

All's Well that Ends Well

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*Scott Haslam
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I have changed some of the names for confidentiality.

Lynne has been asking me for some time now to put pen to paper and finally I have got round to doing it. I have worked in the Learning Disability and Mental Health Sector for just over 10 years, starting off as an agency worker and working my way up to senior project worker.

I have supported many individuals over the years with varying levels of disability **but I had never met anyone (to my knowledge) with fragile X.** That was until I met James. I received a phone call from a social worker I had been working alongside with another service user. He said, "I know this young man, he is having problems living at home and needs to move into adult services. I think you might be able to provide the right service for him, can you help?" He explained a few issues James had and after a brief discussion I

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said, "He sounds like someone we can support, when were you thinking of him making a move from his family into his own house?" The reply was two weeks! After a slight stunned silence I said, "leave it with me, I can't make those decisions, I will take it back to the team and see what we can do". To cut a long story short, James was to come to our service as an emergency referral. Not the ideal way or the way we like to work but something we have done before and with success. We did agree however on a six week transition period to give James time to adjust to the idea and for us to set up a service ie house, support staff, programme of activities/routines etc. As luck would have it a brand new town house divided into two flats had just been built. There was a vacancy in one of the flats, the other was occupied by another service user we already provided 24hr support for. James came to view the flat and said he liked it and this is where it all began.

I will give you a brief description of James's background. James is now 20 years old and he came to New Focus just over 18 months ago. He had been living at home with his mother and brothers and sisters (two of which have fragile X). Jane, James's mum, had some social service involvement and James had about 10-15 hours a week support from a learning disability agency; but even so it would be fair to say that Jane was struggling. James had particularly challenging behaviour. Violent, aggressive outbursts were common and there had been some problems with residents in the local community. Jane could no longer cope with James and support his other siblings, which at times were illustrating equal levels of challenging behaviour. It had reached the point where James had to move out.

New Focus is a learning disability service which provides individuals with support whilst living in the community. James now has tenancy of his own flat and has 24 hour staff support. There is a small bedroom/office area which adjoins his flat so if staff are needed at night he can access them.

To say the transition from James moving out of the family home into his own flat was hard would be an understatement. In fact it was probably the most stressful, challenging period of my working career! At least both, James and myself, can look back and laugh now! Over the six week bridging period the aim was to familiarise James with his flat, new staff and activities (most of which James chose) as much as possible. The hardest bit was to get James to accept that he WAS going to move.

I have a lot of experience working with people who have autism but at the time none with fragile X. Eighteen months on and I am now fully aware that although there are similarities, there are immense differences between the two. However, one massive similarity quickly became apparent. James didn't like CHANGE. Slightly awkward to tackle when James's life was going to, completely and out of his control, turn itself upside down, do somersaults and then back flip into a new environment. All we could do was try to keep things as positive and consistent as possible, cross fingers and try to prepare James and the staff for the possible bumpy ride ahead.

The move in date grew ever closer, the flat filled with new things (something I admit now was a mistake). Although James had some input in what went into the flat it was already fully furnished, even down to knives and forks. Looking back now it would have been better for James to bring old things from home and replace once settled in so he had familiar

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things around him. He did bring his duvet and pillow which helped. James's level of anxiety increased as did his level of aggressive outbursts: the holes in doors and walls began to mount; but the bridging work continued, there was no going back.

James moved in on October 31st – Halloween – and as a distraction we had a party, a few familiar faces and a few drinks, some games and music (James loves music). The evening passed by without any hiccups, James surprised everyone. Although he looked pre-occupied there had been no outbursts or real signs of anxiety. Once everyone left, however, the realisation started to hit home. The tears came, James pleaded to be taken back to his mum's. Knowing him as I do now, looking back on it, James was absolutely petrified. He had never been on his own, he had never slept in a room on his own (at home he had shared a room with two of his brothers in bunk beds). His new flat was on two levels, ground floor was his kitchen/living room (open plan) and upstairs was his bedroom/bathroom.

I haven't the space to go into every detail but the next three months were very hard work for all involved, not least for James who had to adapt to the massive change. Some out of the box thinking was needed and boundaries, rules and routines were drawn up and followed. I will talk about a few things that cropped up.

The first two weeks passed, surprisingly, with no physical outbursts; but, unexpected, were the waves of emotions. James cried, sobbed and begged to go back to his mum's (something that was absolutely not possible). At times he wouldn't eat, sleep, wash or change his clothes. After three weeks he was still refusing to sleep upstairs and would only drift in and out of sleep on his chair in the living room. After talking to James it emerged that it was the act of going upstairs to the bedroom that was scaring him and being alone in an upstairs room. He appeared to be managing to sleep as such downstairs in a chair so we simply swapped the flat around. We brought the bed down and took the sofas upstairs! Hey presto, James was finally sleeping in a bed, albeit in what was before, his living room! Small steps forward! I'm glad to say that James is now upstairs in a double bed (which he struggles to get out of in the morning!) and has no problem about being in his own flat.

The aspect of the transition which caused the most problems was that James really didn't accept that this was his new flat and this is where he would be living for the foreseeable future. He had been away on respite care placements before and had not coped well with them, usually returning home due to his behaviour – verbal and physical outbursts playing the most part in this. As I previously mentioned, the first two weeks were an outpouring of emotion and not aggression. Things took a turn for the worse as James began to realise that his pleading was not getting him back to his mum's. His levels of challenging behaviour and aggressive outbursts increased, behaviour that in the past had had him removed from respite were resurfacing. It is possible that James was trying to get himself removed from his flat and back to his mum's. It didn't work. I lost track of the number of times James was seen walking into the sunset with guitar and Union Jack suitcase in tow and the Police bringing him back. I had pre-warned him that the fire doors and walls were somewhat sturdier than those at his mum's, lessons he quickly learnt through trial and error. Shouting, spitting, swearing and general anti-social behaviour were becoming a daily occurrence and neighbours were complaining. Police were being called and I have to say James was pushing everyone to their limits.

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The team met regularly to discuss what to do next, everyone was 100% committed to making this work and hoped that it was just a prolonged blip. I have to admit after two months things were looking bleak and mumbblings of alternative accommodation, such as secure units, were being discussed as James was struggling to live in the community and was still reluctant to accept the change. We did a bit of work with James alongside the Police. James had had few boundaries or consequences in his life for his behaviour, he was now in adult services and although allowances were made for his disability, he was living in a community setting and like all of us we have to adhere to some rules and the law.

We knew that we needed to offer James an outlet for his anxiety, which usually portrayed itself through aggression; but realised that he couldn't do this while out in public. So we explained to James that if and when he was feeling like he was going to have an 'outburst' he could do so within his flat. The Police and myself, along with James, drew up an Agreed Behavioural Contract or ABC. This clearly laid out what was acceptable and what was not. We made it very simple using pictures and short sentences under each image as prompts, so James fully understood what was expected whilst out in the community. Things such as no shouting and swearing, no spitting, no kicking objects, no running away - all these were addressed. The consequences were also very clear: James, like anyone else, would be arrested for breach of the peace or similar offence.

We have learnt over the last 18 months that James is generally very good at sticking to agreed rules once in place and importantly once he knows the consequences will be followed through if those rules are broken. It was vital that there was a consistent approach with James so a small core number of staff worked with him (about 5-6). Although this was intense for those involved, I believe it was the reason why we have reached a positive outcome and where we are today. James did push the ABC to see what would happen and was rightly arrested and placed in a cell – something he did not enjoy but has, very much to his credit, learnt from. We gave James empty cardboard boxes in his flat, which he would jump on, shout at and rip to pieces. Gradually, James began to learn that his flat was a 'safe' place to be, somewhere he could express his feelings, if he was angry or anxious he express it and staff were to there to support him through it.

It was very important that staff accepted that at times James would lose his temper and there would be outbursts. If James stuck to his agreement and did this within his flat then staff would support him through it. Sometimes James would turn over his table and chairs, throw DVD's etc, but would slowly calm down. Once he had calmed staff were told to help him tidy up (not do it for him, but with him). The temptation is always there to say "you made the mess so you tidy it up" but by doing it alongside James it has meant that he has far more respect and a better relationship with his staff and vice versa. The most important thing I think for James has been that whatever he has directed at staff in anger they have stuck by him and not taken it personally. James has learned to trust staff, which has resulted in him following strategies and routines in place, which in turn has reduced his anxiety levels and thus agitation.

We have worked with James around using public transport, in particular buses, which he found difficult due to noise levels. We are doing a lot of input at the moment around trying to get James away for a few days holiday, which is something he has really struggled with. Up

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Behaviour

to now he has managed one night away so there is plenty still to do. Activity-wise James has become interested in fishing and this has been a real positive in his life. He is also working, doing a regular paid paper round.

Eighteen months on and James is now much more settled. Outbursts are far fewer and tend to only arise when new situations are being introduced. James has learnt to deal with things and is able to talk openly with staff about what is worrying him, rather than flaring up. Things are positive for James now and people that have known him for a long time are amazed at the change in him. There is still a long way to go and James is developing and progressing every day. The staff have put a lot of time and effort in to supporting James but ultimately it is James that has had to work the hardest. Full credit to him for turning things around.

Conference feedback

Kate Woodcock

My name is Kate Woodcock and I am a PhD student working at the University of Birmingham. My colleague and I attended the Fragile X Society family conference in the Holiday Inn in Birmingham on 20th October last year. I was very excited about the opportunity to meet more people with fragile X and their families and also to see some of the families again who I know from when they participated in my research last year. We were also both very much looking forward to hearing the presenters speak, particularly because they included Vicki Sudhalter and Kim Cornish who have been involved in many of the research studies that we have been reading about for a long time.

We both had a fantastic time and found the conference very, very interesting. Not only were all of the speakers fascinating but we were also very impressed by the family members who contributed by asking questions and talking about their own experiences; this really added something very special to the day for us. We both feel very privileged to have been able to gain such a unique experience.

My colleague Lisa Collis is also doing her PhD and is looking at social anxiety in people with a different genetic syndrome called Cornelia De Lange Syndrome. She was particularly interested in what Vicki Sudhalter had to say about anxiety and hyperarousal in fragile X. During the day we both learned lots of very interesting things that we should be able to use to help us with our research in the future.