

Supporting Neurodivergent Children and Young People and their Families

28th November 2023 @ Shrewsbury Town Football Club

Plan for the day:

9.30am – 10am – sign in and refreshments

10am – 10.20am - Welcome to the event – outline of the agenda, aim of the day -Sarah Thomas and Sharon Graham

SLIDE 1 & 2

Housekeeping

Thank you for joining us to day. The opportunity for us to come together has been funded by the Shropshire, Telford and Wrekin Autism in Schools Project, which you will hear more about later. While the Autism in Schools project started with a focus specifically on those with Autism only, the learning from the project is applicable to all those who are neuro divergent, including those living with a Learning disability, ADHD or any neurological difference and who find themselves often at odds with how the rest of society generally operate. The key message for today is that neurological difference is real, it brings benefits and

challenges and the degree to which this happens is dependent on how those who might be classed as neuro typical, decide to understand and respond to this difference.

This morning's session will explore the current culture around responding to neurological difference and how this needs to improve. We will be starting by looking at the lives of those with a neurological difference and their families, listening to their perspective and considering what works or doesn't work based on their experience.

This will be followed by thinking about 'behaviour', how we respond to both the action and the word, what it means or doesn't mean and how changing the culture and language around this one word could make a huge difference to the experience of those living with a neurological difference.

After lunch we will share information about the local support system, what is in place to support those with a neurological difference and what might need to be done differently.

SLIDE 3

Before we start our first presentation, we want you to consider a job advert which we recently saw on Social Media for a role in Shropshire.

“Currently seeking experienced Support Workers to join a community based residential home specialising in the care of adults of with severe learning disabilities and associated challenging behaviour.”

We are not going to discuss this advert further at the moment, but there is a copy of it on each table and we would like to come back to it at the end of the day to hear your thoughts on it.

10.20am – 11am – The Family perspective – sharing the experience of parenting or living with Neurodivergence – PACC

SLIDE 4

Introduce PACC

SLIDE 5

Living with a neurological difference, either as a neuro divergent individual or as a family member of that individual can be difficult, as well as at times being amazing. For those parent carers supporting neuro divergent children and young people life will include;

- An overwhelming sense of love and pride
- A fierce need to protect

- An overwhelming sense of fear, particularly about the future
- A sense of guilt and failure
- A sense of loss and isolation

Balancing this wide range of emotions on a daily basis, alongside learning about a new and in most cases, an unexpected way of living, is a huge task for parent carers and there is increasing research about the impact of this.

SLIDE 6

On the Cerebra website they talk about loneliness and parent carer mental health and state.....

<https://cerebra.org.uk/research/loneliness-and-parent-carer-mental-health/> - 'social isolation is commonly reported by parents of disabled children. It is therefore unsurprising that even before Covid a survey by Contact suggested that '72% of families with disabled children experience mental ill health such as anxiety, depression or breakdown due to isolation'

Some parent carers talk about losing friends who fail to 'get' their life or their child. If family, or others close to us, don't provide the quality of relationship we need this can be upsetting.

“One of the hardest things is lack of family support... it’s quite isolating from that perspective” – Parent Carer

SLIDE 7

The report referred to on the Cerebra website was Contact’s ‘Forgotten Families’ report

https://contact.org.uk/wp-content/uploads/2021/03/forgotten_isolation_report.pdf

In addition to

- 72% experience mental ill health such as anxiety, depression or breakdown due to isolation

It’s key finding were;

- almost half (49%) have felt so unwell that they asked their GP for medication or have seen a counsellor
- 57% say lack of support means they are isolated and not able to work as much as they would like
- 1 in 5 (21%) say that isolation has led to the break up of their family life.

A practitioner recently talked to me about parent carers not interacting in a very positive way with their

team – I pointed out that families who support disabled children have one of the highest rates of relationship breakdowns, suggesting that at times we find it equally as difficult to be as nice to each other!

SLIDE 8

The impact of Covid has only worsened this experience, as the findings from the Disabled Children's Partnership report 'Then There was Silence' showed.

<https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/09/Then-There-Was-Silence-Briefing-for-Policy-Makers.pdf>

This report highlight;

- A deterioration in the mental health and wellbeing of SEND families, along with a reduction in services

Within this context it isn't surprising that parent carers can sometimes be seen as difficult to work with. When learning anything new we all will at times make mistakes and get things wrong, but in by far the majority of cases parent carers are just trying to support their child the best they can in difficult circumstances.

Unfortunately we too frequently see these challenging situations translating into parent carers being in conflict with a system which is meant to be there to support them.

SLIDE 9

At one level this is because the system itself has become part of the problem. A few years ago in 2016, PACC carried out a research project on the impact on parent carers of supporting a child or young person who was a multiple service user. The resulting report was called 'Exploring the Reality' and is available on the PACC website

<http://www.paccshropshire.org.uk/content/uploads/files/PACC%20Exploring%20the%20Reality%20Report.pdf>

This research evidence a number of issues that impact the parent carer / practitioner relationship, issues that have continue to be raised through subsequent PACC reports including;

- Developing Neuro-developmental and LD Pathways in the Shropshire EHWS – March 2018
- State of SEND Shropshire Report – 2020
- Autism in Schools Report - Shropshire 2021

- Mad Sad Glad Report 2022
- PFA Navigator Year 1 Summary Report 2023

Parent carers told us that the system is not joined up and communication between different parts of the system is poor. Parent carers are often required to repeatedly re tell their story, yet despite this they report that opportunities are missed, issues are left to grow, and they are left feeling that they have to reach crisis point before help is forth coming. They have to maintain relationships and communication with significant numbers of different teams, each looking at a slightly different part of their lives. Managing this spiders web of interactions is exhausting. We know that this issue has been recognised by system leaders and work is happening to try to address this.

SLIDE 10

Perhaps more worrying is the reported concerns about a system in which parent carers feel too many practitioners do not have an informed understanding of their lives and that there is a lack of empathy in interactions.

The Exploring the Reality report talks about how families felt they were often not listened too and were

judged, not only by wider society but also by the system they come to for help.

“One of the more distressing aspects of the accounts is the number of times parents feel that they are not believed by the professionals. They want professionals to “witness” their child’s behaviour; they feel they have to “convince” professionals that they need help and that they are judged. Often they state they are not “listened to”. So parent carers are not just set aside from other parents and subject to discrimination from the ‘outside’ (neuro-typical) world, but they also feel they are then subjected to judgement within the system that should be there to support them. This feeling of being judged inevitably impacts on their self-image and at times makes them feel belittled, and, at other times, combatant.”

This area of concern continues to typify the feedback PACC receives from parent carers but perhaps more worrying is that wider feedback from neurodivergent children and young people suggests that they equally feel undervalued, and mis understood.

SLIDE 11

Being Neuro divergent can mean many different things but what neurodivergent children and young people

consistently tell us is that being different and struggling to understand the world around them is hard work and exhausting.

There are rules they don't understand, noises that hurt, things that make them feel scared and unsafe and create emotions that are overwhelming.

Insert quotes from 'Is This Autism? – A Guide for Clinicians and Everyone Else'

“Sometimes the social rules at play in a situation allows for – even positively encourages – interrupting; it’s seen as making for a lively, interesting discussions. And other times interrupting is unbearably rude. And I have never figured out how to tell which set of rules is in play”

“I get triggered when I am in a waiting room and a TV or radio is playing. I’m not sure where my reaction comes from, but when it goes on too long, I start crying and/or get angry.”

Dealing with a daily assault on your senses, worrying about how to behave, behaving differently to others and people not understanding your needs, makes life challenging, and in this context, it is also not surprising

that some children and young people may become distressed.

So we have distress parent carers and distress children and young people, and it is at this point that families will come to the system for help.

SLIDE 12

What PACC has learnt from the first year of our Preparation for Adulthood Navigator project this is when families need to be listened to and their challenges understood more than anything else. It is our experience that when a parent carer goes to the system for help, they are not looking for a 'Golden Ticket' or an easy ride, or something for nothing, they are struggling and need to know that they are not alone.

They are likely to have been struggling for some time, they will have talked to family and friends, searched the internet, read books and spent hours on social media groups, to try to understand what they are doing wrong. They will have changed routines, put in place boundaries, removed boundaries, bribed, begged and cried, but eventually they will have admitted defeat and asked for help.

At this point they are desperate just to be listened too, for somebody to say 'we understand, we are here, and we will walk this journey with you'. That is what we think today is about.

SLIDE 13

Back in 2016 when we were writing up the findings from the 'Exploring the Reality' research we asked ourselves how we wanted it to be different and came up with the vision you can see here.

Reflecting on that work 7 years on, I think this vision still stands and if we can achieve that that equal partnership between parent carers, neurodivergent children and young people and the system all our lives, ours and yours, will be improved.

SLIDE 14

Thank you and questions/reflections

11am – 12pm – Understanding Behaviour as Communication and Positive Behaviour Support – distressed behaviour rather than challenging behaviour – not a quick fix, quality of life, understanding what works or doesn't work for the young person, focus on prevention. (Diane/ Steve / Josh)

Lunch

12.45pm – 3.30pm – How can the system work together to deliver effective support

15 minutes per topic we cant go into lots of details but can raise awareness and provide links to where people can find more information.

- Autism in Schools – the role and impact of the school environment (ST) 30 minutes
- EHCPs and Annual Reviews – developing an holistic approach (SG) 30minutes
- STOMP / STAMP – Using medication appropriately (ST) – 20 minutes
- Dynamic Support Register and Care, Education and Treatment Review (inc Keyworking and Intensive Support Team) – when things become difficult – 20 minutes
- UPP & Healthy Lives Programme – creating a community (PACC) – 20 minutes

2.45pm – 3.15pm – reflections on what you have heard, how will it impact your practice, what changes would you like to see in the system to support this?

3.15 – 3.30pm – Feedback and close