

Joe's Story

Joe Powell is the new National Director of All Wales People First. It's been a long and difficult journey to get to where Joe is now and it's a journey he shares with Llais readers.

I fought so long to be independent. So long to be free and live the wonderful life I now take for granted. But it wasn't easy. The big problem I had when I achieved my freedom is knowing what I should do with it. Living a life sheltered from the so called 'real-world' not only means we are denied a life time of social skills and experiences which help us to progress and move forwards, it means a life which lacks dignity and equality.

Growing up

When growing up as a child I was shy, didn't talk much and had very poor social skills. Even in Playschool and then the infant school I was different, didn't have friends and was behind the other children. An educational psychologist assessed me at the age of four years old and said that there was basically nothing wrong with me, that I had below average intelligence but we shouldn't worry because someone had to be below average.

I became the class clown to hide my inadequacies. I felt it was much better for my self-esteem to think of myself as a lazy person who clowned around but had potential than a person who

wasn't very bright and who was to be derided. Up to the age of about fourteen years of age I used to cry in class when I couldn't understand the school work which meant I was mocked by both the students and the teachers. As time progressed in my first senior school I got into more and more trouble for being silly.

New School

My parents took me to see an educational psychologist at the age of fourteen who assessed me. She told my parents and I that I was very intelligent and suggested that I was maybe insecure and I would benefit from changing schools. I moved to a new school in Gateshead where nobody knew me. I was so shy and intimidated and knuckled down to hide my embarrassment. My work was outstanding, I was loved by my teachers and for the first time in my life I received brilliant school reports and rave feedback at parents evenings. My parents had never been so proud and I felt exhilarated and euphoric and the way my life changed around. I was seen as the nice, quiet and brainy lad which was such a positive contrast. I became so obsessed



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with this image and so scared to lose my positive image that my behaviour became more and more extreme. I swapped being the class clown to being almost mute and very serious which meant that I eventually cut myself from everyone.

Youth Training Scheme

When leaving school I joined a Youth Training Scheme with Northumbria Police and the fact I didn't speak much made it a very lonely experience. After several interviews I eventually gained a full time placement in the station I worked in as a File Preparation Clerk for Northumbria Police. My family and I were so proud and excited; a great weight was lifted from my shoulders as I had finally found work. The only problem was that although my interview was great, I couldn't speak or mix with the other members of staff. Whenever I tried to be outgoing I was racked with remorse and would become even quieter to make up for it. I became very depressed at my isolation. Because I wasn't communicating and because I was too shy to ask for help it meant I wasn't doing my job properly so I lost it.

Asperger Syndrome

I attended as an outpatient at a local mental health hospital in Durham who initially diagnosed me with anxiety and depression. Eventually a very astute Doctor told me that I may have a condition called Asperger Syndrome, a form of autism and that this is what may have caused my difficulties. In those days the condition was so rare most



people had never heard of it (including me). She suggested that I visit the same educational psychologist I saw when I was fourteen to confirm it, which she did. On the way home from the hospital I was very tearful and I told my parents what the doctor had said. My mother was especially heartbroken.

A fight for care services

A hard fight for a care service ensued. Because of the severity of my mental health problems I was funded for a specialist autism care home in Manchester. My family and I thought that going into care would be the makings of me and would 'get me fixed' as my Dad used to call it. Of course that wasn't the case. When I arrived at my service they didn't really get me at first, they didn't understand my difficulties and they had very little to no experience with Asperger Syndrome. One day a very challenging service user arrived in our service who used to attack and threaten staff and service users and would bang and shout all night. I lived there for five years and I got progressively worse. My Dad's job was relocated to South Wales (British Aerospace) and it occurred to us that maybe I could move to a new service nearer to them and have family close by (something I lacked in care).

My new service

It is very difficult to do justice to what happened in my new service within a short article but in a nutshell I went from being a very complex service-user with excessive reassurance needs to having very little to no support over night. I moved into a self-contained flat to help with my independence. Nobody knew how depressed and ill I was. Over time however living on my own and having a regular routine by going to the day centre worked wonders for me. My mental health issues improved no end and I pushed myself (despite all of the guilt about talking) to mix and be outgoing and I made a dramatic improvement. I outgrew my service however and wasn't allowed to move on. The flat which helped me to become so independent, was to be taken from me in order they could use my support package to co-fund another person they had a long-term problem in housing. I had no choice and I was told it was happening. My then social worker let my service dictate the outcomes despite the fact we'd made it clear the move wasn't right for me. I learned later from other social workers that there was no obligation for me to have moved and they had no issues with funding it for me. From that moment on I never trusted my service again.

Individual Budget

A very brave Advocate came to represent me at meetings and she was key to the amazing journey I would embark upon. She helped me to communicate to my social worker what was happening to me. My social worker put me in touch with a local broker in Gloucestershire and he helped me to fight to leave social care. My service were offended by the whole idea, laughed and sneered at my contracts and told me I would be sectioned in three months if I went with my support broker. It was a period of great anxiety and great fear and I felt my service were cold, unapproachable and manipulative throughout the whole process. They told me that Individual Budgets could never work, despite the fact that they had never heard of them before.

Eventually I got my individual budget. I went from a care service costing approximately £130,000 per year with no 1-1 support to a budget of approximately £28,000 per year and had 150 hours of 1-1 support, including 2 support staff, an accountant, my own psychology support and someone to help me build social networks in the community called a Network Facilitator. I lived in my own flat in the community and made enormous progress, but I still feel an awful lot of pain, bitterness and anxiety over the way I was treated.

In demand

My story, insights and ideas became in great demand when I left care. Many brokerage, autism and social service



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departments booked me to tell them about my experiences and to encourage authorities, families and professionals to embrace the personalisation agenda. It was wonderful to be heard but most of all wonderful to be believed and to be given an opportunity to help those organisations who were serious about making things better for people with learning disabilities.

When I saw the advertisement for the role of National Director I knew it was the perfect role for me. Not only was I already doing a lot of the things the advertisement was asking for but also the fact that All Wales People First existed was a major recognition of the difficult

experiences so many others and I had gone through and they shared my core values. I have a wonderful opportunity to help people with learning disabilities to advocate for themselves and to prevent the unnecessary oppression that I and so many other people with learning disabilities have been (and are still being) forced to endure. Yvonne Boxall is doing a wonderful job in mentoring me and I feel privileged and honoured to be working for such a forward thinking and inclusive movement as All Wales People First.

*Joe Powell
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All Wales People First*