

ESPCF Events - Special Educational Needs & Disabilities (SEND) in East Sussex
February – June 2022

What parent carers said

The breakout group topics have been coloured coded as follows:

SEN support in schools & attainment gaps	EHCP processes
Social Care / respite	Mental health

The different themes are in **black headings**

[Glossary at the end of document](#)

Communication

SEN support & attainment gaps

Parents to be **recognised, acknowledged & believed** as experts by experience

Visual guidance is needed from all services

Consistent messaging: no diagnosis should not mean no support

Consider **additional barriers some families face:** English not first language, limited or no access to information and advice. Some parent carers may have their own disabilities.

EHCP processes

Would like to see Q&A drop-ins with LA reps & practitioners for families – **foster collaboration & support**, presently can feel oppositional

Parent carers to be treated as **part of the team** & recognised as experts for their child

Messaging around UAP (Universally Available Provision) should be improved. Parents reported it is inconsistent.

Better comms within schools to share parental knowledge: also include governors, charities, volunteers

Communication with APOs needs to more timely, accessible, reliable and compassionate

Social care / respite

Transparency about what is realistically available

Getting to know the family makes a huge difference

Effective dissemination of information

Mental health

Recognition of impact autism/unmet needs has on mental health

Parents & carers feel their parenting is being questioned

Being heard & recognised as experts by experience

Joined-up communication needed and a seamless pathway between parents and professionals

More comms about availability of different services – also UAP

Training

SEN support & attainment gaps

Improved & more training across all sectors & with families which is regularly reviewed & updated:

- staff/practitioners better able to identify, understand & support SEND
- know how & when to apply for EHCP = more consistency across schools & services
- parent carers empowered & know what to ask for and expect e.g. APDR

Training needs to be **comprehensive and more in-depth**

EHCP processes

Training for SENCOs to be better equipped to support SEN needs

Understanding & acceptance that **behaviours at school and home can be vastly different**

Social Care / respite

Social workers need to be **trained to have empathy**

Mental health

Where the SENCO is skilled, the assessment process is effective

Practitioners more skilled & able to support ASC CYP w/ MH needs

Training needed for schools which have not had exposure to mental health issues

Share good practice / leadership / learning across and between schools, e.g. MH lead/MH governor

Information, resources & support

SEN support & attainment gaps

Early support & intervention backed up by ongoing support structures

Early, ongoing, relevant signposting to free, accessible, and trusted info, resources, groups – national & local = empowered, knowledgeable parents

Local Offer still lacking in some areas (e.g. SPLD)

Transparency: information should be readily offered, not something which has to be sought out

Greater clarity on how to navigate the system

EHCP processes

SENCOs to have **consistent information & experience** about applying for EHCPs – same information for all and not school's interpretation

Use of **easy-to-understand language**

Raise **parental awareness** to support early identification **& join with school knowledge** so it all aligns

Social care / respite

Need to know what is available. Easy access to information would make a difference - caring for a CYP with complex needs is exhausting, leaves little time to seek out info

Lack of choice for respite options, but even small amount makes diff if regular & consistent.

Increased services for those with complex needs including activities that YP can be supported to attend

Increased resources & diverse provision: not enough local services.

Mental health

MHST – great but equitable offer is needed

Improving the whole school support offer for ASC CYP with MH needs & **diversity of support**

Pre and post-diagnostic family support (& be clear about how to access the former)

Pathways

SEN support & attainment gaps

Clear & appropriate pathways with one **central resource point**

Cohesive joined up services

Support while on the pathway – what happens while you are waiting

EHCP processes

Clear pathway – parent carers don't know where to go

Long waits for SALT and OT

Social care / respite

Route to access support: better flexibility; ease of access to assessment; need to assess individual circumstances more thoroughly; better decision making, perhaps a panel

Mental health

A **clear pathway/website** so families can understand where CYP is on the pathway & what support is available at which point & how to access it

Adopt **whole school, whole community** approach

Processes & decision making

SEN support & attainment gaps

Improved collaboration & joined up working between schools, services & families. Stop being passed between ISEND Services and create continuity of trust

To understand how the county works/**clarity of process**

Accountability. It's brilliant to have Additional Needs Reports but when the school does not provide as stated, what then?

ANP is **not specific or targeted** enough

EHCP processes

More **clarity & consistency:** how and why decisions are made

Streamlined, joined-up, collaborative process: parents reported an overly complex & negative system, full of delays & where important info does not always get transferred

Clear that **EHCP decision-making flawed** – demonstrated by refusal to assess & tribunal rulings

Language used in EHCPs is not SMART

Holistic approach needed, not just mainstream inclusion but decision-making around complex cases

Explore different ways to **evidence need more quickly**

Annual review processes are often not followed correctly

Social care / respite

Changing criteria/threshold would make a difference – criteria for support is too high when CYP has very complex needs and requires constant support, but not eligible

Assessment criteria needs to take **impact on family** into account

Services need to be better joined up: assessments consider the full family situation, info recorded so parent carers not repeating / answering same Qs

Inappropriate behaviour policies are exclusionary and increasing mental health need in schools

Continuity in support & service makes big difference

Direct payments need to be realistic – PA salary must reflect skills & responsibility

Mental health

Timescales – E.g. 2 years may not seem long for LAs/NHS, but is for families

Reduce the escalation of need.

Better acceptance of co-morbidity

System changes to accept autism as integral part of a person

Coherent leadership in NHS to address well-known issues (e.g. diagnostic delays preventing access to CAMHS) in the system/pathway for ASC MH needs

Multi-disciplinary assessment hugely helpful

Secure the investment in and development of early help MH services

Inconsistent support during referral process

GLOSSARY

(I)SEND	(Information) Special Educational Needs and Disabilities
SEN	Special Educational Needs
EHCP	Educational Health and Care Plan
ANP	Additional Needs Plan
APO	Assessment & Planning Officer (in ISEND EHCP Assessment & Planning dept)
UAP	Universally Available Provision
SMART	Specific; Measurable; Achievable; Realistic; Time bound (when referring to goals)
APDR	Assess; Plan; Do; Review (in relation to ANPs)
SENCO	Special Educational Needs Coordinator
ASC	Autistic Spectrum Condition
CYP	Children and Young People
MH	Mental Health
SPLD	Severe and/or Profound Learning Disabilities
MHST	Mental Health Support Team
SALT	Speech And Language Therapist
OT	Occupational Therapist
PA	Personal Assistant
LA	Local Authority
NHS	National Health Service
CAMHS	Children and Adolescent Mental Health Services