

NEURO KEY

An Alliance supporting people
with neurological conditions

NEURODEVELOPMENTAL CONDITIONS

‘Unlocking minds and opening doors’

Open Door series by Neuro Key



Contents

| | |
|--------------------------|----|
| Foreword | 3 |
| Neville's story | 4 |
| Marie's story | 9 |
| Mark and Dan's story | 14 |
| Anna and Neil's Story | 18 |
| Collette's story | 20 |
| Learning outcomes | 23 |
| Iceberg of presentations | 24 |
| Acknowledgements | 26 |
| Notes | 27 |

Foreword

Since inception Neuro Key, the working name of the Charity, Tees Valley, Durham and North Yorkshire Neurological Alliance, has harnessed lived experience as an educational tool to improve service delivery and professional understanding of not only the common threads between neurological conditions but also the complexities of the caregiving role. From enabling patients and caregivers to take part in research, deliver lived experience seminars, making sure people can respond to surveys and consultations or supporting people to lead the operational direction of the Charity, we are passionate about our social purpose.

We promote common objectives across all neurological conditions and in-so-doing, offer activity for people themselves to share and learn from each other. We concentrate on the value of lived experience to professional knowledge and the contribution to the evidence base to improve understanding and care in the future. By supporting people to be more confident in knowledge sharing and cooperation across social divides, we sustain a neuro-informed community to improve self-management, neuro-literacy and social capital.

As core members of a range of multi-agency networks and forums, we foster collaborative working partnerships to sustain a high customer service focus. We close the gaps in local knowledge to encourage creative problem-solving and efficiencies by reducing risk and crisis. We strive for excellence with agreed standards and outcomes.

Our Open Door series of resources has been developed to acknowledge the challenges of living with a neurological condition that is misunderstood, subject to media-driven or political myths and is neither prevalent nor the focus of publicity campaigns. The following stories are all real life narratives of experiences of adults with or parent caregivers supporting people with a neurodevelopmental disability.

We have adopted fictional names to protect their identities.

NEURO KEY

April 2021

Neville's Story

Everything I have experienced in life so far has made me who I am today. It has shaped my neurological disorders and created some mental health issues. Being diagnosed late in life left me trying to understand and cope with these strange behaviours alone.

In my mid 20's, I saw a talk show about Tourette's. I recognised many of my tics but instantly went into denial and felt ashamed of my weakness. I look back now and remember that on the outside, I was this confident strong person, in control with a smile on my face yet, on the inside I was like the picture of the scream by Edvard Munch.

Living with Tourette's syndrome, ADHD, ASD and PTSD is no easy task

I had a lot to learn about myself and the impact I have on the world around me. Living with Tourette's syndrome, ADHD, ASD and PTSD is no easy task and they sometimes work together to create something unique but, they also fight for control of my mind.

Childhood and Education

Growing up in the 70's and 80's, my conditions were not really heard of and children like me were often accused of being naughty, defiant, criminal, idiotic, strange, bullying and called names by the teachers such as 'class clown', 'village idiot', 'mindless fool'. I could create an awfully long list of the names and titles I have been given over the years. For the first ten years I was fighting a battle on two fronts.

At home I had a very violent and abusive father. My conditions brought more attention on me than my siblings so I had to learn very quickly to mask, suppress and hide these strange

noises and outbursts the best I could, I was not always successful.

At school, teachers took an immediate dislike to me, I could not stop shouting out in class, I found it difficult to sit still, I was distracted by other pupils around me and struggled to sit near them. Teachers could not

to understand why I could excel one minute and struggle the next and some days I did not engage at all. No matter how many times I was punished for breaking rules it was not long before I forgot about the punishments and broke the same rules again and again. These two battles started me on the road of suppression, masking and hiding my conditions and started my life of exclusion. At school, I was often put in isolation and when I was allowed in the classroom, I had to sit alone in the corner facing away from the other pupils.

At home, I spent a lot of time alone in my room and after a beating I would spend a lot of time in bed waiting to see if the second or third beating was going to come. I was belted, punched and kicked so many times that I built up an almost superhuman tolerance to violence and pain.

As well as the physical abuse, my father was a master of mental cruelty and control and this had its own long lasting issues that would leave me vulnerable in close relationships for many years to come. I spent a lot of time curled up with my dog in her wicker basket, there seemed to be something safe and comforting there. Regular beatings and sexual abuse at home, hatred from teachers, isolation, name calling and constant punishments at school eventually became normality while all the time living with ADHD and suppressing tics left me feeling like a freak.

Around my 10th birthday my father left and took the danger and fear with him. My home was now a safe place to live and my tics hit the roof. I was very ashamed and embarrassed about these tics and the one place they could not happen

These two battles started me on the road of suppression, masking and hiding my conditions

was in school, I could not face any more bullying from teachers and pupils. Secondary school was far worse than primary, the hatred I received from some of the teachers was on another level and this made life hell. The isolation and punishments became worse. I spent more time stood in the corridors than I did in the classrooms. School trips I had to stand with teachers while others ran free, I was banned from school discos and other events arranged at the school. There was an incident when a teacher assaulted me because of my eye tics, which she misunderstood. As I passed the school that night something snapped and I smashed a window in anger, the stress relief I got from this pushed me to smash many more. I admitted what I had done the next day and surprisingly, the Deputy Head seemed to understand.

Not all teachers were bad to me. My French teacher was amazing, he was wacky and zany, very energetic but also took no messing about in his class. The best thing about him was he did not have any favourites but also did not dislike anyone either, even if you were like me. This teacher took my French mock exams from below 50% up to around 90%. I finally escaped school in 1989 with 7 GCSE's, not bad considering my last year was spent bunking off most days to play pool in the morning then going to school for dinner and some afternoon lessons.

Adulthood and work

I joined the army right from school and went into the Junior Leaders Infantry. I always wanted to be a soldier and that is all I planned for. At first things went well then, the tics became an issue along with my short attention span. I also got into a few fights and found myself outside the guard house most days waiting for a blasting by the regimental police. I had swapped teachers and corridors for the Regimental Police and the guard house.

I had swapped teachers and corridors for the Regimental Police and the guard house

There was something else affecting me during this time, now know it was PTSD. My father was in the forces when I was born and looking back, I can see how the smell of boot polish and the uniforms among other things were strong triggers. I was living in a world full of triggers and they brought my career to an end in a matter of months.

I was living in a world full of triggers

Some traits of my conditions would lead me down a very rocky path, lack of fear, disregard for danger and inability to keep to the rules which slowly disappear overtime, these traits would be seen as natural talents to some unscrupulous people.

Although I managed to stay in some form of employment, I also made extra money using my 'natural talents' and it was not long before I was working the doors and doing security which led to evictions and debt collecting, not in the legal way more like something you see in a Tarantino movie, my associates were like characters from the movies. It would not be unusual for me to be woken in the early hours to either be at a major deal or in a property removing multiple people with force. In my mind the people on the other end of my activity were criminals and had chosen to be involved in this dangerous world. Being threatened with knives, machetes and guns became normal and I thrived on it, I needed the adrenalin. I look back now and see how I was used. It is not difficult to coerce someone who is looking to fit in and is eager to please especially when they have specific learning disabilities.

It is not difficult to coerce someone who is looking to fit in and is eager to please

Relationships

I was married at 18 and spent 14 years in an abusive relationship where I suffered physical and mental abuse.

My second marriage turned my life around

found I could communicate with people with ADHD, autism and other disabilities, I still had no diagnosis but had realised the tics were down to Tourette's syndrome but I was still in denial masking, suppressing and hiding my disorders.

My marriage ended badly and in true fashion, my wife, the abuser blamed me the victim and I found myself in court accused of being the abuser. I was judged on being a large male who could not possibly have been a victim of a slim lady, so I must be the abuser. Eventually I received an apology from the police over the phone when, for some reason, my ex-wife admitted to lying. My second marriage turned my life around. I had met someone I could trust and talk to. I was still trying to hide my conditions though. Hiding the conditions took a toll on our relationship and I eventually opened up to my wife after finally talking to my GP and we began to work on things with more understanding of each other.

Diagnosis Journey

After my diagnosis of Tourette's from a neurologist I was left to find my own specialist, after two neuropsychiatrists, I found my messiah. From my first appointment, her understanding and manner was amazing, the doctor patient relationship meant

I would prefer more than 30 minutes a year of support

remarkably similar so on that front for now things are good

Halfway through my marriage I turned my life around, moved away from the criminal fraternity. I began my new life working with people like myself and

the world to me. If I got no answer to my problems, at least got understanding and that was worth its weight in gold. Sadly, she moved on and my life took a dive without her support. I eventually found another specialist who is

although I would prefer more than 30 minutes a year of support. During my diagnosis journey which started in my mid 30's I have been referred to mental health services

many times and sadly been refused help and support each time. Apparently, I just do not fit in or they do not have a department relevant for me. Although my diagnosis improved relationships and understanding with friends and family it did not have the same impact at work, within 6 months I found myself unemployed and the treatment I received from my employer left me unemployable and at an all-time low.

Finding support from others was helpful but it was also a minefield of bullying and jealousy with circling narcissistic predators. I am an Ambassador for a Charity and offer peer support work voluntarily which allows me to manage my time, so I do not overload myself. Being involved in my community in some way raises my spirits, gives me self-esteem and a feeling of purpose.

By this time, I had my diagnosis of ADHD and sensory processing disorder which were very obvious. A few years later would come my high functioning autism diagnosis, which was much more noticeable to others than me. I found a support group where I fitted perfectly, I describe this moment as finding my lost tribe. I have learned many techniques to live with my conditions and I am working to undo the extreme suppressing and masking that cause a lot of anxiety and stress. I talk to students at a local University in the School of Health Department to help educate our future professionals. Day to day for me now is carefully planned around my many triggers and issues. I need strict routines and spend a lot of time waiting for my brain to decide to work. Journeys are planned around toilets for IBS and transport must be safe for my tics and intrusive thoughts, which can be particularly hazardous. I have carried out dangerous obsessions on many occasions and came to harm and near death many times.

I describe this moment as finding my lost tribe

I honestly believe if I die before my time it will down to an obsessive action.

In the home, my wife has hidden or removed many dangerous objects that I obsess about. All electrical items with motors are standing on foam to reduce noise for my sensory issues. My wife as my carer, has many techniques to help me cope with change, avoid danger and find things that are either right in front of me or I have put in a very strange place. In

I must be careful because some music can raise my hyperactivity and the elation can bring on powerful tics

at home. Listening to music is a great mood enhancer although I must be careful because some music can raise my hyperactivity and the elation can bring on powerful tics and this can be disastrous in a public place.

The gym is probably the most essential coping strategy and since the day I walked into a gym at 14 years old I have not missed many weeks in 34 years. As well as the neurological and mental health issues I live with daily, there are a few physical issues as well. Being so heavily focused on my mental and neurological disorders, I often dismiss or put aside any physical issues that come along. In recent years this has come back to bite me. The anxiety and stress caused by my conditions have had a profound effect on my cardiac health. Looking back, the way I dealt with my prolapse disc was not ideal and treated it on the same level as a broken fingernail until it literally stopped me in my tracks. Because

social settings, my family have become experienced in explaining that I am not being offensive, it's either a tic or just the logical, blank unemotional way I communicate. My coping strategies seem to be mainly creative.

Photography helps me focus while out and about and gives me a methodical process, pictures to edit

of my childhood, I have always just accepted pain as something you get used to in time. The way I process it, there is so much infighting between my neurological and mental health disorders there is little time and headspace left to attend to physical conditions that come long.

The associated pain from tics are different altogether because a physical tic can cause pain and the pain sets off the tic more, this then spirals out of control. Eye tics can become so frequent that I cannot see, and the pain is excruciating, neck tics have damaged the vertebrae in my neck and cause a lot of pain in the muscles. Having an above average, high pain threshold has advantages but also means you are not treated for the correct level of pain. With physical conditions, I will tell my specialist once and then not mention it again, this gives a false impression that the issue has gone when in fact it's still there or maybe worse. I think this was ingrained in me as a child not to complain or moan about such things.

Even with all the understanding and knowledge my family and friends have, they still get annoyed and upset with me on occasions and I still get accused of hiding behind my conditions or using them as an excuse. It can be quite lonely when you are the only one like yourself. I have often found myself surrounded by family and friends but felt quite alone.

The anxiety and stress caused by my conditions have had a profound effect on my cardiac health

this was ingrained in me as a child not to complain or moan about such things

It would be impossible to write down everything I live with and the things I have learned without writing a book, so I have done

I have often found myself surrounded by family and friends but felt quite alone

the next best thing to reflect and make sense of my life and published a webpage with insight, occurrences and even a diary from my school days to maybe help others make sense of their world.

Where am I now?

I have an amazing wife, 8 brilliant children between us, 7 grandchildren and counting. I have lots of support within my family as well as some awesome friends dotted around the UK.

From being encouraged and mentored by a local Charity, I not only was invited to become a Trustee, but am a volunteer peer supporter for people with a range of neurodevelopment conditions, an advocate for parents struggling to keep neuro-diverse teenagers functioning in school and recently became a Neurodiversity Community Ambassador for another local organisation offering on-line peer support. All of which has a very positive impact on my life. I have developed a role in education and I am now an expert by experience at two Universities where I am involved with Psychology, Occupational therapy, Nursing and any other departments that asks for my input.

I have developed a role in education and I am now an expert by experience

Although I only receive one 30-minute clinic appointment a year for my conditions, the Neurologist I see has a great understanding and the relationship means the world to me. Engaging with some other projects

was a massive step forward dealing with a part of my life I had been keeping locked away. I became a member of the Armed Forces Bikers Charity who are like a second family with no judgments and lots of understanding and support if needed. Not only do I look at the impact the world has on me but the impact I have on the world around me.

Recently I have started online studies and already completed University run courses in ADHD, Autism, PTSD, Psychological first aid, Trauma, Anxiety And depression and have many more lined up. I have a thirst for knowledge about myself and others with disabilities as well as 'neuro-typical' or non-autistic people.

Marie's Story

6.45am

My day starts.

My hubby is in from working his nightshift as a welder. He's tired and wakes me so he can get the dog downstairs for breakfast. I'm exhausted and in a great deal of pain. My

When both boys were adopted as babies, we were not told there could be any problems ahead

youngest lad is 18 year old and lives with us. We manage Autistic Spectrum Disorder (ASD), learning disability and developmental coordination disorder. He suffers terrible night terrors due to the childhood trauma he suffered when my older son who has Foetal Alcohol Spectrum

Disorder (FASD), Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), learning difficulties and attachment disorder, was going through puberty and his early teenage years.

The eldest lad had to leave us on a section 20 when he was 15 years old. We couldn't keep him safe anymore in the community and he was a huge safe guarding risk for his younger brother. We were not given a choice and he left on his brother's 13th birthday. Both boys were traumatised but the youngest is now under the Learning Disability team for his

anxiety and night terrors.

When both boys were adopted as babies, we were not told there could be any problems ahead, although years later we found the information on pre-adoption records.

My lad has not hurt me in last night's terrors, he seldom does, just screaming and shouting. I don't like it when hubby

I need to get my painkillers, blood pressure medication, asthma inhaler and epilepsy medication as soon as I get up

is working nights, as our lad weighs 17 stone. We had to seek help from our GP as twice he has hurt me in his sleep, once trying to choke me against the bathroom wall. He has also hurt himself going down the stairs head first trying to get away from whoever was chasing him.

I need to get my painkillers, blood pressure medication, asthma inhaler and epilepsy medication as soon as I get up. I'm currently avoiding surgery to remove my damaged bladder as it's too hard to be away from home but I can't take my prescribed morphine as the hubby is on permanent nights.

8.30am

I phone the GP for an appointment for me as I think I have a bladder infection with worsening pain.

9.01am

The eldest lad messages

me to say he is up. I am his appointee and legal friend as he lacks capacity according to doctors' assessments in these areas. He asked for his weekly pocket money last night which is a day early, he doesn't normally get it until the weekly cleaner I have organised has finished today. He has done as promised and messaged to prove he is up in time for the cleaner. He is not allowed to live with us as he has been arrested for wanting to kill me and is generally too unstable and aggressive to live with his brother and our family. I have got him a lovely little flat near to us and his grandparents. However, he remains very vulnerable, the community police, who we are told to liaise with, have no knowledge of FASD and don't really know what to do to support him. This is his third independent flat I have sourced since his section 20 finished at age 18 and he came from being looked after in a 2 to 1 setting in the countryside, directly into supported independent living in our town centre. He failed terribly in all areas as we expected and predicted, having FASD and he was evicted into homelessness. He had to move in crisis from

He is not allowed to live with us as he has been arrested for wanting to kill me

both previous independent flats as he had become a target in the community and under police advice and support because of his vulnerabilities. I had to source new accommodation for him.

I know when the eldest lad goes quiet he is not good. He stops answering the phone, replying to texts, won't let the cleaner or anybody into the flat, even refuses meals and shopping. Then he starts phoning me, screaming abuse and threats, posts on Facebook that he is going to hurt himself. He sends me photos of the blood streaming down his arms, all superficial cuts but lots of them. He cuts from wrist to elbow inside and out of both arms, his thighs, stomach, face and neck. At this point I phone crisis team, it's not safe for me to go to him. Next he tells me outright or posts on Facebook a picture of the tablets he has stored and is going to overdose on or a noose. He generally overdoses. In May last year he overdosed 5 times. I phone 999 they arrange police and ambulance. Sometimes the Police have to break the door down as he doesn't answer. I don't know if it's too late until we get inside. Only once has he been found unconscious from hanging, it was very close, he won't go to hospital unless I go too. We wait in a room on our own beside nurse station, I get constant abuse until eventually he tells me what's wrong and then he calms, I give him his prescribed diazepam (I'm only allowed give him his prescribed diazepam

He failed terribly in all areas as we expected and predicted, having FASD

and antidepressants every 2 days as he overdoses) but he can't seem to calm until he is in a hospital. We need a solution if possible or a distraction to what he couldn't sort out in his head. Generally it's a girlfriend, friend, a drug debt, or being bullied in the community. The longest he goes without this sort of episode has been in his new flat and been 4 or 5 weeks. In the last flat it was weekly. Nobody got in his flat for two months, there were 50 + safe guarding referrals made by police in the year before he moved into his new flat in 2020. He has had 3

or 4 since moving, one for attempted hanging and the others for being vulnerable and self-harming.

Hubby has been to the bank last night and the £150 I need to pay workmen replacing our eldest lad's broken doors tomorrow is on kitchen table. He had argued with this former girlfriend last week and two doors were pulled off the hinges, she was very unstable and he's been calm since they split.

10.20am

Doctor phoned. I've got an appointment for 4pm.

Youngest lad wants to bake today and make lasagne.

11am

He is still tired when I get him up.

My mums' hospital phone, they plan to discharge her on Monday, all her extra care is in place. We haven't seen her for 15 months. I feel awful but because of responsibilities to our sons, it is not easy to get away then we have Covid-19 restrictions to take into account. Our youngest helps me with housework and prep for baking first then cooking. I've had 3mls of morphine so coping OK. I really want to talk to doctor about our lad's new worry. He woke last week with a steak knife beside him and is now worried he is going to kill me in his sleep. Hubby now hides knives before he goes to work. Our lad would never hurt me, he's not aggressive awake, but he is asleep and he often doesn't know who I am, so it makes sense to be vigilant. I don't want him getting wrapped up in this, not making a big deal of it.

11.55am

Eldest lad's cleaner telephoned concerned he wasn't engaging with her at all, appeared to be stoned. Fun and

He woke last week with a steak knife beside him and is now worried he is going to kill me in his sleep

Cannabis and FASD do not mix well

games later for us when that wears off and the paranoia and anger sets in. Cannabis and FASD do not mix well.

12.48pm

The Mental Health team phone to confirm assessment appointment for eldest tomorrow. They could rearrange for next week but I said that is not going to be easy for him. On Tuesday, he must talk to a judge on a conference call with me as his advocate, his solicitor and barrister. I'm not expecting next week to be good, asked for the appointment to be made the week after. I had no idea he had appointment, letters are supposed to come to my address as he will not open a letter.

Our eldest was imprisoned for 3 days accused of stalking two girls. But, the girls had made a fake account with his photo and name and had stalked themselves. This was only realised after he had spent those 3 days on remand. The girls did

not know he was in prison and continued to pretend that he was stalking them on-line. He was released quickly but only after several internal searches for a phone. He also says he was sexually assaulted on remand. Police have accepted liability and offered a settlement. He had a proper capacity assessment late last year and was deemed to have

I had no idea he had appointment, letters are supposed to come to my address as he will not open a letter

no capacity to manage finances by a psychiatrist. I can apply for power of attorney. I don't really want to, I feel I would be really controlling him but I am worried about his pay out by the police as he is so vulnerable. But the solicitor and I have gotten him to agree to save the bulk of it.

Next week, we see if the judge accepts the amount offered on his behalf.

13.05pm

We are making lasagne and planning cup cakes with our lad. We are going to watch a movie after. He is brilliant playing guitar and despite his disabilities has achieved a diploma in music, with the help of an Educational Health Care plan (EHC) and a private tutor. The EHC are normally applied for through the schools Special Education Needs Coordinator (SENCO) and we applied jointly for his. They are very hard to get and make a massive difference to the support given in education. He would never have gotten his diploma without it. He doesn't have private music lessons today so a movie will occupy him.

14.00pm

Hubby gets up, he drives over to check on our eldest and pick up his laundry. He makes sure the lasagne is OK for his tea later tonight. He also sees what shopping he needs. Hubby shops for our eldest twice a week for snacks but we cook his tea every night and drop it off when hubby goes to work. Our eldest can't cook for himself. He had malnutrition when he tried supported living. He lost 6 stone. He doesn't see the need to eat or put food in to the fridge and eat within date.

He doesn't see the need to eat or put food in to the fridge and eat within date

14.10pm

Mam phoned, worried she won't be allowed out of the home as she is in a lot of pain. I feel helpless and useless for her.

14.20pm

Well, wasn't long after that our eldest lad telephoned looking for his dad. Just got paid yesterday and now wants a few cans, obviously not for him. I have not applied for power of attorney through the legal system. I only hold a position of appointee by an assessment carried out by the DWP who assessed him to have no capacity to manage his money.

How do you keep a man safe when he does not see danger?

So even though I make sure all of his bills are paid through direct debit mainly and I pay for all his shopping/ cleaner/ household needs, legally I am not allowed to refuse him his money. So after everything is paid I split up what's left and he gets that money, £80 every Tuesday. It pays for his cigarettes/ supposed to be entertainment and going out, drinks/ meals but generally it all goes on cannabis/ green. He normally owes every penny out to a dealer. So when he asks for cans of beer I know they aren't for him as he doesn't really drink, he normally swaps them for cigarettes or a joint. I allow £20 a week for these 'extras' or a takeaway. I finished the baking then hubby dropped our eldest lad's shopping off then came back for me to go to the GP appointment.

16.00pm

My appointment with the doctor, he's ordered more tests. I broke down crying, he was lovely, he said the worries about our lads and chronic pain had me worn out.

17.35pm

Tea is over, I've had to go to bed, couldn't handle the pain. The eldest just phoned to make sure I had put his cakes in with his dinner. I have. Hubby watched an hour of soaps before going to work. The youngest lad and I had done the dishes before I came up to bed. Now, he is watching YouTube before going on the Xbox with his mate. It is very quiet and stable all round this evening. Hope his terrors stay away tonight. He usually comes off his Xbox game between 21.00 and 22.00 just to make sure the game isn't affecting his sleep.

20.30pm

My friend phones with concerns for our eldest. He calls her aunty and he is close to her. She tells me he has met a mum of two on a dating site. She has just gone home after a brief stay in a women's refuge because of her violent ex-partner.

She says her ex has now left the country and so now our eldest wants to go and stay in her house 20 miles away from home. He is extremely vulnerable.

How do you keep a man safe when he does not see danger?

I will phone the social worker in the morning and update her.

22.00pm

The youngest lad goes to bed. He likes to watch a movie with me sometimes before he goes to bed.

22.15pm

I vomit my night pills, mixture of being ill and worries. I still feel ashamed I cried to the doctor today. I've been diagnosed with depression, anxiety and PTSD due to parenting my boys and poor input of services. I can't get any treatment as they say it would be like treating a soldier in a battlefield. The Carer's centre used to phone me weekly but have stopped in this second lockdown.

I can't get any treatment as they say it would be like treating a soldier in a battlefield.

1.35am

I am woken by the lad's screams, the terrors begin.

3.40am

I am still awake. Lad has had two more terrors but is settled now. The pain is keeping me awake.

This has been the last 24 hours in my life but it has been quiet. When my eldest is quiet we are all happy but very often he is not. Living with FASD, he can't emotionally regulate or problem solve, which of course affects him daily to one extent or another. Ignorance has been our biggest problem in every service from the beginning. The Adoption service should have provided the full pre-adoption medical history and we could have had an earlier diagnosis which would have

changed everything. After adoption again through ignorance, we were pointed in the wrong direction, attachment issues was all they could see. When referred to social services they concentrated on building a team around him. Nothing happened.

They never looked at FASD, only ASD and only after spending months on attachment disorder whilst our lad went quickly into crisis. Eventually after he drove his head through a glass window to get out to the boys who were setting him on fire and smearing him in dog poo, but he considered his best

Not one CPN, psychologist, psychiatrist, police officer or mental health professional I have dealt with had training in FASD

friend's, safe guarding issued us with a choice of letting him go on a section 20 or they would take our youngest to safeguard him. Our lad is sent to a totally inappropriate care home and as a result ended up so vulnerable he was sent much further away on a 2:1 setting costing over £5,300 weekly and we could visit only once a week. Hubby had a breakdown and was off sick for 3 months.

At present all 4 of us are using services and our lad is going to be looked after for two more years at a cost to the Local Authority. My health is deteriorating rapidly. I am now under heart/neurologist/urologists/mental health. My epilepsy is uncontrolled due to stress, blood pressure and angina. I am diagnosed with PTSD and our youngest is having counselling plus diagnosed with ASD and learning disability.

The Police are always out looking for our eldest as he absconds daily. Our eldest has lost all chance of any education but carers still try to get him to training I have sourced with virtual schools. My family has been a complete drain on services. I have campaigned and gone to stage-3 complaint in the Local Authority, which was upheld. All I asked for was training on

FASD to be offered to all social workers. We now have a clinic in our city diagnosing the high number of referrals coming in who now recognise FASD traits through training. Not one CPN, psychologist, psychiatrist, police officer or mental health professional I have dealt with had training in FASD.

Annually, over 5,000 children are adopted in the UK. The massive majority of these children have been removed from birth parents due to drug or alcohol abuse. That means each of those families could end up in our circumstances, it's a massive drain on services and funding.

Mark and Dan's Story

We were fortunate that becoming parents was joyous. Then the sense of responsibility dawned and we had set off on the voyage of parenthood with all its ups and downs. Reflecting now, the end game for any parent is to do their best to nurture their child so that s/he will be well prepared to cope with whatever life may bring their way.

Those working with Dan would need to adapt to meet his needs

Dan is our youngest. He was fostered with our family when he was 7 months and we later adopted him. At birth, the professionals involved with his family were mental health workers.

Social workers became involved when his birth mother was hospitalised.

From the earliest days, it was known that there was a possibility that storm clouds would gather for him as both of his biological parents lived with schizophrenia. There is also documentary evidence that there was another potential storm cloud. It was hovering over Dan the moment he was born. It is recorded that Dan's birth mother had a 'long-standing problem with alcohol abuse'.

Dan's life began to unravel very soon after he started his secondary education. After a couple of years trying to weather the storm as a family unit, we approached the Post Adoption Service in our Local Authority. Their work soon began to investigate the possibility of Dan being in the prodromal stage of developing schizophrenia. The other focus was the possibility of attachment issues. We were familiar with both of these conditions. It was decided that Dan was not experiencing psychosis, so the focus remained on Attachment. Both my wife and I had been taught Bowlby's theory of attachment in the 1970s. That was a long time ago, so it was 'back to school' to relearn and find out how things had moved on. We were fortunate because our Adoption Social Worker shared our view that while some aspects of Dan's life made sense viewed through the lens of attachment, there were other aspects that were not a good fit at all.

One specific additional piece of the jigsaw was that Dan's vocabulary could very easily mask his verbal comprehension and thought processing difficulties. Those working with Dan would need to adapt to meet his needs.

The most important comment by the Clinical Psychologist was that he felt everyone should consider the possibility of Foetal Alcohol Syndrome (FAS). Not one professional who has worked with Dan since that date has shown any evidence that the significance of this comment was understood. In all of the documentation we have kept, the only person to mention FAS in a meeting with professionals was me. We exclude our Adoption Social Worker from this comment about lack of response, as within a week or so responsibility for managing Dan's case was transferred to another team.

We carried on our research, while still trying to support Dan whose life was as chaotic and unpredictable as ever. Everything came together when, in 2016, we had a telephone consultation with the Doctor. He told us that Dan should

He is now on a waiting list, the assessment may identify other comorbidities

be fully assessed for FASD. We feel that Dan is living with Alcohol Related Neurodevelopmental Disorder (ARND) with a comorbidity of Autistic Spectrum Disorder (ASD). He is now on a waiting list, the assessment may identify other comorbidities. If FASD is not confirmed it will be back to the drawing board. That is the historical context for Dan today.

The spectre of FASD was there at his birth, but came into the light when he was 16.

Although professionals failed to recognise the significance of Pre-Natal Alcohol Exposure (PAE) and its lifelong consequences, there were plans and attempts to put things in place for Dan to transfer seamlessly from adolescent support networks to adult support networks. In reality no plans have borne any fruit to help Dan. This continues to blight Dan's life and our lives as a family.

I want to focus on four issues around this transition to adulthood, and how this means the 'system' continues to fail him.

1. Chronological Age

Dan's first psychological assessment identified that he was functioning at a level about 7 years below his chronological age. Nothing had changed 18 months later. We have now learned that as a rough rule of thumb, someone living with FASD will be functioning at an age level of 50% of their chronological age. For us that means in reality, Dan is still living life as a teenager and it is far from clear that Probation (the only agency currently involved with Dan) has grasped this.

2. CAMHS to Adult Services

All the talk about this when Dan was in his late teens hit a buffer very quickly. The referral was made and for several months there was no response. When chased up the reply was curt and brutal, 'Dan does not meet the criteria'.

we were having a conversation through a closed door

More recently we approached Adult Services to see if this was still a dead end. If you think of a door opening, it is wide open when it

reached 90°. There was an interest in what we are saying, an acknowledgement that in terms of FASD, our knowledge is greater and perhaps a willingness to learn. But the door is firmly closed, so using the analogy of the door we were having a conversation through a closed door. We were told that even if they accepted what we are saying, that would not happen without a diagnosis.

3. Probation

Some years ago, we attended a meeting convened by Dan's Probation Officer. This Officer made a statement, which was subsequently recorded verbatim in the minutes of the meeting, which we have;

'I began by clarifying I did not have permission from Dan to share information with his family. However, given the index of his offences, his previous history of aggression at times to his family and their safety I felt it was important to share information with them, to give advice and to share planning so that they can take the necessary steps to protect themselves and support Dan not to re-offend and to take up meaningful activity.'

This led to a period when we were able to work with Probation and play a part in supporting Dan. We weren't told everything but our contribution was valued to a certain extent. Dan had avoided

The very limited communication we have received from Probation rings loud alarm bells

a custodial sentence on the understanding that he would accept a placement at a local Project in our county. That placement broke down, he was living in a flat and that situation deteriorated. Working with Probation, we were able to get Dan to agree to return to the Project. In the last 12 months, Dan was preparing for early release on licence and a new Probation Officer was allocated. Dan was released but things broke down, a pattern we have seen for the past 10 years and he has been recalled.

The new Probation Officer has taken the polar opposite view about how information sharing is managed appropriately. We are now persona non grata. We have written to Probation about the change in their position, which has been ignored completely. We can see no reason, why an explanation could not be given.

Where on the spectrum of thought is their reason for refusing to talk with us? Do they consider us to be unfit parents? Or do they consider Dan to be a fully competent adult? Without any communication it is hugely frustrating. We have no way of knowing if we have a comparable understanding of Dan's needs and whether we are working separately but in parallel or in opposition. We are currently in deadlock, knowing that all we have learned about FASD, a collaborative approach

is an essential element to any support. The Adult Services person did tell us that Probation had made no contact with them as of last autumn. Our view is that Probation is taking the high-handed arrogant position of 'we know best', which we believe will fail Dan.

4. Understanding of FASD

We have no evidence that Probation have any understanding of FASD. There is nothing to prevent them from talking to us about our understanding of the condition. We have appealed to them to consider the 'evidential' approach to supporting Dan, because that is the kind of approach that is understood within the Criminal Justice System. No response. The very limited communication we have received from Probation rings loud alarm bells suggesting their level of understanding is poor. They were very surprised that we thought Dan was impulsive. They 'would not advise Dan to breach the conditions of his licence'. They have read the reports we sent them and take them seriously. We have asked Dan for permission to speak with you and he said 'no'.

Competency or capacity

The whole of Dan's life has included various expressions of paranoia and hypervigilance, too many to list. The one I will mention relates to a conversation about a letter he had sent to his birth mother and not getting a reply. The significant element of this out-of-the-blue conversation was that I told Dan I knew how to contact his birth mother and would find out what had happened for him. At the end I said I could let her know how he was. In a flash the response was 'NO'. This

the struggle he has with cause and effect thinking, abstract concepts and planning

is Dan's default position and it is linked in our view to the struggle he has with cause and effect thinking, abstract concepts and planning.

We are also aware of conversations or thoughts coming from those within the Criminal Justice

System (CJS) in North America about someone with FASD being 'fit to enter a plea'. Those conversations appear to reflect on vulnerability being suggestible, wanting to please and how that relates to capacity within the CJS. We are also aware of the question of Fluctuating Capacity. We recently read an article in Community Care that considered that the term 'material time' in the context of the Mental Capacity Act 2005 is often misunderstood. This rang true for us. The person who completed the Vineland Adaptive Behaviour Assessment for Dan went on to give some support to professionals about how to adapt their way of working with him. Central to this advice was not to ask questions that could be answered with either yes or no. If you ask Dan 'Do you understand what I have said', he will say 'yes'. His verbal reasoning and thought processing struggles in conjunction with other executive brain deficits, makes it questionable whether he understands at the time and/or can go on to reflect and make appropriate choices.

a Probation Service that refuses to enter into any meaningful communication with us

These areas are interconnected and complex. They are not helped by having a Probation Service that refuses to enter into any meaningful communication with us. At one stage, when Dan was in Prison, we tried to have a conversation with their 'health care' about FASD and this was not acted upon, another dead end. Speaking with an NHS Trust and a CCG, the aim of these contacts was to discuss their plans for an FASD pathway. The Hospital suggested we contact a young man living with a diagnosis of FASD. The CCG only sent an automated reply from their Corporate Services.

As a family we have experienced 2 avoidable and tragic unexpected deaths of young people. One was murdered by a serial killer and the other died as a result of a catastrophic head injury sustained during a fight. We are also very aware of the links between drug misuse and premature death.

Against this background, we read the abstract of research assessing the average life expectancy of someone with FASD at 34 equating to 42% of the life expectancy in the general population. We have

the best response we get is a mumbled word of sympathy

shared the anxieties and concerns this evokes for us with professionals and the best response we get is a mumbled word of sympathy.

In conclusion, we have very good documented evidence that confirms FASD must be considered as providing an understanding of life through Dan's eyes. It also offers hope for him and insight into how professionals can adjust and accommodate his needs and make their work more effective. The Doctor's expertise and opinion confirms this.

We have not mentioned finances and accommodation here. We know Dan is entitled to benefits, but experience tells us that navigating the DWP system is something Dan will not manage. We could act as advocates, but getting his consent is unlikely. We have chosen for the time being to continue to be bank of Mum and Dad. Our only involvement

At the centre of this is a person who is struggling and who is 'falling through the cracks'

in accommodation was when Probation allowed Dan to 'sleep rough' on a cold November night, seemingly in breach of his licence. He made contact and we found him a room in a local hotel.

We are still hitting our heads against a brick wall as Dan approaches his

28th birthday. Is it a lack of curiosity and a lifelong learning, is it the lack of space and opportunity to look outside of a 'speciality' to the insights from other sources, is it sheer exhaustion from caseload pressures and the need to keep their heads above water?

At the centre of this is a person who is struggling and who is 'falling through the cracks'. From the realisation about life expectancy, we have a sense of urgency which makes our levels of frustration and anger so great. Whatever happens next, we love Dan dearly. We will support him to the best of our ability.

Anna and Neil's Story

Since Neil's birth he has faced a variety of health issues, physically, mentally and emotionally. The problems started with lactose intolerance, rhinitis, asthma and jaundice. We had weekly visits to the hospital to deal with one problem or another, thankfully this began to ease off by the time he was 18 months old, but he began to show experience strong allergies

he couldn't stand the vibration of the clippers and the feeling of hair touching his skin

to almost everything he encountered and his anxiety about things was begging to show. By the time he was 2 years old his constant fear and behaviours began to show a lot more.

Neil could not be left alone for any length of time as he would begin to scream and could not sleep alone as he would wake up multiple times during the night hysterical.

It was obvious Neil's development was delayed and a health visitor spotted early signs of autism and separation anxiety disorder. Feeding was exceedingly difficult as Neil would not entertain many foods and even for food he would eat, he obsessed and it had to be separated on his plate so each item did not touch each other. Neil wouldn't touch many liquids and would not allow anybody to touch his hair making it impossible to get it cut. I will never forget the first time we tried, his entire body shook and he screamed, he couldn't stand the vibration of the clippers and the feeling of hair touching his skin. Looking back, I now know this is down to his sensory issues.

During this time, I had another child, Rees, brother to Neil. Aged 3, Neil was a little better coping with sensory issues mainly because we had learned what triggered him and how to avoid too much sensory input. It was at this time he went through a smearing stage and we found faeces smeared on his bedroom wall multiple times. Although this was a short stage it was very alarming and concerning but helped confirm my thinking that this was autism. We enrolled Neil into nursery, but this caused many physical issues related

to the stress and anxiety of change and being left. While at nursery, he trapped his thumb causing a wound that required surgery and developed sepsis, this only added to his anxiety. Neil also had multiple bouts of tonsillitis resulting in a tonsillectomy.

At 4 years old, he was still in nappies due to developmental issues and he began to suffer bullying at school because he was different to the other children. Having no friends and poor social skills, Neil was attacked by other children multiple times resulting in serious injuries. His eardrum was perforated after a pupil pushed a pencil into his ear, his hands were stamped on resulting in a broken finger and he was punched in the face resulting in massive swelling and excessive bleeding. Each assault resulted in hospital treatment and was very traumatising for Neil and the family. During my final meeting with the school Head teacher she admitted to failing to keep my son safe, she also said they thought Neil has autism and other learning difficulties, but they don't have the amenities to help him. She recommended I should look to move him to a school that provide for his needs.

It took many complaints and even police intervention before I was able to move him to a better suited school. There was an immediate change for the better in the new school. He seemed a much happier and healthier boy in a school that now provides for his needs. This school is not classed as a special education school but has an excellent track record for dealing with children with learning disability and many parents have chosen this school for that reason.

During this period, Neil, Rees and I had to flee to a women's shelter to escape domestic abuse from their father. Although I did everything possible to protect and shield the children during this time it has had a profound effect on Neil. His father had initial contact but after meeting a new partner and starting another family he lost interest in Neil and this has affected him badly. Luckily my new partner has become a great role model for my two boys. Neil's confidence has grown since he came into our lives and totally transformed us as a family, making us a stronger unit.

It took many complaints and even police intervention before I was able to move him

Having a diagnosis for autism, dyspraxia and developmental delay, Neil and I can get the help, understanding and support needed to assist him. He now has a Special Educational Need plan and SEN inclusion and a support worker. He is aged 6 now and is improving immensely with the help and support we receive.

Routine was very hard at first as things can be so unpredictable. Neil has a strict daily routine with no changes unless absolutely necessary and it takes much planning and plenty of notice for him. He 'stims' constantly, repeating physical movements, makes sounds or obsessively moving

He is very sensitive and gets emotional very easily

objects which is prevalent in autistic people. This becomes even worse when he is emotional whether through happiness or stress. Neil takes everything literally. He is very sensitive and gets emotional very easily, often resulting in meltdowns or tantrums because he is on overload. Still extremely sensitive about his skin and often scratches until it bleeds. He sleeps with a weighted blanket and in the same position each night.

Neil has a lot of accidents due to his dyspraxia and needs a lot of help getting dressed and maintaining his appearance too. He is an extremely sensitive and anxious boy but to me he is just Neil, my loving son. Talking to his teachers at school, I've realised how different he is to the other children in his age group.

Rees has ADHD and is very hyperactive and 'in your face'. Neil loves his brother and they play a lot, but Rees can also be too much for Neil's sensory issues. I found it hard at first when the word autism was mentioned as Neil was just Neil to me.

Talking to my Dad who has a diagnosis of Tourette syndrome, ADHD and high functioning autism is a great help. My Dad helps me see things from an autistic point of view and talks to Neil and helps him learn to understand himself. He also guides me with my ADHD and Rees with his. I've come to learn from this that people with the same disabilities have a level of understanding for each other and that is worth its weight in gold.

Having a child with autism is never easy, there are so many obstacles to deal with and everyday can be different. Things can change suddenly and cause stressful situations. I have ADHD and I struggle

with change so I feel I can

relate to both boys in different ways, Rees with his outbursts and Neil with his routines and the emotionally support. Neil loves to have his one on one time with his grandad and nanny.

Overall, I find living with a child with autism is no different to me as he is all I know, my perfect little boy.

Things can change suddenly and cause stressful situations

Collette's story

After falling pregnant at the age of 42 with child number 5, I was happy but concerned due to my age. I loved being pregnant. It was an ok pregnancy but lots of heartburn in the last 3 months and yes, the old wives tales are true, my baby had a ridiculous amount of hair! A planned c section at 39 weeks and he arrived at a very cuddly and chunky 10lbs. Gorgeous. But, he looked very different to my 4 other children. Fairly soon, I realised he was different but couldn't put my finger on it. He fed constantly and breastfeeding alone wasn't enough. He never slept and hated being cuddled or swaddled. This was hard. He was very vocal early on too and very sensitive to noise. He didn't really crawl but from being young would pull up on furniture and loved music and dancing. At 9 months in church wearing his pyjamas, he just got up and ran up and down the aisle during Mass. This was the start of an awful time with people at 3 different Churches. It was clear we weren't welcome. We no longer go to church.

Early signs of obsessions were appearing at this time

As a toddler he was extremely challenging, very noisy, he told me at age 2 he liked his noise, was very demand avoidant and was not driven by rewards at all. Punishment was confusing for him. He was harder work than my 4 other children put together. By the time he was 2, I was at breaking point, no support from his dad or any support network. I went to the GP and begged for help so we were referred to Child and Adolescent Mental Health Services (CAMHS) and Sure Start. I had mixed feelings about this but was willing to try anything. Sure Start offered us a place at a nursery which was a godsend. Again they felt he was different but were impressed with his memory and singing and dancing skills. Early signs of obsessions were appearing at this time particularly around the boy band Take That.

Aged 3, we had a school afternoon nursery place. This didn't work at all as he never slept and was exhausted. We continued with the Sure Start place and waited for a school morning nursery place. CAMHS were gathering information

at this point but were inconclusive so they sent me on a parenting course.

He had problems with school nursery but they refused to communicate effectively with me. He was very bright and they didn't acknowledge this.

He was teaching himself to read but they wouldn't let him have a book. We used to go to the library but we weren't welcome there either due to him being noisy and extremely active. He escaped from nursery into reception class and sat with his brother. I wasn't informed I only knew because my other son told me. CAMHS were still assessing him looking at Autism or ADHD. The challenging, aggressive and impulsive behaviour continued to strengthen. School were denying issues but I knew they were struggling from other parents.

Then the discrimination started. My child would be the one to not get party invites even though the class children liked him, the parents didn't. I was informed by his reception teacher that 2 parents had complained about him and requested he was moved classes. This continued throughout primary school.

The Year 1 teacher was the Special Needs Coordinator (SENCO) but again she also denied any issues and called him quirky. I found this extremely offensive. Throughout each primary year the issues escalated with school still insisting there were no issues. I was made aware that my child was being made to sit in the corridor every day. When I questioned this, it was denied again until I got other children to tell me in front of staff. So then apparently it was due to him distracting other pupils and was seen as bad behaviour. Again, effective communication was not happening.

In Year 2, we were given a diagnosis of Autistic Spectrum Disorder (ASD) which the school refused to accept along with a thorough Occupational Therapy assessment with recommendations which the school refused to implement.

I was made aware that my child was being made to sit in the corridor every day

Despite my regular requests for support it was never there, even small adjustments would have made life a bit easier. A short while after, CAMHS took the diagnosis away and decided it was a parenting issue and sent me on another parenting course.

CAMHS took the diagnosis away and decided it was a parenting issue

I requested my son had 1-1 supervision which didn't happen. This resulted in an incident which led to him being excluded, even though his actions were out of his control. CAMHS were still involved but remained inconclusive. It was decided again, a parenting problem as my child was 'out of control', so..... another parenting course for me. There were no problems with my other 4 children. I just wasn't being listened to.

I just wasn't being listened to

The situation was toxic for the other children too. I opted to change primary school after this incident. It was a good move, smaller school so a lot less sensory overload for him with smaller classes. He did well there, the school had an SEN unit and even though he wasn't in the unit, the staff had a little more understanding. He achieved top marks in his KS2 SATs. Just one term into Year 6, we got a diagnosis of Tourette's syndrome. It was both a shock and a relief. But he still had a teacher question the diagnosis.

The domestic abuse has led to a diagnosis of PTSD.

By Year 5, things really accelerated at school. His anxiety was through the roof which brought more challenging behavior but for him, the behavior is a way of communicating. It came to a peak at a school football tournament where

In Year 5 the dad left the family home. This was a relief as there was domestic abuse towards me and my youngest son.

I approached secondary school before applying for a place at the same school that my 4 other children had attended. I suggested he may need an Education Health Care (EHC) plan. I was told that school would make that decision. When informed of my sons conditions I was greeted with a sharp intake of breath and was told that a previous pupil with Tourette's had been removed from the school due to behavior issues. I pointed out that even just having Tourette's brings behavioral issues as does the many comorbid conditions that come with Tourette's. I guess with hindsight I should've taken more notice of this reaction.

My son's time at school has been horrendous. He's in year 10 and I'm still not being listened to. A SENCO who is dismissive, ill-informed but who should be part of the solution is a big part of the problem. She makes decisions about my son based only on her opinion, not skill and no actual facts or consultation with me. Everything with my son is still classed as bad behavior with constant punishments and consequences. My son now has significant mental health problems. Anxiety is constantly through the roof. This has a massive impact on our home life. My other son and I at home are classed as being at risk. He is extremely violent and challenging every day. He has become extremely demand avoidant even though I try to keep demands to a minimum. He doesn't understand the reasoning.

My mental and physical health has been affected too. It's still been classed as a parenting problem and 3 years ago I was

The domestic abuse has led to a diagnosis of PTSD

I wish others could see this side of him and build on it

put on yet another course by a social worker. This was a disastrous relationship. She was young and inexperienced, extremely judgmental and unprofessional. She was no help whatsoever. She just didn't listen to me or my other children. She was only interested in ticking boxes.

My son is gifted in many ways - sports, music, performing arts, singing and dancing. I wish others could see this side of him and build on it. He is a superb competitive swimmer and an excellent cricketer. But even with sports we've had serious issues with other parents including bullying and discrimination. To the point where he no longer wanted to take part and wanted to end his life at age 13.

However, he was given a detention the day of his operation

This is when the self-harming began.

The School teachers still won't make reasonable adjustments for him despite my all too frequent requests. Interestingly,

when he was on crutches after an operation they made adjustments for him. There's the difference between visible/invisible disabilities. However, he was given a detention the day of his operation. The school has continued to be a problem during the Covid-19 lockdown even when I explained yet again, the issues for my son. He sees things very black and white - school is school, home is home and the two don't mix. He was even given a detention when he was isolating at home, how on earth was that supposed to work and who exactly was supposed to benefit? Besides, he does not respond to punishment but they just will not understand.

We're still under CAMHS as I do feel there's still more diagnosing to be done. This is just not bad behaviour. Professionals dismiss parents when they should be listening.

Input from my son," My disability is part of me and should be understood and acknowledged and not punished. I should be listened to more, nobody listens and that makes me angry. I try so hard and it goes unnoticed ".

What else can any of us say to that?

Learning Outcomes

| | Be able to; | Relevant for |
|---|--|---|
| 1 | Demonstrate a multi-disciplinary approach to design a care pathway for someone with a neurodevelopmental condition | NHS personnel Social Workers Education Criminal Justice System Mental Health teams |
| 2 | Value the insights of parent or kinship caregivers and their lived experience | NHS personnel Social Workers Education Criminal Justice System Mental Health teams |
| 3 | Critically evaluate a suicide prevention policy and provide accountability | NHS personnel Social Workers Education Criminal Justice System Mental Health teams |
| 4 | Offer parent/kinship caregivers psychological or other therapeutic support | Mental Health teams Occupational and Vocational Therapists Social Workers Voluntary sector |
| 5 | Manage a non-judgmental approach to assessment of presentations | NHS personnel Social Workers Education Criminal Justice System Mental Health teams |
| 6 | Identify emergency situations and assess risk of harm on support plans | NHS personnel Social Workers Education Criminal Justice System Mental Health teams |
| 7 | Establish condition-specific awareness training | Education Mental Health teams Social Workers Criminal Justice System |
| 8 | Deliver accountable, timely, appropriate communications for parent or kinship caregivers | NHS personnel Social Workers Education Criminal Justice System Mental Health teams |

What can we learn from these narratives?

How can services respond more appropriately?

Are the needs of parent carers taken into account?

THE NEURODEVELOPMENTAL ICEBERG

Easily distracted

Restless

Disorganised

1/8th the tip of developmental delay

Impulsive

Autism

Attention Deficit Hyperactivity Disorder (ADHD)

Learning disability

Foetal Alcohol Spectrum Disorder (FASD)

Defiance Disorder

Obsessive Compulsive Disorder

Tourette's

Instruction processing

Vulnerable to manipulation, substance abuse or crime

Planning ahead

7/8th of managing daily life hidden below the surface

Concentration

Susceptible to anxiety and depression

Misinterpreted as non-compliant in a system of rewards and punishment

Decision making

Retention, memory recall

Sensitivity to sensory input

Impaired neuro-transmitters

Cause and consequence thinking

Impact can be mild, moderate or severe, incurable and for life

PRESENTATIONS OF NEURODEVELOPMENTAL CONDITIONS

You can change the environment, you cannot change the person

Presentations explained

| Presentation | What this means | Development age of an 18 year old adult |
|--|---|---|
| Cause and consequence thinking | Impulsive, emotional, poor comprehension of meaning or impact of behavior on self and others | 7 year old |
| Concentration | Easily distracted and confused under pressure, propensity to obsessions | 8 year old |
| Decision-making | Difficulty understanding or following concept of rules, past experiences/lessons | 11 year old |
| Learning Disability | Levels of presenting behaviors can be mild, moderate or severe | 6 - 16 year old |
| Impaired neuro-transmitters | The neural pathways for thought processing are weak or damaged | 6 - 16 year old |
| Instruction processing | Delayed processing speed to instructions, cannot draw a relationship between words and actions | 8 year old |
| Planning ahead | Unable to reach idea of goal setting or completion of tasks | 8 year old |
| Retention memory recall | Struggles with short and long term memory recollection | 6 year old |
| Sensitivity to sensory input | Extremes of sensations about light, sound, clothing or food | 6 year old |
| Susceptible to anxiety and depression | Reduced emotional maturity, can be violence or trauma informed | 11 year old |
| Misinterpreted as non-compliant in a system of rewards and punishment | Do not understand what is expected or meaning of 'misbehavior', pronounced flight or fight response | 7 year old |
| Vulnerable to manipulation, substance abuse or crime | Low self-esteem, trusting, poor understanding of difference between being liked and being used, poor judgment or common sense | 7 year old |

Acknowledgements

The Neurodevelopmental Conditions addition to our Open Door series aims to bring a sense of real daily life to underpin organisational, national and local commissioning strategies to recognise services should be needs led, not expect a person with a neurodevelopmental condition to be 'treated' and change. With a tenable skill vacuum in Education, Health, Mental Health, Social Care and Criminal Justice

services about the range of neurodevelopmental disorders, parent caregivers feel isolated from the advice, guidance, information and support they need.

We are grateful for the collaboration with our participants who present incredibly powerful stories. We hope these narratives can provide inspiration to improve professional skill and raise the profile of un-met need to the wider community.

Further information available from

FASD Network UK

Newtown Centre
123 Durham Rd
Stockton-on-Tees
TS19 0DE
E: fasdnetwork@mail.com
W: www.fasdnetwork.org
Twitter: FASDNETUK
T: 07743 380163



Daisy Chain

Calf Fallow Farm
Calf Fallow Lane
Norton
Stockton-on-Tees
TS20 1PF
E: info@daisychainproject.co.uk
W: www.daisychainproject.co.uk
T: 01642 531248



Autism Matters

57-59 Mandale Road
Thornaby
Stockton-on-Tees
TS16 7AE
E: info@autism-matters.co.uk
W: www.autism-matters.co.uk
T: 01642 601262



Tees Valley Buddies

On-line resource
E: teesvalleybuddies@gmail.com
Facebook: /TeesValleyBuddies
Twitter: Twitter @TeesVbuddies



Main Project

16 High Force Road
Riverside Park
Middlesbrough
TS2 1RH
E: info@iammain.org.uk
W: www.iammain.org.uk
T: 01642 608012



Disability North

The Dene Centre
Castles Farm Rd
South Gosforth
Newcastle upon Tyne NE3 1PH
E: reception@disabilitynorth.org.uk
W: www.disabilitynorth.org.uk
T: 0191 284 0480



NEURO KEY

An Alliance supporting people with neurological conditions

Our Open Door series is collectively created to share our expertise and ultimately, benefit the whole neuro community. However, we need to sustain this Charity. If this resource has been useful for you, we would appreciate a donation to help keep the work going.

Scan the QR code with a smartphone and go to the donation page on our website.



Neuro Key

St Mary's Centre
Corporation Road
Middlesbrough
TS1 3DW

E: admin@na-tvdny.org.uk

W: www.na-tvdny.org.uk

Twitter: @NA-TVDNY

T: 01642 641825

Tees Valley Durham and North
Yorkshire Neurological Alliance
Registered Charity No: 1119043

Design by www.nickballdesign.co.uk

