

## PA USERS TELL THEIR STORIES

### PA USER 1

I often think that the term "independent living" is an anathema. It changes something which is natural to a special state of being. It compounds the idea that crips are generally a passive, dependent species, struggling to break out of their warped and dilapidated bodies; reaching out for a reflection of normality, grasping for independence as an alternative to the meagre fare of care and control which our society deems is what most people who need personal assistance should exist on.

I have always believed that living is about independence, control, spontaneity, personal development, responsibility. Why should the fact that I need somebody to wipe my bum deny my aspirations to exercise independence and achieve whatever my potential may be? The fact is that "independent living" should be the starting point; a foundation on which to build; the development from child to adult. Of course we all know that it is not as easy as that.

Perhaps I ought to put these thoughts into context. I use, and indeed need, personal assistance in most areas of my physical life and always have done. I need someone to get me dressed, washed, out of bed and into bed; someone to give me a piss, wipe my bum, drive my car, assist with the housework and so on.

When I was a kid this was all done by my mother and father, like it is for most kids I suppose. Well at least until I was seven and shipped out to institutions. I'm not really sure when the transition from the ordinariness of using personal assistance as a child and the dependency culture of being a disabled person who needs personal assistance happens. I do know, however, that the front line of this transition is often located within the four walls of the residential establishment. It is here where being dependent on physical support becomes synonymous with being controlled. It is here where one's physical life becomes standardised, routinised, pigeonholed, organised, planned. Bed-times, meal-times, bath-times, toilet-times. The clock rules and we become programmed. We piss and crap to order and spontaneity goes.

Sometimes I think about those institutional times and try to analyse the effect of the regimes I spent twelve years under. Formative years in which I was in effect trained to be dependent. I'd like to think it was like the metaphorical water off a duck's back, but I know somewhere deep within the clock continues to tick.

I graduated from this background as a fully fledged, "severely handicapped" crip. I was handicapped in many ways, the most striking being my retarded clothes sense. My suitcases, which filled the back of the St John's Ambulance driving me to university, bulged with neatly labelled, easy-fit, Velcro-fastened crimplene creations. I wore trousers about eight sizes too large, baggy Y-fronts, vests (to keep the chills out), striped pyjamas for god's sake. I was eighteen, I'd never bought my own clothes and I was about to be released into an environment where clothing spoke volumes. The sad thing was that I believed the fact that I needed to wear these things. They were more comfortable for me, they were easier for me, they looked better on me. Like hell, they just made me look like a prat; like a good, sexless cripple. At least I had fought off the surgical boots and braces I suppose.

My mentality was also distorted, disabled into accepting that I should maintain ways of dealing with my physical self which had been imposed upon me. One enduring memory is spending hours getting tied up in nylon slings and chains and dangling from overhead hoists feeling like meat from a butcher's hook, silently screaming as the nylon wrenched my legs apart or virtually castrated me. The feeling of cold, dank nylon on my skin as I was winched swinging and dripping from the bath still sends a shiver through me when I think about it. The fact is that I thought I needed to use these contraptions; that there was no alternative. So I bathed sparingly and crapped inconsistently and braced myself whenever I did.

My first contact with a personal assistant was almost comical. Somehow I had ended up at university. Another institution yes, but at least it wasn't a Cheshire home. Now it would have been too much to ask for me to have chosen the university. In fact it was like almost delaying the inevitable permanent incarceration. I was told to choose this particular academic institution, not because of its excellence in the field of study which I wanted to pursue, or its varied social life, or because it had the third cheapest beer in the country, but because it accepted crips and provided personal assistants - only during term time of course. I was probably the only person in the country who had the same university down five times on my UCCA form.

So there I was being wheeled out of the aforementioned Ambulance and I was confronted by an ordinary looking bloke the same age as me, with a crew cut and a northern accent and this person would be wiping my bum. No uniform, no high pitched voice, saying hello and not having an attitude problem. My parents believed him to be the electrician fixing the overhead hoist and went to look for matron. I have never looked back.

Taking control of one's personal assistance needs is not easy. We always say that we, the cripples, are the real experts. To be honest, however, I wasn't. I'd never done it before. I was used to being told what to do, when to do it, where it should be done and how it should be done. The PA had never really seen a crip before and also didn't know what to do, thank god. So we actually learnt together. I suppose I should remember the freedom of having my first piss when I wanted it but I don't. The transition from dependency to spontaneity sort of happened.

## **PA USER 2**

Having been asked to write about my experiences of 'Independent Living' whilst not having a clue where to start, I resorted to my dictionary, with a feeling that my own definition of such an in-apt term for my life would be somewhat different. My trusty tome however (a Penguin pocket edition no less!) revealed stunning revelations ...

**Independent:** not dependent; not affiliated with a larger controlling unit; self-governing.

**Living:** having life; alive; existing in use; true to life.

These seem to me high ideals to be sought after, but do I - living in my flat (aided by assistants), going out and about and generally doing the things that the majority of people take for granted - fulfil this enviable role? I like to think that I'm 'not

dependent' : at least as much as the next person. "No woman is an island" and all that. I'm certainly not "affiliated" to any controlling power (as far as I know!) and Yes, between all my indecision's and revisions, I am self-governing. Phew! As for the definition of Living, I do 'have life' (though its doubtful early in the morning). I hope very much that I 'exist in use' and definitely aim to be 'true to (my) life'. I wonder how many disabled people - those who are removed out of one home and stuck in another so-called home of four walls, existing around visits from 'Home care' (where is the genuine sense of caring from one individual to another in that?) yet are said to be "... in independent living now," can attain that? Thankfully I am now in a position to try. So how and when did this transition from a dependent to an independent person occur?

I consider myself lucky (though I admit luck should never have had to play its part) that I evaded Residential 'Care'. Aged eighteen, I think most people are still only pretend adults. Having left 'special' school with a very distorted view of the world and its seemingly 'able' inhabitants, I was big on pretending adulthood, maturity, confidence and a lot else which I felt were appropriate for a Normal girlie my age. I was living in a small bungalow with other "Creative Young Physically Disabled People" (the brochure read, or as my Dad called it, "Arty commune") aided by Community Service Volunteers (CSV's) and having an OK-ish time. But I knew I could only have a relatively short stay in this little safe-haven and, used to being 'moved' (within school) I did get itchy for change. It was suggested that I go to college. For want of a better idea because at this stage I still was not having many of these for myself! - I grunted an "er ... yeah, alright ... " and filled in an UCCA form. Fortunately, things did not go according to plan. Due to one or two distractions - like a million things more enjoyable than studying (even watching "Neighbours") I failed the two A-levels I had attempted. In fact I did not want / was not ready to go to college then. I was twenty by now, yet still nodding my head at someone else's intentions for me, because somewhere inside lay fear that well, maybe other people really did know best ...

Finally a year later I did get to college, having realised for myself it was quite a smart thing to do. It was bloody hard work, not least because of having to hack life with my own assistants in tow. At the end of my first year in college I was given my council flat and moved in. So now I was in the hallowed halls of 'Independent Living'!

I remember the literature I had previously been sent from a local Centre for Independent Living (C.I.L.) full of 'care plans' requiring I time myself going to the loo for the sake of Social Service Provision. Those plans had terrified me and had put the idea of leading my own life firmly on a back-burner, not least because the C.I.L. people, disabled themselves, had told me before "ooh ... you're very young to live independently ... we don't think you'll cope." How many other young adults get told they are too young to want an adult life? I was at college now with my own home and I did want that life. I wanted it for me. I did cope - just - and because I started out with CSV's there was not a care-plan in sight ...

Of course, life is still not easy. I could rant on about my battle with Social Services, but we all know about that. The coming and going of assistants is the biggest drain on my time and energy. There are depressive moments when I've willed Mr Leonard Cheshire "Come! Take me into your green-house. Water me and feed me - not to

mention toilet me - with your tender love and 'care' ... " (Thank God he's a crap genie who doesn't answer delirious wishes.) There were times when I've felt conned by Independent Living, thinking "Is this it?" until I realised that this is it; this is reality; this is being an adult. Living independently is about so much more than getting up and going to bed when you want. It is, I think, about integration and contributing to all who also - whoever and wherever they are - attempt to lead independent lives. As defined by my dictionary, (notice how I still defer to another authority?!!) it is having a useful existence. I believe Independent Living is being true to that life, a real life.

### **PA USER 3**

I've had an easy ride. From age 11 I went to an integrated school, had my 'O'-levels at 16 and my 'A'-levels at 18. I went to a (more or less) accessible university and was a graduate at 21. I live in a ground floor flat, have a car and a job. The state regards me, through its benefits system, as 'severely disabled', and that system generally assumes people like me to be long-term unemployed. Were I willing, I could be used as living proof that society doesn't discriminate after all. The playing pitch is level, so stop making such a fuss, rights activists. Cut your chains from parliament and catch the next mobility bus home.

The truth is, of course, that the opportunities that lay open to me are far from universally available. My first experience of personal assistants, was, like many others, with Community Service Volunteers as a student. The move from living with your parents to having someone of your own age who'll assist you to do whatever the hell you like is a liberation on a huge scale. My new found autonomy took some harnessing, but I gradually came to appreciate that if I was going to survive independently, my lifestyle had to get a little more 'regulated'.

Before I left college I applied to the Independent Living Fund. Again my timing was impeccable. This was the golden era when you could get full funding from the ILF without even needing any contact with your local authority. It was so simple. An ILF assessor came and sat on my bed and went through an 'average week' with me and a few weeks later they offered me an 'award' which would contribute towards the cost of my 'care plan'. I went on to use this money to employ my first personal assistant.

Armed with Hampshire Centre for Independent Living's 'Source Book Toward Independent Living', I advertised locally, sent out application forms and eventually interviewed about 10 people. It was certainly a demanding and fairly stressful experience, but it's worth it to find someone you're compatible with. It was at this time I began to realise the importance of organisations of disabled people in providing peer support. I could not have done all this without knowing others had successfully gone through it before me.

I then had the foreboding task of assuming the responsibilities of an employer, tax, national insurance, person management, that kind of thing. I got into a bit of a mess with this at first but you get the hang of it eventually. There are very few tax offices that will grant self-employed status to personal assistants so this side is an unavoidable task to most PA users who employ PA's themselves.

You learn also that you have responsibilities to the people you employ on a personal level. No-one is obliged to be anyone's counsellor but it is important to consider the needs of your employees. In this sense personal assistance is not an easy option. It takes more effort than other models, since there has to be a price for real autonomy. I learnt from other PA users the crucial notions of interdependence, and not treating your PA's as faceless 'body slaves' who are there to act as your 'arms and legs'. I am still constantly learning about communicating with PA's, as this is the crux of a good working relationship.

I became increasingly interested in the 'politics of disablement' and got involved with various independent living organisations in an unpaid capacity. Now I work as a personal assistance advisor, where my job is to advise other people on setting up PA schemes and to negotiate funding for those schemes. Ironically, since Community Care came 'on stream' in April 1993, it's become a good deal harder to live independently than before. Having to persuade your local authority to allow you real control of your life can be a lottery depending on where you live. The biggest barrier, however, is the attitudes of social services to the idea that disabled people have a right to enough support to enable an equally spontaneous and autonomous lifestyle as enjoyed by non-disabled people.

In years to come we will, I have little doubt, look back on this time of struggle with some shame. Independent living is not really about the availability of resources, but about the status disabled people occupy in society. As this improves, personal assistance will seem the obvious solution to an ordinary need, the need for physical support in daily life. So if you are just setting out on the path to independent living, expect a struggle, expect to meet 'care managers' who don't understand what you're getting at, keep in touch with your peers and support each other. It's easy for me to say "don't give up" but at least the tide is turning politically. The securing of our civil rights in law is only a matter of time. So believe, have faith, your right to physical support from people other than your partner, family and friends is your right, and one day will be enshrined.

#### **PA USER 4**

There are many myths about disabled people. A prevalent myth is that we are extremely brave, coping with horrifying affliction and still able to have a laugh. The truth is that if somebody disabled as a result of an accident was brave before that accident then he or she will be brave after it too. If a prat becomes paralysed then it's quite likely that he or she will continue to be a prat. Other myths are that we rarely go out of our homes, that we are frequently in pain or are subject to other physical nastiness, that we must necessarily have inferior sexual relationships (totally erroneous but another big favourite) that we need counselling and other subtle forms of therapy, even if it's only occupational, and that we need more peace and quietness than other people.

What we really need in similar quantities to non-disabled people are rights to equality and what we need more of than non-disabled people is money. Money to live independently, money to pay for physical support. Disability is expensive.

If you see a lot of gloomy disabled people around, they're not feeling sorry for themselves, they are just pondering what they hell they're going to do and worried witless about the cost of living in the community. Unless of course they have been able to get out of their institution for a few hours, in which case they'll be worrying about getting back in time for their nightly bowl of gruel and whether they can get parole so they can worry about the cost of "care-in-the-community".

I broke my neck taking a corner too fast on my motorbike. This fleeting moment of ill judged excitement left me paralysed from just below the collarbone. About eighty or ninety percent I suppose and lacking sensation from the same level. But it wasn't very long before the loss ceased to be a problem; well not a big problem anyway. I think all of us can learn to cope with the most extraordinary circumstances; physical, intellectual, emotional, social, cultural and sometimes several of these at once. This is not to lightly dismiss the horrors of sudden, massive paralysis on a fit young body; there's not one tiny aspect of it that's even remotely to be considered enjoyable-not for a while anyway. Its just there like a whacking great zit on your nose so you make the best of it and after a while it recedes into the background and you almost forget about it.

Very soon after my accident, a nurse on the spinal injuries unit said that I'd left one life, the old life, behind and that I must start a new one now; new and different from the other, different but not inferior to the first. This could be taken as a glib homily, but it wasn't and I didn't and it happens to be one hundred per cent true. Only by understanding and accepting this fact can non-disabled people relate to disabled people. Believe it and they can be equals in the truest and fullest sense of the word. It sounds simple enough but us crips are so accustomed to being treated different to the point of being alien that we've long since given up hope of being treated sensibly. This right was lost to me the instant I broke my neck. It is not that society is uncaring, its just not geared up to accommodating difference.

In these so called enlightened times we still hear stupid, ignorant people saying that Her Majesty's prisons are too soft and prisoners treated too well. Not only have I visited prisons (even the open ones are awful) but I was in one for fourteen months, having to wait in the spinal injuries unit for my local authority to come up with a suitable flat. The misery of living in a hospital was relieved only by a two months stay in a Cheshire home, which was very good. The place was comfortable and relaxed. Although I enjoyed my stay, it was still to me a benign prison. There was not enough living space and trips outside the spacious grounds had to be carefully organised. This was a good one. Most other residential homes are just grim, dead and empty. Nobody should have to live like that and its inexcusable that we let it happen when it is actually cheaper to have people living independently.

When I was finally allocated appropriate accommodation, I was at home but without any independence for five months or so. I was got up by the district nurse and hurried thought ablutions without time for a cup of tea before the minibus carted me off to a day centre which I disliked, ostensibly for lunch although it was it was usually two thirty before I was back home. I'd then be alone until nurses put me to bed, usually when I was watching a good film on TV. The experience of a mature and assertive adult having almost all control of their life taken from them is so bad that it is truly difficult to find words to describe it. PA's mean that this sort of thing can never

happen again. Its one of the most impertinent, maybe the most important thing in my life.

Its difficult to over emphasise the importance of living in your own place and to be able to come and go anywhere you please and at any time you please. Simple basic things that everyone takes for granted. Not privileges but human rights.

## **PA USER 5**

I caught polio in 1957, at the age of 27 and since that time I have been dependent on others for my care. I am 80% disabled, affected in all four limbs, tummy and back. I cannot dress or undress myself, I cannot leave the house unaided and I am a wheelchair user. Over the last 39 years I have seen a vast amount of change in the 'caring' scene.

In 1990 I heard about the Fund for Independent Living, I applied and was successful. After the system had been running for some time the "powers that be" decided to change the rules. This rather concerned me and I sought the advice of an advocate. He thought it best if we reviewed my whole care situation. He told me about a scheme called Independent Living Alternatives (ILA). In order for me to get help from ILA I had to be in receipt of a complete "care package" involving both social services and the Independent Living Fund which would then provide funding for my personal assistance.

Fortunately, the advocate I mentioned was successful, ILA was to supply me with two carers each working for 3.5 days a week. The carer who is on duty lives in, while the other carer lives in a house shared with other carers. It works extremely well, with one person on duty at a time and providing me with the 24 hour care that I need. They start at whatever time suits me and finish likewise in the evening. They all drive and therefore they are around to take me wherever I want to go, day or night. I go to art classes, I do four lots of voluntary work and I have a wonderful social life. I get up when I like. If I have had a late night, I don't have to rush out of bed in the morning. My life is so flexible now that I hardly know it myself.

When all is said and done I am more free now that I have ever been and consequently I am enjoying life to the full. I still have to restrict myself to a certain extent, in order to live within my physical limits. I can be taken to meet my friends and when my friends bring me home they don't have to come in and put me to bed. As they are all getting older as I am, it is wonderful that after many years of incredible support life can be easier for them too.

I cram as much as is possible into each day and I often wonder whether I am doing it to make up for lost time or because time is now running out!

