PATRICK TOMLINSON ASSOCIATES

Web Site – www.patricktomlinson.com **Contact** – ptomassociates@gmail.com

SHARED ADVERSITY, SHARED UNDERSTANDING: FOSTER CARING WITH A DISABILITY

JON POWTON (2019)

SHARED ADVERSITY, SHARED UNDERSTANDING: FOSTER CARING WITH A DISABILITY

JON POWTON (2019)

Introduction

I am delighted to introduce this inspiring guest blog by Jon Powton. I came across Jon recently when I read an article in the Guardian, a national UK newspaper. He was featured in it about being a foster carer with a disability. Jon talks movingly of becoming disabled; of the adversities, prejudices and discrimination experienced; of the barriers to becoming a foster carer; of being a foster carer – the challenges and rewards; of the care system and politics.

The reality of exclusion of people with disabilities from foster care (and many other aspects of life and work) has gone 'under the radar' for too long. This is a great loss to us all. Jon is doing an excellent job of raising awareness. I hope you enjoy this thought-provoking article and please share.

Patrick Tomlinson

Disability and Adversity

Adversity is a word you hear quite often as a foster carer. It seems to sit hand in glove with the profile of many of the children who come into the care system. The adversity, hardship and horror that some children and even their families may have faced, can leave lifelong scars that few other people can truly relate to.

From most people's perspective adversity applies to us all in some way on occasions in life. We've all experienced low points in our own way. The death of a relative, or a serious injury that has made life difficult for a period - losing a job, the ending of a relationship or financial hardship. There are many reasons, but with time and support those scars do tend to heal, and often we can change our circumstances to improve things. I suppose one of the main groups who can experience lifelong adversity similarly to 'looked after' children are people with disabilities or serious life-limiting illnesses and conditions.

I wasn't born with a disability, I grew up around it, and lived in a house with it all my childhood.

My grandfather was confined to a wheelchair and lived with my parents, my siblings and I until his death when I was eleven. He died from complications caused by Muscular Dystrophy. The very same condition that I was diagnosed with six years later. This was a bombshell! It may seem naive considering the circumstances of my childhood, but no one ever thought that me and my brother would have the same condition. So little was known about when I was born back in the 70s. Nobody truly understood how it worked or how it transmitted through DNA.

It led to a hard time for me. Seventeen isn't a good age for anyone at the best of times. I felt anger and bitterness about this dream shattering news, the disappointment about my life goals being taken away and fear of my new future - all suddenly being piled on top of the insanity of being a teenager. It was not an easy time at all. In fact, it was the best part of a decade and a half before I was anywhere close to coming to terms with it, if we do ever actually come to terms with such a thing. Maybe it's more of an acceptance thing in the end, an acceptance of not being able to change it and its inevitable impacts!

Perhaps the hardest part for me was the memories I had of the illness that I'd witnessed first-hand in my Grandfather. The slow creeping decay as the condition develops and chips away at a person's function. The gradual fading away, the lack of dignity that this illness can cause in the end. I know that in some way this will inevitably be my fate. I knew it then, and I know it now, which makes the acceptance part very real and very significant!

I have seen both sides of disability, firstly not having it and being able-bodied, then having it and not being fully able-bodied.

> Caring for a life-limiting condition is not the same as caring with a life-limiting condition.

I have perhaps the unique perspective of both points of view. Now I am a foster carer, I'm the person with the condition doing the caring.

Inevitably as expected I became disabled slowly over time in an ever-decreasing spiral of capacity. I trained to be an engineer, and I worked in heavy industry for as long as my condition would allow. The fact that I was eventually 'turfed out on my ear' because I was disabled, I will omit from the tale, mostly because it sounds like sour grapes. I then spent several years trying to get back into work within my original skill set, and ultimately failing because I have a disability. I was often the best candidate in the interview until I mentioned my condition. Funny how things can change...

This was perhaps my first taste of disability adversity - the way employers run away from it and don't see beyond the heightened insurance risk or the perceived lower productivity. I have become gradually aware over time to how these new kinds of adversities creep up on you. For a person with a disability, adversity isn't something that stands alone. It comes with a whole host of other issues that pile additional weight onto it. Discrimination, bigotry, attitudinal prejudice, bullying and exclusion also play a major part in day-to-day life.

It can present itself in many ways. Some are obviously cruel and intentional, like being laughed at and called names because you walk differently or look different, not being given equal opportunities and so on. Some are unintentional like events that don't have proper disabled access, toilets or parking. There are lots of reasons, many I haven't mentioned.

Society itself has a lot to answer for in the way people with disabilities are treated, especially considering that 1 in 5 people have a disability of some kind. Most people only see disability that is either extreme or obvious. *Most* ***of us don't look like Stephen Hawking, but for some reason are expected too, and that anything less somehow doesn't seem worthy of the title. Because*** of their discomfort around serious disability, people form a negative opinion about it that they apply to the word in all circumstances. Most disability is in fact hidden, for example, diabetes, or a hearing or visual impairment.

> I can't tell you how many times I've been told to get out of a disabled parking space because I don't 'look' disabled. I have Muscular Dystrophy, not man flu...

I've recently become involved in a project to examine why more people with disabilities are not actively recruited to be foster carers, and why people with disabilities often don't engage with employers or events. This has allowed me to highlight some of the key issues around disability and the lack of proactive inclusion for disabled people in mainstream society. It is illegal in the UK to discriminate against gender, race, sexual orientation, religious denomination, disability etc., etc. We are all aware of the politically correct version of how it should be. We are unfortunately also all very aware of how things far too often play out in reality.

It is perhaps better to phrase it as,

> *'**Not being excluded isn't the same as being included'***

As no one actively telling you can't do a thing, is not the same as someone actively engaging with you and telling you that you can. Albeit similar in terminology, in practice the differences are huge. As I said, I personally know what it is like to apply for dozens of jobs and be the lead candidate right up to the point I mention my disability. I know how it feels to be laughed at on the street. I know what it's like to not be able to attend events because it's on the third floor with no lift. This has given me the ability and the right to speak out about it from first-hand experience. I know what it's like to be a foster carer with a disability and be told I shouldn't be one!

Society doesn't engage with disability because historically, all the way back to antiquity a person's value is judged on their productivity. Even now, how many companies have a 'piece work' production mentality, where the more you do, the more you earn. It's called the pay packet society. This ethos is carried to this day into mainstream society. Perhaps in many, it's a subconscious thing, but in my experience often it's not. It filters down through generations where disabled in real terms becomes a label that seems to mean lesser than abled. This paints all disabled people as incapable of anything and everything, in complete ignorance of their actual skill set!

This is the reason most employers don't want us. This combined with the obvious insurance factors, the health and safety aspects or the provision of support they need to put in place to facilitate disabled people in the workplace. Great word facilitate, great in hyperbole, not so good in reality.

How many disabled people's CV's are ***'Kept on File for further positions'... We*** all know what it means. It means ***'Not good enough',*** but it's just impossible to prove, so why challenge it... I see very little facilitating in the wider world at a pace that meets the needs of disabled people. Let's face it, realistically as an employer why give yourself the hassle of employing Mike, when you can employ Bob who doesn't have a disability? Well, perhaps with a little more insight into disability, employers would see the hidden skill sets disabled people possess. Such as, the constant ability to adapt, the drive to overcome challenges, the determination to prove themselves equal, the compassion for others, the pride at being productive and of value, the loyalty they show to the companies who give them equal opportunities. The strength of character and all the things you're all going to list that I forgot. We don't live in the 1870s. This is 21st Century Britain, A former superpower, a former ruler of most of the known world, a former industrial powerhouse, former a lot of things. Surely our great past should have given everyone enough intellect and skill to quickly find a way into the future where this country leads the way in getting the most out of everyone's ability, even those who can't climb stairs or lift heavy things. How much better off would we all be if we stopped writing 20% of the population off before finding out where their value is?

It would be remiss of me not to talk about fear, the fear people have of disability. I have met people who have asked me if they can catch it, today in the 21st century, CAN I CATCH IT....seriously, if that is still a thought that people have then not enough inclusion is going on. I have two children living with me who have been with me for eight years, from being small children. They don't even often see disability or notice it in people that often. They have become so included in disabled being normal that they just see people as people. They have no fear of a person with a learning disability, facial disfigurement or a person in a wheelchair. To them, like it should be to us all, disability is normal life, and disabled people are not to fear or mock, they are to help and involve. This is what inclusion brings - natural equality and compassion.

No-one chooses to be disabled, no child's first choice is to be fostered.

I do understand the fear of disability. Even as a person with one I still have it; I quite honestly find very severe disability a little unnerving. This is purely because I feel vulnerable, and is a failing in myself, that I try to overcome. For example, I was once pushed over and injured by someone with a very profound learning disability, not deliberately I must add, but due to my own lack of balance and my condition, I couldn't prevent it. This was enough perhaps understandably, to create unease in me around people with those issues, I struggle with their unpredictability.

For most, it’s their lack of exposure to disability as children that plays into their lack of understanding and unease around it. It is and always will be human nature to fear what we do not understand. Some people just don’t want to get over it, they just can’t deal with it, and look at people with a disability like I look at spiders. Though if we endeavored to bring disability to people more often and earlier, not just when the Paralympics is on, perhaps we can fuel acceptance in new generations. I will however never accept spiders.

The question as to why disabled people don’t engage is tricky. Like everyone who judges disability as a thing, we also critically judge ourselves, I know I do. We can and do create some of our own problems and build upon our reluctance to have another go at things in the face of more ridicule or further rejection. We can also have an elevated sense of entitlement on occasions where we all think the world owes us special treatment. Some people with disabilities have this as a permanent personality trait. The vast majority do not, for me it comes and goes. It would be ridiculous to say that I do not have my own fears of myself, and of my limitations and of my future. I suppose I do on occasions allow them to impact me negatively. The key bit of that is ‘on occasions’ not permanently and I constantly try to rise above it, but I accept it is harder for some than it is for me. These fears make me reluctant to engage too, and I battle with myself to do so. I think the battle is the war I need to win in myself to change things. So, I push aside the fears and anxiety as best I can, and throw myself headfirst at life and the role I now have. Win or lose I am determined to try because the children I care for are more important than I am. They are what matters most to me, not my limitations. I do it for them and want to change the world for them. Like anyone who sees themselves as a parent, foster parent or otherwise we all want the best for our kids!

It is at this point I must sing, (***If somewhat reluctantly as I’m not here to plug***) the praises of the fostering agency I work with, the National Fostering Agency (NFA). After engaging with me about disability and disability recruitment into fostering – NFA changed their training venue in my hometown because it had no disabled access. This was entirely of their own doing when they realised the situation, and they actively engaged with me to find a more suitable location. This follows on from the amazing support they have given me from the very first conversation I had with them when I wanted to foster!

It’s proactive engagement like this that feeds into a better future for everyone. The children who need safe, happy homes; disabled people who feel valued and relevant; and the staff who gain insight and experience around disability and its issues, which helps them have a more inclusive and positive view of disability to carry forward throughout their careers.

I was asked when writing this to show some ways in which I have met the challenges I have listed, and that has proven difficult to answer. To be honest, I don't have a strategy as such, I try to face things head-on. I do have a sense of humour, but I feel the same hurt and anger as any other disabled person when I get mocked in the street or judged as incapable. Shouting and screaming isn't the answer, I tried it, and it doesn't work, but neither is hiding away a solution. I just get on with it. I try to be the best and most engaging person I can be and change people's view of disability one person at a time. I hope that's enough. It'll take more than me to change the world, but I can change my bit of it. I still get annoyed on occasions and tell people they are being stupid and ignorant, but only after I try reason and common sense. Some people are just too moronic to recognise it. I have a low tolerance threshold for stupid, sorry.

> I do try to show people that a condition or a limitation isn't a definition. I'm not defined by my Muscular Dystrophy; I'm affected by it.

It may seem ridiculous to some, but my condition gave me some things back for all it took away. It gave me compassion, mental strength, and a dogged determination to be seen as the same. Not to mention an understanding of 'adversity' that I can use to relate to the children whom I care for. Like them, I know what it's like to suffer at the hands of others. Those experiences gave me the strength to overcome it and that's what I need to give them.

Adversity is not a disabled dance troupe, nor is it owned by the disabled, though perhaps they do have a stake on the longevity of how they experience it. Adversity is suffering, it's pain, it's depression, fear, shame, it is turmoil and it hurts like hell. Exclusion isn't the solution. Tolerance is a skill that must be learned by us all, me included. Exposure to the things we fear and lack understanding of is the only way to learn about them and overcome them. But I suppose there is little point in me preaching to the converted. So, I suggest if you are a disabled person reading this, go and engage, challenge misconceptions, challenge bigotry with intellect. Go and do the show and tell at school, openly talk about it, you are the expert on the true meaning of disability. Sow the seeds of future acceptance by challenging the current ignorance!

Becoming a Foster Carer

If you want to find true value and acceptance, then perhaps go and foster and use the skills you have that no one else recognises. I have seen first-hand what it feels like to see children accept and inherently promote disability as normal. It's an amazing thing to see, and it's an amazing skill to give them, to not be afraid and to overcome what life throws at them, not just with resolve and determination but with pride in themselves.

> I foster because of my abilities, not my disabilities.

But I recognise that I have gained some unique skills and reference points about life because of the experiences disability has forced upon me. It is the emotional competencies of a foster carer that are most important. Disability only comes into if it seriously affects the job demands.

I have just tried to find the silver lining on my cloud.

I would expect many people who read this to think, ‘That’s not for me, I can’t do that, I don’t want to lose my benefits, I don’t want to look after crazy damaged kids.... etc., etc.’ This is the point where I need to set straight some of the misconceptions people have about kids in care. The children and young people in care don’t have the skills that you have. They don’t have the ability to process life in the way you do, why would they, nobody ever taught them how. They don’t have the benefits of the upbringing you had from your parents, or the strengths you found in the life you may have had to forge for yourself. They are victims, they are not the cause of their situation. It was caused by all of us, all the people in society who turn a blind eye to the failings in ourselves and the systems we put in place.

> Poverty and lack of social mobility, poor education, substance abuse, lack of options and inequality. These are the problems that create the situations that usually bring children into care.

And yes, some people just are not fit to be parents through their own failures, but that itself always has a deeper routed cause often based in the above!

The children I have met in the course of my fostering career have been varied and different. Some have bigger things to resolve and deal with than others, but they are all affected by the failures of others. They are affected by the same stigmas and attitudinal prejudices that we as disabled people face. Many resonate with the same fears, angers and self-loathing that I had. Most importantly though, they do have the ability to heal, they just need our help to do it. Some of the most amazing and most surprising people I have ever met are looked after children. They are not bad. Some have just experienced bad things that they have normalised. Some have experienced things that would break us. They have not only lived it for years; they have somehow survived it.

I agree fostering is not for everyone, but that’s not to a person’s detriment. It takes courage to admit you can’t handle it, but I believe it takes more courage to try. It takes more to give yourself to it, to make any difference you can to these children no matter how small, no matter how ungrateful they appear at the time. In the end, it’s valuable, one day they will recognise that value and maybe that little bit of horror you changed will help break a cycle for the next generation. Their children won’t be victims like they were, because of the skills you gave them.

I realise the thought of losing benefits is always a big issue to disabled people, and everyone thinks they are going to end up on the streets selling the ‘The Big Issue’ newspaper. It’s just not the case. Fostering is hard, it can be thankless, and it is often emotionally draining. To many, disabled or not, it has little appeal. The UK government recognises this obvious fact and have tried in many ways to make doing it viable and rewarding. This is why fostering falls into a special category called ‘home-based therapeutic care’. This means that disability benefits are not affected by being a foster carer, you can foster and still claim what you claim. There may also be significant tax breaks. Wherever you are, I would always recommend you get independent professional advice. You may find out that your financial worries about fostering are unfounded.

Over the years people have said to me that fostering is easy money, or money for nothing, and have questioned how hard can it be? *The answer is,*

> *it is absolutely hard enough to be massively under-subscribed. Hard enough to break your heart on occasions.*

It is in no way like looking after your own birth children. Imagine the hardest parts of raising your own children, then times it by sexual abuse, starvation, neglect, attempted murder, physical abuse, foetal drug and alcohol addiction, psychological abuse, torture and sexual exploitation or trafficking.

Do you think children without problems come into care? That they are in care because they have not experienced one or many of the above, and it's just a holiday. No child comes into care because their home life is good.

The Challenge and Reward of Being a Foster Carer

To those who criticise foster carers, and many do, or those who question a fostering agency's business model's morality, saying it is wrong to profit from fostering - I don't know, I don't run the business. I would suggest no more so than it is to profit from being a Physiotherapist or a Dentist working in private practice. Is it wrong to run a profitable business in the human services? Or is the profit the reason the businesses are successful? Surely if the outcomes for children are good, then the cost is worth it. In England, there are many Local Authority Children Services in crisis or struggling. You don't tend to find it with tier one independent agencies.... just a thought. Isn't the private sector driven to do better, to succeed? Surely the motivation for any business to work is its ability to provide the best service and be better than its competitors!

It is easy to say it's easy, easy to belittle by those who don't do it and don't understand its realities. I would suggest if it's so easy then please go and give it a go for a year. I won't even say I told you so, when you realise just how spectacularly you are wrong!

Be warned though, to any of you who think fostering is just some sort of path to easy money or some sort of job for old rope. You will very quickly find yourself wrong and it's probably not for you. It's not a job for anyone without huge commitment, dedication and perseverance. It is a professional and difficult role, for which you must be trained. The very best is expected and demanded of you and it’s 24/7/365. It takes great mental strength, drive and determination to succeed to do it well. Fostering is a Job that very quickly becomes a vocation for those who love it. Vocation or not we are professionals, who play a major role in the rehabilitation of children’s well-being. We are at the vanguard of caring for and slowly fixing those who society disavowed, abused and mistreated. Nobody has ever remained a foster carer for the money. Any that set out with that in mind will not last. But it is impossible to do it without money - self-esteem doesn’t pay the mortgage, the rent or the gas bill. Moral high ground doesn’t put food on the table or allow me to clothe, feed, transport, take on holiday, pay for school dinners, trips, toys, Christmas, birthdays etc. No fostering allowance pays for the love and care and attention I give my children, that’s free and always has been. The fostering allowance merely facilitates the provision of a home for them to live in and the required necessities to allow a normal life for the children.

To the disabled person, if you do consider it, you should not expect special treatment because you have a disability. You will be (and rightly so) assessed like everyone else and surely that’s a good thing. You will succeed or fail based on your ability to meet the needs of a child, not your disability. If you fail, then that’s because you cannot meet those needs. Be realistic and be prepared to be treated like everyone else. A lot of able-bodied people can’t meet the needs of a child either. Hand on heart it’s the most rewarding thing I have ever done. It actually matters. It’s worth it and it changes lives. To me, it is a privilege to be able to look after other people’s children and change their futures for the better. So, if you believe you can do it, find out. Currently, in the UK there is a need for 10,000 foster homes. There are 13,000,000 people with disabilities. 0.07% of the disabled community who could solve the national tragedy of foster care shortage. Less than one-tenth of one percent! There are also big foster care shortages in many other countries, such as the USA. The same principle applies.

Fostering has given me a purpose beyond myself, it has given me back a sense of self-worth that the world tried to beat out of me. It has made me a better person and I am stronger because of it. I would recommend it to anyone who wants to challenge themselves and rise above the stereotypes and labels society wants to put on you. But most importantly, help give a future to these children and young people.

Reference

Ryan, F. (2019) Being a foster carer is the best thing that I've done with my life, in *The Guardian* https://www.theguardian.com/world/2019/may/15/foster-carer-best-thing-disabled-people-shortage

Contact Jon Powton if you have any questions - Jon_powton@hotmail.co.uk