who relies on a wheelchair and communication aid. Since starting selfemployment, I have started using a new AAC device. After a few upgrades, this device is now proving better than any I've used before, however, I have had to customise and learn to use my new device and this has taken a lot of time. I'd like to be able to use the same stored speech several times over, however, I'm asked to speak on so many different issues, and most times I have to compose a fresh speech. I love dance and writing music, so anything that gets me towards doing that is not a chore, it's a pleasure.

My system of support is vital to my business. I cannot see a time when I will be able to do everything for myself, but one day, I may have to pay my support worker out of my profits rather than by using Access to Work to pay him. My support worker and my personal assistants have to work in cooperation and at times their duties overlap, but mostly it has become clear which tasks are about helping me to do my work, and which are about my personal assistance needs. It goes without saying that all my staff have to be flexible, committed and completely reliable.

If I was office based at all times, then transport would not be such an issue, but as I usually work at a distance, maybe 6 hours drive away from home, my transport is vital. My vehicle, as well as my power chair needs to be well maintained and fuelled. Before I had my own van, I had a well trained taxi driver for local work, and the staff on the trains all knew me and were prepared to give assistance. Travel further a field was a problem, especially when having to use taxis in big cities, whose drivers must have been absent when disability awareness training was being given!

After considering if any existing 'jobs' would suit me, self-employment was the obvious choice. You are your own boss, which suits me fine, as I hate being told what to do.

As a person who uses Me, I have very specialised skills, and interests which I have planned my work around, and I can choose which jobs to do and which to reject. The best part is the thrill of being responsible for yourself. You personally take responsibility for your success or otherwise!

There were many elements of preparation in my life, before I got where I am now. The key to my working life was getting my first communication aid. (This only happened for me when I was 31, and then through the efforts of friends, not any statutory body) About 8 years ago, I moved to my own home and thus gained control of my life and activities. I was able to attend meetings and courses to give me the necessary skills and qualifications to lead me to my self-employment.

Joining many groups and organisations built my confidence in my MC use and gave me opportunities to tryout speaking in public. During my years of voluntary work, I got to know what was happening in the areas I was interested in, and I found out who else was doing what I wanted to do, and how much they charged etc. I researched the 'competition', and found that there was very little. I am so far the only person giving dance workshops and using MC in this country if not the world! While working for 'free', I was given many letters of thanks for the jobs I'd done, and these I kept as evidence of the need for my services.

I don't see my having to use MC as a negative thing. I try to find the positives in it. Many people have never met an AAC user, and you are remembered. You don't have to try as hard as some to be individual or different. You already are, and if you show you are happy with this, then the message that comes across very strongly is, I think, it's *cool* to be different.

I've several branches to my business, which means that any problems with my device do not stop me from working. I can just get on with something else, which does not need speech, for a while. However, it is very important that I do not let down my customers, which is why I need a second device. I also save it onto a memory stick, or onto tape.

My device is programmed with special pages to use over the phone, which is useful when speaking to people who have never heard of a communication aid, especially overseas call centres!

I plan my sessions well in advance, and have several ready stored sentences to use, as many people are impatient and won't wait for you to compose word at a time. For presentations, and large scale training sessions, its important to find out about the room size, and layout in advance. I can then be prepared with speakers and amplification equipment if needed.

PROS AND CONS

What are the pros and cons of running a business?

Well, for me, the positives are, the brilliant way I feel about myself, which is worth more than money. It's priceless. I'm now fitter and stronger than ever before. While the money isn't the greatest motivator, it's nice having a bit more, and knowing that I've earned it. Getting this far has encouraged me to develop further ambitious dreams and plans for the future.

I know I'm doing something really worthwhile, promoting 'AAC in mainstream settings, by demonstrating inclusion in a wide variety of settings. And finally, , people now treat me with greater respect and take me seriously.

THE DOWN-SIDE

There is a downside, but for me it is outweighed by the positives. My home is also my office and equipment store, bedroom and kitchen included! I'm very short of space. I can't get away from work for very long even if I wanted to. Phone calls and e mails arrive at all hours of the day. I have the same anxieties which I guess affect every business man. Worry about work drying up, unlikely! The timing of jobs, giving a whole month with nothing substantial, and then thirty days solid work without a break. Stimulating!! Being approached by groups who can't afford my fees, for example some local schools wanting me to give workshops.

As a person using MC, running a business is not easy, but, if I can do it, then so can lots of other MC users in

the future. I went to a special school, where I got very little useful education. I had no help with communication until I was 31, when friends fundraised to buy me my first aid, 10 years ago. I attended a boring social services day centre, which nearly mashed my brain for about 13 years, and I had a very difficult time with family issues.

The role model aspect of the work I do is extremely important to me. If I hadn't heard about Anthony Robertson, then I probably wouldn't have tried setting up a business. Put simply, think about what you love doing. Do It!! And try to work out how you could sell or market it, to make money from it.

My business has several parts. My main interest and love is dance, so the main part of my business is giving inclusive contemporary creative dance workshops. I also give performances, both solo, and duets with my dance partner. I sometimes give group performances following workshops.

When I was trying to find a suitable power wheelchair to use for dance, I found hardly any information about any form of dance for people using electric wheelchairs. There was also a distinct lack of any sort of information about this type of dance. As a result, I decided to do a research project into power chair dance, and have completed this work, dancing with 6 professional, non disabled dancers. I've compiled masses of notes and video tape about our findings, but need the time to edit it all and put onto DVD to spread our findings to all interested in dance.

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My dance workshops and performances are mostly done to music which I write myself on computer. It's so hard to find the kind of music I want, and also performing to someone else's music involves big fees and royalties. I really enjoy writing this music, and have produced two CDs of my own pieces, so far! I sell these through my web site.

Before I developed my dance interest, I was regularly giving talks about my own experiences. This has now become a big part of my business, and more and more professional bodies are showing an interest in the 'expert customer'. It's a good feeling to be telling doctors and nurses about how it really is. Most satisfying! Often, my dance work and disability issues work fit together, and I will be asked to give a short performance, and then speak about my life or a particular issue.

I think my experiences as a service user, and equipment user, are valued, and its good to be able to put the clients point of view. I am very keen to promote full inclusion and equality in all aspects of life, and can speak from experience' about access issues, about inclusive education, and many other issues. If I'm not taken seriously at first, I certainly am when they get my invoice. I sometimes think that presentations which I get paid for are listened to more carefully than when I was just giving them away for free. I'm always delighted to be asked to tell about what a difference MC has made to my life, and about how I'm now working, thanks to at last getting the equipment I need.

As a result of being very flexible in what I do, I was able to accept an offer to act in a BBC3 comedy pilot programme. This was filmed and broadcast earlier this year, and repeated several times. I've been told that I'm wanted again, when it's made into a series next spring. I didn't go looking for this work; it just came to me as an unexpected email summons to attend an audition at BBC in Manchester. I didn't think I'd get the part. I was right. But, they wanted me in the programme, so rewrote the script, with an MC user in it. I was very pleased to do it and it was a great experience. I was warned that pilot programs rarely go on to be series, but then heard that this one is, so I've that to look forward to!

New work enquiries are coming in every day, by phone and email. An Arts Council of England grant is enabling me to run inclusive dance workshops in Wirral schools. I've many presentations and disability equality training sessions booked. I've a new TV comedy series to start filming in January. It's quite difficult to fit it all in, I'm not planning to tell you now, about how much money I made in my first year. I'll just say that I've done well enough for my bank to give me a mortgage to purchase my bungalow.

Alan Martin *Performer & Teacher*

Email: mouse_on_the_move@btinternet.com