



Megan Tanner

THE EXPERIENCES OF
BEING AN AUTISTIC
FOSTER CARE GIVER
WORKING WITH UK
SOCIAL SERVICES

“I thought there was something wrong
with her...”

Disability Studies

Collection Editors

DAMIAN MELLIFONT

&

JENNIFER SMITH-MERRY

LIVED PLACES
PUBLISHING



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**Dr Jennifer Smith-Merry
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Abstract

How can social workers and neurodiverse foster carers collaborate to provide the best support for a child or teen in need? Building strong relationships between social workers and neurodiverse foster carers can be challenging. Drawing from her own lived experience as a neurodivergent foster carer, Megan Tanner explains how a successful partnership can create the best possible outcome. Working to remove pre-conceptions and judgement surrounding neurodiverse foster carers, this book is ideal reading for students and practitioners of social work and related courses, disability studies, autism and autistic studies, DEIB studies, psychology, and social work policy makers.

Keywords

Lived experience; DEIB; social work; policy; mental health; anxiety; neurodiversity; relationships; communication; trust

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Trigger warning

This book contains explicit references to, and descriptions of, situations which may cause distress. This includes references to and descriptions of:

- Ableism, discrimination, and micro-aggressions

Please be aware that references to potentially distressing topics occur frequently and throughout the book.

Introduction

When I told people I was a foster carer the usual response was, “Wow. I bet that is so rewarding”, or “How wonderful. What a valuable job you do”.

I would give a positive reply because I really did love fostering, and my children and my teenagers. It was rewarding. There was another truth, though. I was also broken by an organisation that could not or would not accept my difference, my neurodivergence, and refused to make any reasonable adjustments. I love being autistic. No matter what I faced I would not change being autistic for anything.

My diagnosis

I started my journey with fostering in 2011 and in August 2019 was diagnosed as being autistic. I would love to say that, when my local authority and fostering agency found out, they sat me down and asked what reasonable adjustments I felt would be helpful, or that they challenged their assumptions and decisions about me now that I had an official diagnosis. But no. I was told I needed to redo my medical immediately!

For what? How could the results change now that I had an official diagnosis of autism? I was the same person as I had been in 2011. I had not changed. I refused and asked them to check the legality of their request! I was not asked to take the medical again, thankfully.

It has been said, “If you have met 1 autistic person you have met 1 autistic person”, and this is very true. Autism is not linear as some believe, it is a spectrum, and we all have different attributes within it. So, in writing this book I can only use my experiences. I am not able to assume those of others (that is part of my autism). The lived experience examples and stories are mine and I hope they will go towards helping the system understand ways in which they can be more inclusive for neurodivergent foster carers.

It has only been in the past few years that autism has become more widely understood and diagnosed. I was born in 1978 and, even though I displayed traits during my childhood, autism was never considered as a reason for my behaviour. Autism is also less frequently diagnosed in females.

Many more boys than girls are diagnosed on the autism spectrum: more than four boys for every autistic girl, according to the latest numbers from the Centers for Disease Control. Researchers point to genetic differences. But clinicians and researchers have also come to realize that many “higher functioning” autistic girls are simply missed. They’ve been termed the “lost girls” or “hiding in plain sight” because they’re overlooked or diagnosed late. They don’t fit the stereotypes or their symptoms are misinterpreted as something else. And they may be better at hiding the signs, at least when they’re young.

(Arky, 2023)

This could mean that there are a lot of adults who are autistic and undiagnosed within the foster carer community, especially females. If we can understand “difference”, we can make the

workplace environment better for all people, diagnosed or undiagnosed.

It is important to note that, when I started my fostering journey, I did explain that there was a GP's suggestion that I was autistic, and I was waiting to have an assessment. For the first few years I did not have a diagnosis. However, as you will see, my behaviours were pretty obvious. A quote I often repeat in various situations is, "If it quacks like a duck, it is a duck". I was clearly a duck. So, in 2011, I presented as an autistic person, and, in 2019, I was proved to be an autistic person. Social services were fully aware of the waiting lists and how costly it was to go privately for an assessment. Clearly, the understanding should have been that getting a full diagnosis was going to take years and that should have been an important fact in my file. However, as we can see throughout this book, prior to and following the diagnosis in August 2019, nothing in their attitude showed any understanding of autism and how it would present. Whether I was "suspected" or "fully diagnosed" it did not matter. Nothing was put in place to alleviate any difficulties I faced with the organisation.

I believe social services, as it was called when I started fostering, is now known in the UK as social care. I struggle with this concept of "care", so until I hear and see that it is a "care" system and not a "service" system I will continue to call it social services. The experiences I describe in this book are not those of a system geared to "care".

Celebration of exceptional social workers

I do not want this to appear to be all negative. I do want to celebrate the positive people and times too. Sadly, these positive contributions only help to highlight the difficult and negative issues. Many things could have been different. They did not need to be the way they were. The memories of these outstanding social workers prove this. In an email from my first supervising social worker, just before we went into a meeting I was anxious about, I was told that they had not been informed whether XX would be attending or not. However, it continued, if that is the case, “pls, pls, pls hold fire”, and to let them do the talking. They explained that they may seem a bit slow in putting things forward but it was usually better to allow others in the forum to speak and then present your case! They promised they were still supporting my application to become a long-term foster carer and they were also confident that the application would be approved. They clearly understood that I would find the process tedious but they reiterated that it was their job to take any pressure off. They even told me to turn to them during periods of distress ... and, if it would help, give them a sharp kick under the table to release any frustration! They thanked me and explained that they truly valued and appreciated my time, energy, and commitment to this and they were so glad that I was sticking with it despite the initial challenges! They continued, “You’re fab to work with ... and it’s not me who’s a superior worker but you!!! I’m so sorry that it’s taken time for your efforts to be openly recognized. Look forward to seeing you later.)”

They knew I struggled with a certain manager and that I became very anxious with this manager's "communication techniques". So, they gave me the tools to help. They encouraged and supported me; used humour, reminded me that I was not alone in this meeting, they were there, and they had my back and best interests at heart. They would do their job. They enabled me to be relaxed without heading into fight or flight mode when walking into the meeting.

I only had two supervising social workers during my years as a foster carer. This is a blessing as both of mine were amazing. The chapters in this book are meant to highlight issues, but I do want to say I have had a few good people behind me during my fostering journey, and, although supervising social workers do not have that much power when problematic issues arise within the system, they are invaluable. Being able to use them as supporters, to talk to, to vent on, to know there is one person at least who knows you, understands you, and is on your side means the world. So, to E and A, if you ever read this book, thank you!

When it comes to child social workers I cannot remember how many I had over the years. It must be in the tens. The turnover was fast. Many were agency workers who only dipped in for a week or so to the detriment of the children and young people they were there to help. Good as they may have been, they could not make effective change in their short-term intervention.

I remember one child social worker from years ago in particular. By the time she came along I had enough years of fostering under my belt to be wary and protective, both of myself and the children and young people in my care. However, she shattered my defences within a short time by being utterly child focused.

She would pop over on her way home long after her working hours had finished. She understood that the “normal” methods we were told to do in parenting sessions were not working with our child. We had a meeting and she allowed me to find and try ideas that could work. For this I am so thankful! She related to me as someone who had worth. I never felt “less than”, difficult, or simply a work appointment. She celebrated small wins. She knew that, on some days, due to the extreme behaviours our child was displaying, I would be drained, even feeling like I could not do it any longer, and she would tell me to go make a coffee while she sat with our child and gave me a break. When she found out I had left fostering I received this:

Such a shame, maybe you will foster again when the time is right. You are an amazing carer, and I will never forget what you stepped up to do for “X”. Big hugs.

(Child social worker, personal communication)

This was years after our child had moved on in the system. Neither of us worked for that local authority any more. It would have been completely acceptable for her to have forgotten me. I know she would have had her fair share of foster carers in the interim. This message meant, and still means, so much to me.

So, yes, I have had child social workers who were legends, who reduced the stress levels of living with and parenting highly traumatised children and young people who played out their trauma in their behaviours. They relit my candle flame when I was exhausted. If ever you read this book, then thank you, S, for being incredible!

The sad problem is that social workers like E, A, and S were few and far between. These are three truly exceptional social workers in 11 years out of goodness knows how many. Many were too tired, overworked, or afraid to stand against the norm for the children they were there for. Despite their best efforts they could not change the system, even if they tried. And that is what is needed – but that is another book!

Survival mode

I think if you keep people in survival mode, and you keep them in fear, and you keep them at War, and you keep them angry, and you keep them in pain, and you keep them confused you can control their attention by controlling their emotions.

(Dispenza in Bartlett, 2023)

When I heard this quote it reminded me of being a foster carer. I was in survival, I was in fear, I was angry, I was hurt, and I was confused. My attention was constantly on where the next unexpected, disappointing issue was coming from with the adults. But I should have been relaxed, happy, worthy in my role in social services so I could look after my children and young people with no other pressures. My question is why does the system want or need their foster carers to be in this position? What is going on? If something does not make sense, then something is going on that is not right. Would we even dare to scratch the surface of that suggestion? Would it even matter if we did? After all, Ofsted pronouncements of failings can go on for years, even decades, with no real positive change happening. And that is an easily verifiable fact.

For balance, it can be a postcode lottery with regards to how foster carers are treated. I am sure there are local authorities who actually do equality and inclusion well.

Parenting

Parenting for anyone, whether neurotypical or neurodivergent, is difficult, exhausting, and stressful. For foster carers, add into the mix the need to face extreme trauma, neglect, abuse, adverse childhood experiences, child on parent violence, challenging, violent, or dangerous behaviour, child sexual exploitation, verbal aggression, high risk activity, defiance, self-harm, dysregulation, absconding, police visits, drugs and alcohol misuse, school issues, rape, sleep difficulties, foetal alcohol syndrome – the list goes on. Parenting goes to the next level of “difficult”. Fostering is emotionally draining for anyone.

We need a system, true social care, which appreciates that we, as foster carers, live with these children continuously. We do not clock in at 9 a.m. and out at 5 p.m., with weekends and annual holidays off. We deserve a social care system which desires to support us so we can parent the children and young people in our care with no added stress.

If this book is able to make a change, then let that be the change. Support us, accept us, believe in us, and celebrate us. Be the organisation that refuses to add unnecessary stress onto humans who are actually in the arena. Become social care and not social services.

So, what does this book look like?

Each chapter of this book goes through an aspect of my autism, how it presents in me, and the difficulties I had as a foster carer with many of the adults within the system. I have used actual, lived experience examples from my years as a foster carer, then, at the end of each chapter, I have suggested a few reasonable adjustments that can easily be made. The term “reasonable adjustments” and any other specific terms I have used are explained in the Glossary.

The Equalities Act 2010 means neurodivergent people are “protected” within the work environment and it is illegal for any employer not to make reasonable adjustments to help us at work. The National Autistic Society states: “Employers are legally obliged to support you and make reasonable adjustments” (2023).

Employers can be required by law to make reasonable adjustments to the workplace. Failure to do so may be discrimination.

Adjustments should respond to the particular needs of the worker. Examples of adjustments include changes to work premises, changes to work schedules, modifying equipment or providing training.

(Australian Human Rights Commission, 2023)

These reasonable adjustments are in no way comprehensive but hopefully they will spark ideas.

This book itself shows how this is so often neglected and, when it is flagged as a problem, nothing is done about it. This needs to change! Not only for neurodivergent carers but for all if we are to see retention of foster carers and less burnout in those working within social services.

Social services needs to comply and make reasonable adjustments. As I have said it is not difficult to create a safer environment for carers. It just needs to be something which is actually wanted and it can be done.

I hope this book helps you understand and include “difference” and gives you some ideas on how to be inclusive.

I want to say to you the words of Michelle Obama: “Don’t ever underestimate the importance you can have because history has shown us that courage can be contagious and hope can take on a life of its own” (Gajanan, 2017).

So read this book and go out and be the change we need.

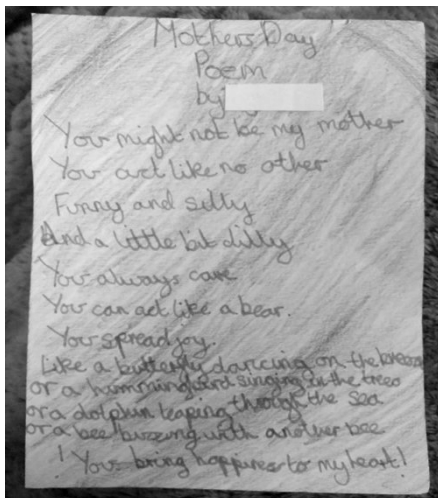


Figure 1

Learning objectives

1. To understand difference.
2. To question our personal judgements and prejudices.
3. To see the added value neurodivergence brings.
4. To be unafraid of different communication styles.
5. To be able to implement reasonable adjustments.

1

The benefits of having autistic foster carers

Why might autistic people make good foster carers?

Let's be positive and start with the benefits of being an autistic foster carer. These are numerous. The chapters in this book are going to look at all of the issues which actually arose from my being autistic, so, for balance, we need to understand what autistic foster carers can bring to fostering.

In a study on "The Strengths and Abilities of Autistic People in the Workplace": "The main strengths identified from this data revealed cognitive advantages such as superior creativity, focus, and memory; increased efficiency and personal qualities such as honesty and dedication; and the ability to offer a unique autism-specific perspective" (Cope and Remington, 2022).

In parenting my autism has huge benefits. Here are a few from the top of my head. Any stories I add throughout the book are from my own lived experiences, or those of my tribe who are now in their adult years, out of the care system and who have given

permission for me to use them. Most examples will be about me as this is about my autism and the effects on my fostering journey, but this section will need a few about my tribe as they were an integral part of the whole experience.

My autism allowed me, as a foster carer, to create routines which were immovable. This may sound counterproductive, but, in fact, as the children and teenagers I fostered were highly traumatised, they needed the stability of routine as this helped them feel secure. Routines did not change; I did not flipflop; they were safe.

My autism gave me the “out of the box” creativity to find a “better” way of parenting when the training courses provided for foster carers were not helping. I am deeply interested in child and adolescent development. I became involved with Non-Violent Resistance parenting.

NVR stands for nonviolent resistance. It is an approach that Gandhi and Mandela used during their socio-political movements. It has been developed into a parenting technique by Haim Omer that I believe should be embraced in the whole of parenting, or it can be used simply to focus on “challenging behaviour”.

NVR consists of 9 pillars that work together and stem out of the main core that we call “Parental Presence”. NVR is relationship based at its centre. By the parent/carer building strong connection with their child/ren and becoming a firm and secure anchor we see the parent/carer becoming more empowered, positive, safer and stronger in their child/teens life. This produces effective results.

Parents and carers use these 9 pillars instead of the “behaviour management” parenting techniques (i.e. reward and consequence, time out, etc.).

(Tanner, 2020)

I studied brain development, and emotional intelligence, and was able to put into practice those details which transformed my parenting style. This gave me more understanding of the young people in my care and helped me be fully focused on the child’s needs rather than trying to make them fit into something they could not. Foster carers are given “Positive Behaviour” training and expected to use it. However, most of our children will self-sabotage or simply not work with those techniques. So, rather than try and force something that was not working and make the child the problem, I would go on a quest to find something that did work. It would become my special interest and hyper-focus.

My autism enables me to evolve, change, and use different techniques instead of the age-old, “Just do what I do”, or even worse, “Just do what I say”.

One of my favourite quotes is by Dr Grace Hopper, “The most damaging phrase in the language is. ‘it’s always been done this way.’” (Hopper, 1987). I quite agree.

My autism makes me very observant. I notice auras and energies, and I can tell when my child is emotional in some way. I can tune into them emotionally without them having to seek me out, when, maybe, they cannot ask for help or explain what is wrong. Does that mean I always understand, agree with, or like the emotions they were feeling? No. But that was for me to vent about with

the adults in my support group, including my supervising social worker. It was not up to me to change my child's current state of emotional reality, but to hear it. Many neurotypical parents try to alter their child's present emotional truth and become embroiled in the situation. But I found it more valuable to listen, perhaps because I was used to not being listened to.

My autism makes me very empathetic (not sympathetic!), and my children needed a lot of empathy, grace, and understanding for what they were going through and had been through. Behaviour is communication. It is easy for me to look behind the visible behaviours in a way that is not always easy for neurotypical parents to do. I find neurotypical parents can have a conscious or subconscious love affair with imposed consequences. An imposed consequence is something we put in to control the child's attitude or behaviour and make them stop what they are doing. For example: time out, deprivation of liberties, removal of freedoms or privileges. They may work in the short term but have no long-term effects. The child also can forget they had any accountability and blame shift onto the parent. No child sits in a "time out" contemplating their actions and giving a truthful apology at the end when one is demanded from the parent, "That's your 10 minutes done. Now say sorry and give me a hug". They sit there hating you and obey with the sorry and hug just to get out of time out. No teenager has their iPad removed after being rude to their parents and, while iPadless, sits and considers their attitude problem. They forget their accountability and simply hate you. Imposed consequences do not make them understand their actions. Which is why we have to keep threatening or repeating this method. Also, this method

of consequences almost always will escalate any situation. Try keeping that child in a “time out!” Get ready for the backlash and drama when trying to remove something from your teenager.

Among my children, one, who is now a fully-fledged adult, is the star in one of my favourite memories, and they do not mind me retelling it. I think it highlights both how the children may behave because of past trauma and why they may do certain things, and my response and how it would differ from the accepted norm. I had taken this little one to see a matinee of *I Believe in Unicorns* in London. We had a fun train ride, a great theatre trip, and then came back home. They came into the house, got the dustpan and brush out of the cupboard, put them on the kitchen floor, and then absconded. As was the rule, when I could not find them in their usual hiding places, I called the police. They came, found the child, and brought them home. The police explained that the child had said they had absconded as I had made them clean all day! Of course, I had not moved the dustpan and brush as I had not thought about it, so there was the dustpan proof. In front of the officers, I asked the child to take whatever was in their pocket out and hand it to the police. The child, eventually, begrudgingly, did. There were the train and theatre tickets from our trip dated for that day!

For some parents, this would be seen as “naughty behaviour”, or worse, and needing a consequence at the very least. After all, the police had been involved and that is always uncomfortable for foster carers. However, I saw it as a child who had had a good time, which was an unknown feeling at this point for them. Having a good time did not feel safe for them, and even though they liked me, liking me felt like a betrayal of their biological

parents. It did not need a consequence, it needed empathy. That was something I was able to give. There was nothing more than the natural consequence of being found out. The situation was over, but lessons were learned on all sides that day.

I hear from nearly all my neurotypical parents that they fear the judgement of others. I have no ability to consider this.

My autism meant that, many times, I was able to do things other parents could not because I had no consideration that someone might judge my choices. For example, one of my younger ones had what I still affectionately call “shoe gate” every day. They just hated shoes, and this could, and regularly did, turn into rows. I did not like this as I would rather keep connection with the child, and arguing on a daily basis did not help build our relationship. So, one morning, I let them go to school without any shoes on. (The shoes were in their bag for when they got to school.) They walked barefoot from the car park, through the school playground, and into school. I did not give it a thought. I told friends I had finally ended “shoe gate” and we had had a better morning, and they were horrified. “But what did the other parents think?”, I was asked. It had not crossed my mind that other parents in the playground had enough time on their hands to watch me walk my child through that school playground in bare feet. Also, in my head I thought what business was it of theirs?

But I learned two things from this. First, the child found a natural consequence, walking without shoes was uncomfortable, and that changed their attitude to shoes. Secondly, I realised that many neurotypical parents would attempt to make their child conform, and have the constant, draining rows, simply so other parents did not form judgements on them. To me this was

madness. Having arguments with your child and making them conform in things which were not important simply for strangers' approval was unnecessary. Equally it did not stop anyone from being judged.

I knew I had experienced "difference" and discrimination throughout my life, so I could relate to my children when they hurt because of those things. Many times, my children would come down at night. At night everything is quiet, it is dark, and a child's mind has space to think about the painful things. Neurotypical parents can get frustrated with this. As we see in a later chapter even a social service manager believed that "once in bed, it's bed". I was able to give half an hour so the child could share their troubles and pass the worry onto someone else, because I understood how frightening nighttime can be.

My autism meant that bluntness and directness, and my refusal to justify myself, helped many an argument with a teenager end more quickly than it would necessarily have done in a neurotypical household! Teenagers will dysregulate and they say cruel things. I learned that neurotypical parents are more likely to respond emotionally to what is being said, therefore elongating the argument. For example:

Teen: You're the worst mum ever.

Mum: How dare you? Do you want me to list everything I do for you?

You can bet the teenager and Mum will get into an unnecessary argument and escalation now.

With me the conversation is more likely to go:

Teen: You're the worst foster carer ever.

Me: Thanks!

Or, if my teenagers said mean things to me, I would generally reply, "Err, rude!" and carry on my life watching *Grey's Anatomy*, or whatever, till they calmed down, when I could then discuss the underlying issue. In the heat of the moment I did not need to justify or explain or validate myself and answer what was really just a series of angry sentences to provoke or continue an argument. I was able to allow a dysregulated teenager time without getting emotionally pulled in, dysregulated myself, or ending up in conflict with them.

Finally, my autism gives me the ability to think of on-the-spot ways to solve potential dramas, which I find hilarious. I have a quick sense of humour. After breakfast one day my child told me they were going on hunger strike – forever! This was in protest at having to eat cereal, toast, or porridge instead of sweets for breakfast. Seemed fair to me! I appreciated their stand. If I had been verbally on this with a "Don't be silly!" or "That's not OK!", it was clear anything I said would be used to create an argument. So, I told them I appreciated their stand, got the calendar and marked off 40 days. I then replied, "No problem. Jesus did 40 days without food. I'll come back to you on 13 March and I will then have to step in and get you to eat. I'm sorry as it might disrupt your hunger strike but let's face that in 40 days!"

This child maintained their hunger strike for two hours till morning snack time! This was always going to have happened. The child was clearly going to want food and in two hours they had forgotten all about their protest. My "humorous" (for me) way of dealing with the situation avoided an "in the moment" drama.

An older teenager decided they were not coming home one night but were going to sleep in a tree in the park. They rang me to tell me their decision. If I had reacted with, “No. You will be in by curfew or else!”, there would have been an escalation. They were betting on that happening. The teenager clearly wanted an argument. So, knowing the teenager well, I got a blanket, went to the tree they were in, threw it up so they would not get cold, and asked them to take care as if they fell asleep and fell out of the tree there might be a bump! “See you in the morning”, I said and then I went home. The teenager was back pretty soon after, and before curfew. I have many drama-avoiding anecdotes. My sense of humour defused many possible dramas, thankfully!

Cognitive strengths

Auticon’s website states:

Some cognitive strengths tend to be more prevalent in the autism community:

- distinctive logical and analytical abilities
- sustained concentration and perseverance even when tasks are repetitive
- conscientiousness, loyalty, and sincerity
- an exceptional eye for detail and potential errors
- thorough target versus actual comparisons, and a genuine awareness for quality
- a strong interest in factual matters and comprehensive technical expertise

(Auticon, 2023)

These things are so important in fostering. Let's look at the plus side of our cognitive strengths:

1. To be able to be logical and analytical over behavioural challenges with our children and teenagers is incredibly important for a foster carer. This means we tend to be able to cope with a lot and not get as stressed or reactive with our children as a neurotypical may. Also, considering we have so many meetings of various kinds, being logical and analytical means that fact and truth are in these meetings. This should be a given but, in my experience, as long as the neurotypical professional delivers their point unemotionally, and with authority, no logic or analytical fact or truth is needed. For example, in one meeting I explained that I had a list that the child's Dr and I had prepared of reasons why we felt this child needed an autism assessment. I read the list out. One professional replied that the child had not displayed any of those characteristics to them. They concluded that the issues were 'due to their diet'. It should be noted that this professional saw the child for less than one hour per week over a very short time frame and I had lived 24/7 with them for several years. I was shocked and asked whether they were "kidding me"! I was then informed that this linked professional had more experience of autism than I did. (Ironical!) There was clearly no logical or analytical thought behind their decision that any issues the child may have were due to diet. No acceptance of the medical backup for the need for an assessment. I was the only one bringing logical and analytical thought to this situation. However, because this professional had a specific degree, a low tone of voice, and an air of authority it was decided by the other professionals in the meeting that these numerous,