

Emotional Wellbeing and Mental Health Support for
Children and Young People
with Neurodevelopmental conditions

Parent carer consultation workshop

Monday 8th November 2021



Contents

Introduction	Page 2
Workshop structure	Page 3
Break out 1. Mapping parent carer experiences and gaps onto Thrive	Page 3
Feedback on Thrive model	Page 3
Summary	Page 4
Parent carer comments	Page 5
Breakout 2. Single Point of Access for EWB and MH	Page 15
Miro board comments	Page 15
Breakout room comments by area	Page 16
Appendix 1. Notes from main sessions	Page 18

Introduction

Parent carer forums hear repeatedly from their members about how hard it is for neurodiverse children and young people to access appropriate support for their emotional wellbeing and mental health. This has been highlighted by PaCC in a number of reports (2014, 2016 and 2019) based on feedback from parent carers about their own and their children’s mental health and wellbeing.

This was also highlighted in the [Sussex-wide Review of Emotional Health & Wellbeing Support for children and young people](#), *Foundations for our Future*, May 2020:

“We heard that particular groups of children and young people appear to be more affected by accessibility issues. This was especially the case for those who have an Autism Spectrum Condition.

We heard that these services are not currently adequate and that there was a lack of post-diagnostic support in Sussex which impacts on the accessibility of support.

We found that there is a waiting time for access to Neurodevelopmental assessment services.”

In recognition of this, and as part of a range of stakeholder engagements around implementation of the recommendations from the Foundations for our Futures report into EWB and MH support for children and young people, Brighton and Hove PaCC facilitated an online EWB and MH consultation workshop for parents and carers of neurodiverse children and young people. ESPCF, WSPCF and Amaze supported and helped to facilitate the workshop.

33 parent carers whose young people have accessed or needed emotional wellbeing and Mental Services attended. There were parent carers from across East and West Sussex and Brighton and Hove. A number of parent carer support group representatives also came, including Mascot, Tictock therapy and SEN Day by Day.

Professionals attending were:

Simone Button, Programme Director Foundations for Our Future

Kirstie Haines, Specialist Advisor, Sussex NHS Commissioners

Martin Komen, Responsible for commissioning mental health and emotional wellbeing services in East Sussex

Lizzie Izzard, Lizzie Izzard, Assistant Head of Mental Health Commissioning, Brighton and Hove CCG

Sally Kean, Children's Commissioning Manager and CETR co-ordinator for West Sussex

Beth Osborne: Project Manager for Foundations for our Future (FFOF), supporting Simone (FFOF Programme Director)

Workshop structure

As well as providing an opportunity for professionals to hear directly from parent carers about their experiences of provision for CYP with neurodevelopmental conditions, there were three main aims of the workshop:

1. Map ND parent carers' experiences onto Thrive framework and identify gaps
2. Gather parent carer views on a single point of access for EWB and MH
3. Parent carers to hear about current work across Sussex on EWB and MH, and neurodevelopmental pathway (see appendix 1).

Simone Button began the session with an overview of Foundations for our Future and the Thrive framework (minutes in Appendix 1), which was followed by two breakout sessions. At the end Kirstie Haines gave a summary of current work in Sussex on the neurodevelopmental pathway target operating model.

Breakout 1: Mapping parent carer experiences and gaps onto Thrive.

Breakout 2: Accessing mental health and wellbeing support and a Single point of access

Attendees also had the chance to add to a 'Miro board' to provide virtual post-its. Notes from the breakouts have been combined with the post-its under the 5 needs based thrive groups. The comments and quotes are grouped under specific themes that came up. Finally, a section on SPoA.

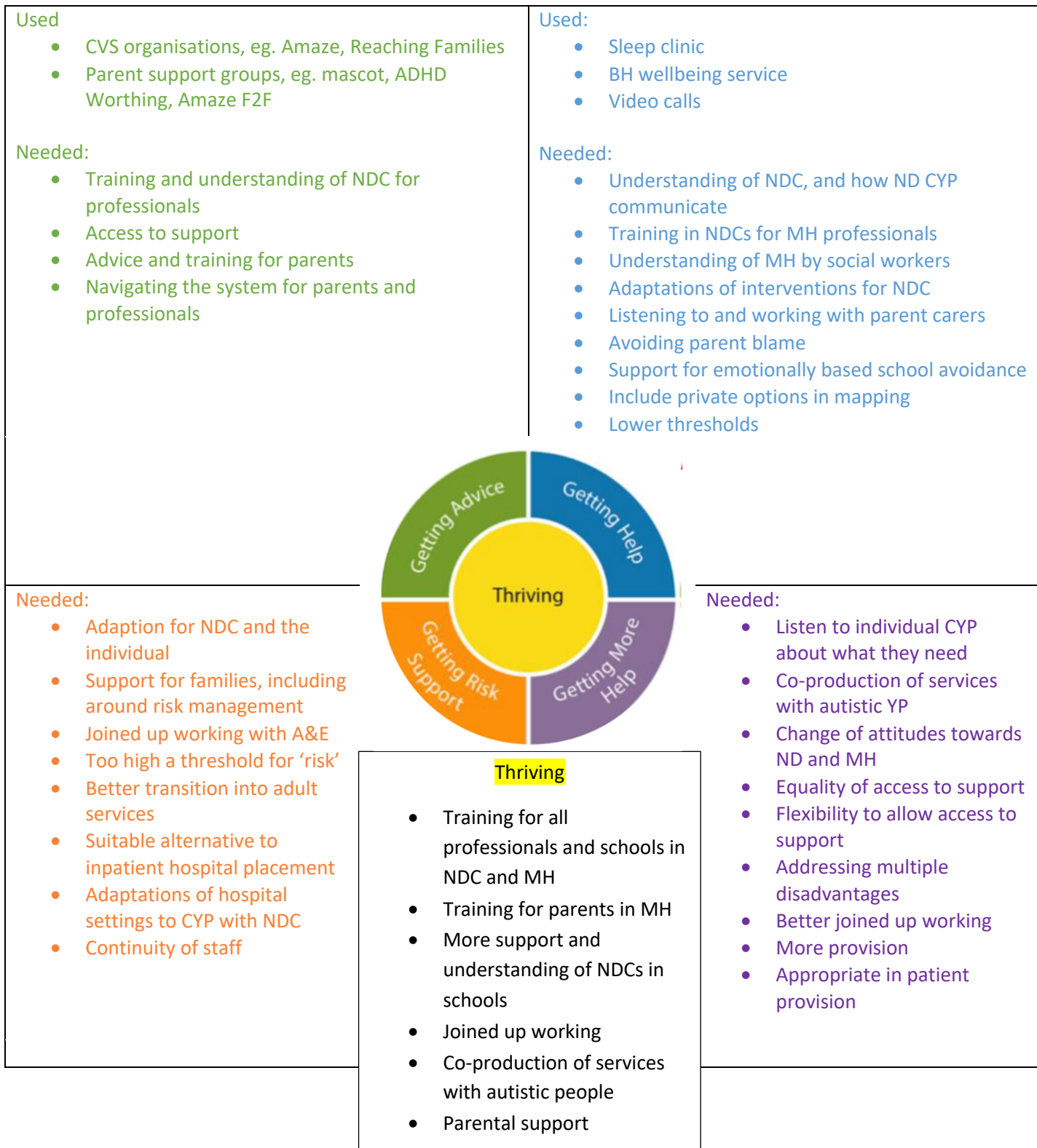
Break out 1. Mapping parent carer experiences and gaps onto Thrive

Feedback on thrive model

- Looks great, but on the ground, nothing is changing
- Seems like a logical framework
- Still got to get into it and have the services there
- Difficult to translate it into something practical

Summary of themes

This graphic is summary of the themes that emerged during the workshop, under each of the Thrive needs-based groupings. More detailed feedback, from the Miro board comments and breakout room feedback, is below.



Parent carer comments (Miro board and breakout rooms)



Getting Advice

What is used

- Families with CYP with NDC turn to Amaze - not using Local Offer (nothing on LO about Tourettes for instance)
- Amazing Futures groups and peer support
- Parent support groups e.g. Face to Face and ADHD Worthing - chatting to families in same situation is very powerful and reassuring
- Reaching Families info is good - factsheets, workshops, Facebook groups support

What would help

Understanding of ND

- GPs - lack of understanding, empathy, awareness of NDCs - they need to listen to CYP/family and take concerns seriously and not dismiss them. Also they need more training about what's out there
- Early Help teams - do not have specialist knowledge - and some families wary as nervous of social service team
- To have services which look at a young people with MH and ND conditions together and not separating this.

Access

- Co-morbidity of NDC and MH cannot exclude any CYP from accessing support
- Support that fits the child's needs, e.g. not just online provision as many children struggle with looking at a screen
- We found the barrier goes up as soon as ND diagnosis is mentioned, there's no help as soon as I say there's no mental health issue.
- Need specialist skilled staff

Advice and training

- Medication advice - potential medication is rarely discussed unless in crisis
- Triage advice line for parents at the early stages

- Self-help training and support on sensory needs - trauma-informed, collaborative parenting
- Parent courses
- Training for people in the place doing assessments etc for e.g. MH leads in schools. There are different training needs for different schools.

Understanding the system

- I have been in services for 8 years, across all tiers, but still don't know what actual support there is. It's questionable what help there is.
- Early intervention - but not sure what's available. Early intervention is a big gap. Where do we go with first concerns?
- The only referral/pathway I'm aware of is through CAMHS - but are there any other services that are supposed to support parents before that stage? What's supposed to happen and support children?

Other

- Over reliance on getting info out via Facebook which some families try to avoid as bad for MH
- Self-refer actually into support
- Professionals need better knowledge about what else is out there to support families and CYP needing MH support especially in the voluntary sector, support groups etc - develop a map of support/strategies?
- Really important that signposting isn't just through schools, but other settings as well.

West Sussex

- Gap in signposting currently in WSx - not clear where to go and what's available



Getting Help

What is used

- Sleep nurses works well (East Sussex)
- Video calls for son have worked well as appointments have been quicker and at short notice but easy to access without any prep or travel involved.
- BH wellbeing service – professionals not adapting

What would help

Understanding of ND and adaptations

- If early intervention professionals were very well versed in ND they would be able to make referrals for assessment much earlier
- All services need to adapt how they adjust to meet needs of CYP with ASC eg sending social story, video before-hand of what to expect and ask CYP to consider what they might like to say/ask when they arrive to help reduce anxiety
- ALL mental health professionals should have training in working with ND people. Eg CBT is often deemed 'unsuitable' for people with ASC. This isn't true, it just needs a bit of adaptation. We need to move away from the idea that professionals need to be 'specialists' to work with ND, because there are hardly any training routes to gain this specialism anyway.
- Engage young people according to their preference, fun, via games, supporting non-verbal, etc.
- Understanding that autistic people communicate, using different words and body language to communicate distress, is done in a different way but this does not mean it is any less real.
- Mental health professionals have no expertise or understanding of how those on the spectrum experience mental health difficulties or how to communicate with them about this.

Parent carers as a resource

- Parents need to be involved in treatment if needed. For ND people the standard model of client 121 with a therapist can be a real barrier to access.
- Parents are going through a grieving process of mourning the NT child they have been told they have had for so long then suddenly this all changes and they have to re get to know the person they really have. Professionals do not understand or support in this process.
- Parents are labelled as overprotective because their children's needs are not understood nor are they listened
- It's difficult to get anyone to listen, parents are blocked out and not seen as part of the solution. Parents know their children very well yet are not listened to.

School avoidance

- Emotionally-based school avoidance support, should be available early on, should be available for early intervention prevention ESBAS
- Kids on school refusal don't get support needed

Thresholds

- Thresholds for accessing services are too high to access them - as by the time you reach a threshold you're already in crisis.

- There is no provision for eating disorders unless people need hospitalisation. There should be specialist eating disorder services much earlier.

Other

- GPs are amazing but a crisis is looming. Move triage away from GPs
- Mapping needs to involve private options too (those using private free up services)
- Current administrative processes are highly inefficient
- Children in private schools need equal access to those in state schools
- Social workers do not understand about mental health
- Patient gas lighted by Psychologist being told she was not feeling what she was and she was fine. Despite multiple suicide attempts and struggling with self-esteem and social interactions.
- Counsellor to be based at the school and to understand different conditions
- Better communication

West Sussex specific

- Daughter told by YES service she was acting babyish and should stop it. Which is hardly good counselling practice
- YES team in WSx are thought to be good if you can get it, but there is an 8 month wait so it's too little too late. Support needs to be more timely
- YES do not understand those on ASC and won't support those who have active suicidal ideation.
- Aspens in WSx offers intensive 1:1 weekly sessions supporting CYP communications and strategies - but needs more capacity **NB. Some autistic people are concerned about Aspens due to use of ABA practitioners**



Getting More Help

What would help

Listening to ND CYP

- MH workers need to listen to CYP more and adapt their practice (which can be very inflexible) - need to better understand the needs of CYP
- CYP are not 'difficult to engage' or not engaging. Services are not flexible in how they engage. Stop blaming children in crisis when they are too distressed to access services.

- Making sure that professionals are co-designing support with autistic YP and adults who have lived experience of a variety of severity of mental health issues

Change of culture

- Change in perceptions and attitude - ASD related mental health is no less important than neurotypical MH

Access to support

- Every professional at CAMHS should be able to work with ND people. It's totally wrong that people are turned away due to their disability. It's surely illegal under the Equalities Act.
- People should be able to be seen in school not just in the evening. For a lot of people this means they won't access support.
- Having adaptive support with communication support available to speaking and non-speaking autistic people. For some young people an approach more similar to that of the learning disability teams may be more appropriate (even for those without a learning disability)
- For highly anxious children there needs to be greater flexibility as to how their support is provided
- My son has been denied support because of his ND condition even though it's possible his mental health need has nothing at all to do with his diagnosis.
- Community MH centre in Haywards Heath is not wheelchair accessible
- Help with rarer conditions needs to be readily available
- If thresholds are too rigid people get moved from one tier to another to fit into the framework even if that's not best for them. Sometimes it's better to retain continuity of professionals and for them to alter what they offer, not move the YP into a different service.
- Not able to access screening tools for anxiety
- Son very good at masking. Throughout all process feeling scared, helpless and isolating giving son 24 care and support whilst feeling isolated. Family also having to isolate and mask from outside world and community pretending all ok. Mum physically tired after dealing with all 3 areas of CAMHS and keep being told sons doing ok.-

Multiple disadvantage

- Worried about other families who are not able to fight so hard eg: EAL (English as additional language), no confidence and/or ND or health issues themselves.
- Son 14 coming from eastern family there are cultural differences as cannot discuss these issues in local community without fear of shame.
- Lots of barriers for accessibility – eg: EAL, cultural differences, ND parents.

Joined up working

- Need better communication between pros working with a CYP- so team working around the child

More provision

- CBT seen as fix all when only helps 50% of population. No other help available except talking therapies which are totally inappropriate for those who are non verbal some or all of the time
- Medication - why only an emergency option?
- None of our group have ever received a service but have battle for up to 10 years for it. So there are just not enough services available.
- We often have to wait until we can prove our children's suffering before getting help, instead of pre-empting it
- CAMHS - frustrating not able to access very limited support, high thresholds
- Choice of support

Education

- Lack of secondary and post 16 education provision for those on with mental health needs and or autism
- Unless issues are overt, the current default advice is "you won't reach the threshold for an EHCP"... it's like a filter, so only the people with the time and resources will try.

In patient experiences:

- Chalk Hill - struggled to even provide the food she could eat
- Chalkhill staff could not provide wheelchair for child who had trouble with moving because they were so undernourished.
- No meaningful risk assessment undertaken on leaving hospital and no support put in place to safeguard except 24x7 parental intervention
- Hospitalization under mental health act is inappropriate for those on the autistic spectrum yet there is no other options made available. - in patient



Getting Risk Support

What would help

Adaptations

- It's about an attitude of wanting to cater to those who are diverse rather than a one size fits all mentality
- Please can we ensure that services for young people are made suitable and accessible for ND people rather than always separating them out. Many issues are not about their diagnosis but are general things. So the general services need to be adapted to suit them.
- A one size fits all service mentality does not work with autistic people because they are all different and have varied needs

Support for families

- Parents need more support throughout but especially at crisis point. They are expected to get on with it and manage a mix of pros/services - would be helpful for them to have a named key worker to check in with them on weekly basis, also more respite
- Holistic needs of family incl siblings need to be considered and provided for
- Carers are undervalued in society which leads to them being ignored or side-lined. That the government only gives £250 a month to carers who are undertaking full time care shows how little they value the work done to support those who have big capabilities but are discriminated because they have some area they find more difficult.
- Social workers need to support the whole family not just one child with a diagnosis.

A&E services

- A&E - is not the solution anyone wants - they've not got the facilities to safeguard a child trying to commit suicide
- A&E departments need to share with schools wellbeing teams and other professionals if there has been an incident (eg overdose). Parent carers don't always share this info with all the people involved with the young person.

Risk management

- Risk management- the emphasis is on the parent/carer to manage risk is hugely stressful with very limited support - eg UHS visit once a week plus phone or text support.
- At this high level of risk and disengagement professionals need to be able to do home visits or go and collect people to take them to appointments.

Thresholds

- The thresholds for 'risk' are far too high. Parents of young people self-harming etc are told they are not 'high' enough risk, or cannot services as soon as the risk dips below a very high level. Young people get into a cycle where they escalate behaviour in order to be taken seriously.

Transition

- Having good care continuing into suitable adult services that can meet the needs of this population.
- Current **transition** arrangements produce a cliff edge for mental health services, there is no continuity of care nor expertise in adult mental health around autism

In-patient

- There does need to be a facility that provides high level of treatment and care for Autistic people to go to instead of hospital.
- A facility is needed for when UHS & CAMHS think admitting a child to Chalk Hill would create even more risk to the child. The current result is myself, parent was left on 24 hour watch for 3 years.
- Having suitable inpatient settings, as 25% of those on wards have ASC, but very few have any adaptations for understanding of what is needed in caring for and autistic YP

Other

- NO ABA/PBS
- The whole system works against parents trying to arrange long-term support for their child because social workers and health professionals change so frequently any positive relationships or trust are broken
- Section 117 poorly understood by mental health or social services. And these services do not work well together to provide a comprehensive care package or risk assessments

West Sussex

- Wsx education send provision is so underfunded it cannot meet its statutory duties to complete the paperwork for EHCPs



Thriving

What would help

- With neurodivergent children, it's looking at that prevention part - it about looking at the wider system. What can we change about the systems.

Provision

- None of this is worth anything if the support services aren't in place
- Having suitable and well organized support to help reduce anxiety and distress. having access to the right support and the right time to be able to access the things they need or want to
- A self-monitoring online child-friendly check-in tool

Training needs

- Training for profs, specialists, GPs, teachers should be compulsory - too many sessions not well attended
- Very little expertise or understanding of why those on the autistic spectrum will be more likely to have significant mental health difficulties. Thus no common understanding of what professionals should be looking out for
- Why aren't all parents offered training in supporting mental health of young people as part of what the school offers???
- Information to be available and taught for professionals and Children on differences and mental health/ well being

Schools

- It would be really useful if every school, primary, secondary and college, had an ASC teacher specialist full time, not someone who pops in once a term.
- There are ASD kids in every classroom. Why doesn't every teacher know how to support their MH needs?
- All teachers and children should be comprehensively taught about neurodiversity, and supporting neurodiverse peers, in schools
- Comms campaign with schools to build awareness of disabilities/MH conditions to build understanding and acceptance - schools to run workshops/assemblies
- PHSE curriculum could do much more to support young people with ND to know what to look out for or expect re mental health at different life stages eg, pre-puberty, exams, transitions into college or work etc.
- Teach all teachers and support staff about masking
- Focus on mental health in classrooms doesn't yet reflect the level of mental health issues in young people

Joined up working

- Lack of joined up thinking between services mean that child left in the middle with decisions about their care being made in a "smoky room" and horse trading between services. The focus becomes internal politics not the child.

Co-production with autistic people

- Experts by experience (not carers) should be consulted about future service provisions.
- Training must be designed and delivered collaboratively with autistic people so people can get a true sense of what these experiences look like rather than assumptions made from an outside view.

Other

- Use what works and don't re-invent the wheel. Facebook peer support groups are doing a good job. Courses from Yvonne Newbold are fantastic.

- If there is a crack between services it is certain that an autistic young person will find it
- Please don't forget about PDA (pathological demand avoidance) because the strategies parents are taught for ASC are unhelpful or even make things worse for PDA.
- Access to the TCAT would be helpful before hospitalised or institutionalised. With their expertise I'm sure they could be effective through maintaining wellbeing thorough effective prevention and promotion strategies.
- Things like "the exceptions panel" does not promote a sense of value for the young person and makes them feel un-valued or a burden. This does not help their self-esteem
- Support services are institutionally disablist and can see no value in those who are different
- More information about MH services including courses for parent carers, where to go, who to go to
- Parents to get support

West Sussex

- Autism in Schools (part of national pilot) in 21 WSx schools to be evaluated and rolled out

Breakout 2 Single Point of Access for EWB and MH

Below are the comments from the breakout rooms and miro board. The miro board comments are split into ND specific comments and general comments about a SPOA. Comments from the B&H and East Sussex breakout rooms are separated out below. NB. West Sussex comments were amalgamated into the Miro board comments, and so are included in this section.

Miro board comments

ND specific

- It's wrong that at the moment you can only be on one 'pathway' at a time, eg my child has ADHD and ASC and has to sit on a 2 yr list for his ADHD assessment before he's allowed to access ASC support
- Should offer web/text/email/phone access including self-referral by family but also include a physical hub that CYP can attend and feels safe in (sensory appropriate, familiar) accessible 24-7 in case of crisis
- Trauma and ND are often both present and also misdiagnosed so its key that social care is part of the SPOA for SEND support.
- Child development centre and CAMHS seem to pass children from one to another- perhaps due to resources? But this is very frustrating for parents and children trying to access help and assessment.
- Info, support and SPOA need to be delivered in a way which assumes that the carers are also neuro-diverse
- Networks where everyone understands ASC needs would be far stronger than having a single access point.

General

- Lack of joined up thinking will only lead to a single point of access as being the dumping ground for other professionals abdicating their own responsibilities to make reasonable adjustments.
- Single point of access mustn't cause a bottleneck
- Various professionals eg GPs will need to be well trained about new SPOA and how this links to other services e.g. to support physical health
- We can't assume that people will seek out the SPOA but there needs to be outreach work to take it to the communities and people who need it.
- I hope that the SPOA will have a pathway for 'those people who don't fit in to any of the pathways'. There will always be those who fall through and don't fit neatly into any service.
- One worry about SPOA is that if it goes wrong - reliant on only one place/person - it can go very wrong. Needs to be quality assurance built into system to monitor waiting times and quality of response and subsequent service/support offered and impact made

- SPOA needs to believe parents who say children are at risk. There are many who mask in school and in appointments with GPs etc.
- Social workers MUST be part of the SPOA.
- For a lot of YP their route to accessing mental health comes via a Front Door for Families referral.
- SENCOs are the natural first point of call for many parents so it would be great if they were really well trained in the SPOA and know the full map of what is on offer.
- Route in via SPOA shared record so we are not repeating our story over and over

Breakout room comments by area

B&H breakout

- Better advertisement/more publicity and how to access it
- Clear pathways for different conditions/services
- More help at beginning of the journey
- Which way to turn when families get stuck/stranded when deviating from a specific pathway
- More knowledge, support and advice
- Community groups and charities doing a great work, e.g. mASCot, Amaze, PaCC. They need to be part of this
- Help to parent who experience MH
- Better time management instead of a 'revolving-doors' system

East Sussex breakout A

- In East Sussex there's already a SPoA but I'm not sure how knowledgeable they are about giving advice to the parents.
- There needs to be clear comms about who parents will be talking to e.g. not just safeguarding.
- If it's just safeguarding for SPoA is that going to put a barrier to parents who don't want to go down that route.
- Need more transparency to break down barriers - so not going to social services who it feels may judge you because safeguarding.

- People need to understand who they're talking to e.g. in SPoA, who's looking at your info? Who's making decisions? How knowledgeable are those responding and giving advice?
- Need honest communications with parents. Explaining steps the whole way through. Clear explanation for those at beginning of journey,
- Need timescales of when parents will hear back from services - by who and when. No point in referring to charities and other organisations if they are already under resourced/have long waiting lists, and/or there is a barrier/difficulty in obtaining funding for their services.
- There needs to be transparency about who is making the decisions as well as honesty - no point in making promises that cannot be fulfilled.
- After using SPoA last year - a referral was made from school into CAMHS, the following week there were more questions from SPoA who put a case forwards to CAMHS who couldn't help, and SPoA also signposted to charities who couldn't help then signposted back to CAMHS.
- Making sure that everyone knows the clear process when it's in place.
- Would GPs be happy to refer to SPoA? It's hard to get a GP appointment.
- At the moment parents can refer to the SPoA but the message feels that they don't really want us to.
- Need to give parents confidence that they can refer into SPoA.
- Don't want to go through phone call with SPoA and then do the same thing again with someone else.

East Sussex breakout B

- GP, schools, self-refer. No information available for P/C around ND CYP with MH needs. Professional knowledge around MH needs for ND CYP. MHSTs – do you they have ND knowledge as well?
- Website
- Chat Health – through school health, what are they doing
- CLASS and CLASS+
- Not repeating your story – single record.

Appendix 1.

Minutes from the main session.

1. Welcome

All attendees were welcomed to the workshop, with introductions from attending professionals.

2. Overview and aims for the session

The workshop is to have a space to hear from parents and carers of young people with neurodevelopmental conditions about the THRIVE framework and emotional wellbeing and mental health support that is and isn't available (using THRIVE to support this conversation).

Simone Button presented slides to provide:

- an introduction to Foundations for our Future programme of works which has come from an independently led review of emotional health and wellbeing support for children and young people in Sussex. The review report identified a number of key themes and recommendations to improve the experience of children, young people and their families and the emotional wellbeing, mental health care and support provided to them.
- an introduction to the implementation of the THRIVE framework across Sussex, which is a person centred and needs led approach to delivering mental health services for children, young people and their families

3. Mapping parent carer experiences onto the Thrive framework and how to fill gaps

Breakout session 1 - to get feedback from each group on questions:

1. Emotional wellbeing and mental health support/services/advice for your child. What has worked well: Map these onto the thrive framework
2. Gaps in emotional wellbeing and mental health support, and how do you see these being filled? Map these onto the thrive framework
3. What are your reflections on the Thrive framework? What are the positives, and what are the challenges?

4. Accessing mental health and wellbeing support and a Single point of access

Breakout session 1 - to get feedback from each group on questions:

1. Getting information about and accessing EWB and MH support: what works well what gaps/barriers are there, and how do you see this working better? Map onto thrive framework below.

2. What is needed to make a single point of access work for families?

5. **Current pan-Sussex work on the neurodevelopmental diagnostic pathway**

Kirsty Haines provided an update on work that's currently underway with the neurodevelopmental pathway development.

They are looking at all neurodevelopmental conditions (NDC), and also looking at children who are on the journey to a diagnosis or who may have traits of NDC but not received a full diagnosis, to make sure there's a whole service offer.

Overview of model - has a pre-referral and pre-diagnostic element, and it's about making sure there are services available from the start. From workshops which have taken place it has been highlighted that this is not as administratively efficient as it could be with inconsistent communication and some poor handling of referrals, showing the need for this to be a slicker process. Also looking at a single assessment framework to avoid going through multiple frameworks. There are 8 different providers providing 15 different diagnostic services across Sussex which from a parent/carer perspective is tricky to navigate so the aim is to have one entry point to the pathway and then to be able to navigate through this and between different organisations smoothly.

Post-diagnostic support - to make this stronger. Should not be dependent on having a diagnosis and should be able to enter without a diagnosis without having to re-enter the Sussex system.

Have put together NICE guidance and national best practice, completed workshops and developed an improvement plan. Will be setting up a referral hub, putting together consistent information for people and parents on waiting lists, and have been working on building the diagnostic pathway in different areas e.g. single assessments, and strengthening the post-diagnostic offer.

These developments are happening in partnership with PACC and information will be shared on what is happening and progress being made.

- Discussion included:
 - a query around people in East Sussex not having to go through the diagnostic process if they already have a diagnosis and if that this should also include private diagnosis, as often due to waiting times etc people are having to go down that route, it's then people get told it's not valid.
 - what is the role of transforming care for people with autism. Kirsty noted there's national work on transformation care which is available, Kirsty to provide link.

6. Summing up and next steps

Diana noted a big theme from today's session being people turned away from services because of their NDC or having MH issues attributed to their condition, and instead what is needed is training for professionals and knowledge of the child to be able to adapt to the NDC needs.

Simone noted a huge thanks to all attendees for the rich information collated today, and noted from conversations:

- The focus on what is being delivered and the challenges of having an ASD and other NDC, as well as EWB and MH - is a key issue to address.
- A lot of things talked about are in the investment planning currently taking place e.g. Aspens. However, unfortunately the shopping list of services we want to invest in is greater than the resource available, so we're needing to make decisions about prioritisation and to make decisions about getting more resource into Sussex.
- A lot of the conversation about SPoA and how it works best is being picked up in work we're doing in Foundations for our Future on SPoA core principles.
- Pleased that there has been good feedback about the THRIVE framework.
- We'll be looking further at how to keep everyone informed better about the work that's going on in Foundations for our Future. Although it's a Pan-Sussex piece of work we are working to make sure we're addressing the needs of the local populations.