



SHROPSHIRE
Parent
And
Carer
Council



Supporting Neurodivergent Children and Young People and their Families

DECEMBER 2023

Information & Support, Influence & Change

Plan for the Day

- ▶ **9.30am – 10am – sign in and refreshments**
- ▶ **10am – 10.20am - Welcome** - Sarah Thomas (PACC) and Sharon Graham (Designated Social Care Officer (DSCO) for SEND, Disabled Children's Team, Shropshire Council)
- ▶ **10.20am – 11am – The Family perspective – sharing the experience of parenting or living with Neurodivergence** – Sarah Thomas (PACC)
- ▶ **11am – 12pm – Understanding Behaviour as Communication and Positive Behaviour Support** - Dr Steven Farmer (DClinPsy Senior Clinical Psychologist, BeeU Mental Health Service, Children & Young People's Learning Disability Team)
- ▶ **Lunch**
- ▶ **12.45pm – 3.30pm – How can the system work together to deliver effective support**
 - Autism in Schools** – the role and impact of the school environment – Sarah Thomas (PACC) & Ali Bellaby (Headteacher – The Keystone Academy - Youth Engagement Schools Trust)
 - EHCs and Annual Reviews** – developing an holistic approach – Sharon Graham (Designated Social Care Officer (DSCO) for SEND, Disabled Children's Team, Shropshire Council)
 - STOMP / STAMP** – Using medication appropriately – Diane Turner (Dr Diane Turner (Clinical Psychologist, Clinical Lead for BeeU Learning Disability & BeeU Intensive Support Teams)
 - Dynamic Support Register and Care, Education and Treatment Reviews** (inc Keyworking and Intensive Support Team) – Joshua Kernohan (Intensive Support Team, MPFT)
 - UPP & Healthy Lives Programme** – Creating a Community – Sarah Thomas (PACC)
- ▶ **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**



“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.”

The Family perspective
– sharing the
experience of
parenting or living with
Neurodivergence.

Shropshire PACC - An
experienced led
organisation

Three work area;

- ▶ Influence and
Change
- ▶ Community Support
- ▶ Information Provision

[www.paccshropshire.org
.uk](http://www.paccshropshire.org.uk)





The Family Perspective – sharing the experience of parenting or living with Neurodivergence

Research

- ▶ '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'

<https://cerebra.org.uk/research/loneliness-and-parent-carer-mental-health/>

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

Forgotten Families – Contact Report

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

'Then There Was Silence'

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

"My daughter's mental health can be so bad, that she spends most of it in her room. A good day is if she comes out to use the toilet. So when she's like that I get into trouble for not taking her younger sibling to school. I can't leave her and they don't help me so either way I can't get it right."



'Exploring the Reality'

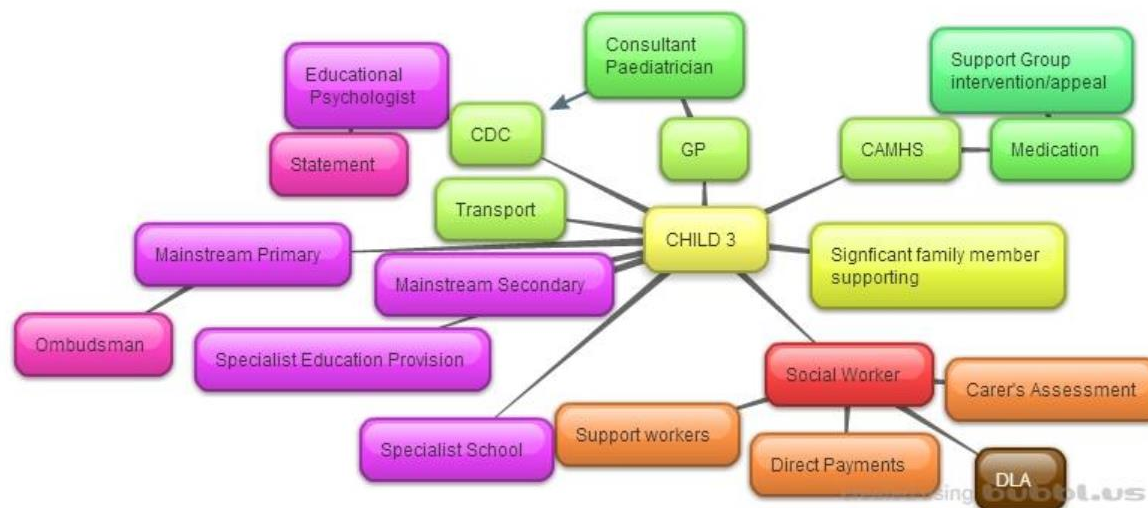


Figure 2 - Mind map of Child 3's services showing support systems around ASD

System's Lack of Understanding & Empathy

“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.”

Living with a Neurological Difference

When clear communication
isn't as clear as you think



www.autability.co.uk

- ▶ "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."

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

We need your help!



Exploring Reality Vision



“It is hoped that parent carers and professionals will work together to establish a common framework for partnership. The balance of power should be shifted from the caregiver (the professional) and the care receiver (service user) to a three-way partnership between parents, young person and professionals, where all parties are equally valued.”



THANK YOU!

Sarah Thomas
Participation Lead
PACC – [enquiries@paccshropshire .org.uk](mailto:enquiries@paccshropshire.org.uk)



Lunch Time

Tabletop discussion

- ▶ What can you do in your roles to support the PBS and Quality of Life approach we have discussed this morning
- ▶ What are the barriers?
- ▶ What needs to change?
- ▶ How can you influence this?