



The Essex Alliance

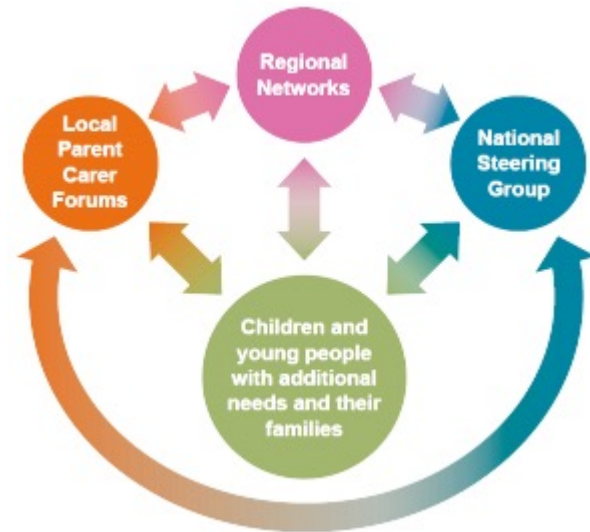
*Working together to represent the parents and carers of
Southend, Essex and Thurrock*

*Parent Feedback from Keyworker
Engagement Event
March 2022*

Who is The Essex Alliance

The Essex Alliance is made up of three Parent Carer Forums (PCF): Southend, Essex and Thurrock.

A PCF is a group of parents and carers with children and young people, up to the age of 25, with SEND. A Parent Carer Forum's aim is to make sure the services in their area meet the needs of children with Special Educational Needs and Disabilities (SEND) and their families.



PCFs operate in almost all local authority areas across England

We are also members of the:

Eastern Region of Parent Carer Forums (ERPCF)

<https://easternregionofparentcarerforums.org.uk/>

National Network of Parent Carer Forums (NNPCF)

<https://nnpcf.org.uk/>

It's important to note that PCF's apply for a grant from the Department for Education (DfE) to support their development and strategic involvement in local services. The grant is administered by Contact for disabled children. It's important to note that as a PCF we are **not** able to advocate and support individual parents as part of this grant conditions.



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What we did

We held 3 virtual engagement sessions with 17 parents, many of whom have had lived experience of a CYP in crisis.

Due to the time provided to submit the feedback, the sessions were conducted at short notice, which will have impacted on attendance.

We are mindful that we are targeting a specific cohort of parents or carers, who are often seldom heard due to the difficulties that their child or young person is having. This would also impact on attracting members of the wider SEND community.

We have several parents who are willing to work with us to conduct some in-depth case studies cases over the coming months. A template for this is to be written to ensure it meets not only the needs of the engagement but of the families also.



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Your experience

What is/has worked for you and your family?

Themed from 35 comments

- Communication / Belief in parents
- Reasonable adjustments
- Professionals' knowledge of wider provisions
- Peer Support
- Sibling/Family Support/advocates
- Play Therapy

- Unschooling / low demand lifestyle
- Private provision
- Professional support
- Multi Agency working
- Nothing



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Your experience

What has not worked for you and your family?

Themed from 51 comments

- Referral/assessment wait times
- Lack of multi agency working
- Barriers to services/ criteria for access not transparent
- Feeling judged/Parent Blame/Gaslighting
- Repeating story
- Child's needs not understood (impact of needs on Education, lack of understanding generally - anxiety/Mental Needs ASD/ADHD/PDA)
- Incorrect signposting
- Lack of early intervention/ right support at the right time
- Refusal for support (EWMHS/Crisis team/Children with Disabilities CWD Team)
- Lack of support/understanding/acknowledge/gatekeeping from professionals
- No respite
- No accountability for guidance not being followed within education
- Unnecessary hospital admissions
- Discharged from community pediatrics with no support
- Referred to A&E at Crisis
- No accountability when parent asking for help



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Thinking about the Keywork service and what it could provide:

What would be important to you?

Themed from 47 comments

Advice and Support:

- That they Keyworkers needs are supported so they can take on families/CYP emotions
- Provide emotional
- Easily Contactable
- Ability to understand family needs and dynamics
- Gain Trust
- Help with strategies
- Be consistent
- Ability to understand family needs and dynamics
- Be consistent

They need to be able:

- single point of contact
- navigation of the system
- Work across the system
- Have a good knowledge of services and provision
- Paperwork
- coordinate services
- Help manage/coordinate appointments
- advocate for CYP/Family
- Help in crisis – respite
- Ability to work across the system
- Support meets needs of CYP – not offer a tick box service
- Support a tell it once approach

In-depth understanding of:

- Autism Spectrum Disorder (ASD)
- Learning Disabilities (LD)
- Pathological demand avoidance (PDA)
- Trauma
- Anxiety
- Suicide ideation
- Sensory processing needs
- Selective mutism
- School refusal
- Correct terminology (for example avoid terms such as “mild autism” or “high/low functioning”)



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Thinking about the Keywork service and what it could provide:

What would you definitely want?

Themed from 42 comments

- Contactable when needed
- Consistency
- Knowledgeable on SEND/ Meet and understand CYP needs
- Trust and transparency
- Not overworked/overloaded
- KW have the right escalation processed that accountable
- Support at meetings
- Understand guidance and legislation
- Listen/good communication/empathic
- Longevity of provision
- Person centered approach
- An advocate for family and CYP
- Trauma informed
- Realistic respite plan
- Clear explanation of what will happen and when
- Accountable



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Thinking about the Keywork service and what it could provide:

What would you definitely not want?

Themed from 36 comments

- A parenting course/parenting advice – at this level should be CYP focused
- Some one uncontactable
- Tick box exercise
- Some one who controls and dictates
- Not to be referred to as “mum” (or Dad)
- Another professional that can't help
- Lack of lived experience
- Someone who does not like CYP
- Prioritising education over mental health
- Another professional/service to keep track of

- Lack of understanding on CYP SEND
- Someone who thinks “safeguarding” instantly
- Dismissive, judgmental, doesn't listen, patronized/blamed
- Understands home/alternative education (doesn't assume it's a safeguarding concern)



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Given that people are likely to get a keyworker at a point of difficulty or crisis:

What would you want them to do?

Themed from 43 comments

- Support Family as well as CYP
- Communication: Listen, be calm, be patient, be clear, have empathy, don't be afraid to talk about things
- Consistent – stick with the family throughout the journey even when hard
- Be flexible - multiple options to contact the, meet them and flexible with times, refusal to engage and last-minute cancellations
- Be supportive
- Be person centered, don't work to an agenda

- Be our voice - advocate between family CYP and the services
- Read paper before so understand family situation
- Take the time to gain trust
- Don't force going into CYP safe space
- Give the parents a break – make them a cuppa
- Provide Validation
- Help with the admin and appointments



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Given that people are likely to get a keyworker at a point of difficulty or crisis:

How would you want them to do it?

Themed from 27 comments

- Be clear about availability and service
 - Be available when in crisis
 - Be clear on step down process
 - Meet at the house, away from the house meet the family needs
 - Open heart and mind
 - Be sensitive, patience and kind
 - Support before crisis – by this time its to late.
- Be flexible
 - Be responsive
 - Talk to all services involved
 - Communicate effectively – meet the needs of the family or CYP
 - Work at pace for family CYP



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Given that people are likely to get a keyworker at a point of difficulty or crisis:

What might they do if they had some small amounts of money that they could spend to help support a situation?

Themed from 41 comments

- Sensory equipment/help/assessments
- Equipment – communication aids/adaptations
- Therapy – Sensory/Animal/Trauma
- Respite – Services/ one hour a week/ take CYP out for an activity
- Access to groups/hobbies/interests
- Practical Help – for example shopping if needed
- Family Support, courses, webinars, advocacy

- What CYP needs/enjoys – not what meet criteria
- Technology support
- Travel support
- Family day out/activities
- Support for siblings
- Help with emergency household items
- Private appointments
- Small amounts of money wont help.



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The impact of the service:

What outcomes would you want to see achieved?

Themed from 31 comments

- Better Quality of life for whole family
- Improved mental health and physical health for whole family
- Ability for family to cope better with extreme situations
- Understanding of where CYP sits in Health and Education
- Knowledge of services e.g.: pathways/ transition to adult services
- Empowered – Family and CYP
- CYP and Family to feel:
 - Heard
 - Supported
 - Safe
 - understood

- Reduction in family anger and complaints
- Know what support and provision is available
- Interventions – quick and effective
- Right Provision/services at the right time
- A trusted relationship
- Reduction in stress
- For CYP to have an advocate outside of the home
- To have autonomy
- Not to feel failed by services
- Not to feel blame or shame



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The impact of the service:

What difference should it make that we could see?

Themed from 31 comments

- Happier CYP and Family
- Less support or involvement from services
- Healthier CYP and family (physically and emotionally)
- A calm parent
- Not afraid for CYP future
- CYP needs met and understood
- Reduction in complaints and parent anger
- Empowered families
- CYP able to engage in therapy etc
- CYP feels valued and a member of society

- Right support/access to services and provisions at the right time
- Prevention from escalation
- Inclusion
- Reduction in stress
- Working with professionals as a team
- No fear
- Connected as a family



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Any other comments:

Themed from 17 comments

- Sounds amazing but if service becomes overwhelmed then the Keyworkers wont be able to deliver
- Concern how this will work in reality
- Lack confidence due to other services and provision
- We have been through this, support would be great, but reality is funding not enough to deliver
- Needed for all Neurodiverse conditions
- CETR decisions need to be accountable
- This has potential – I hope it works
- Disappointed – to little to late, damage all ready done
- Those deemed ineligible will feel angry and frustrated

Questions asked by the attendees?

- Are parents told/aware when CYP is on the DSR?
- Have they accounted for future demand?
- Are the DSR register and the assessed risk level going to be shared with young person and family. Transparency?



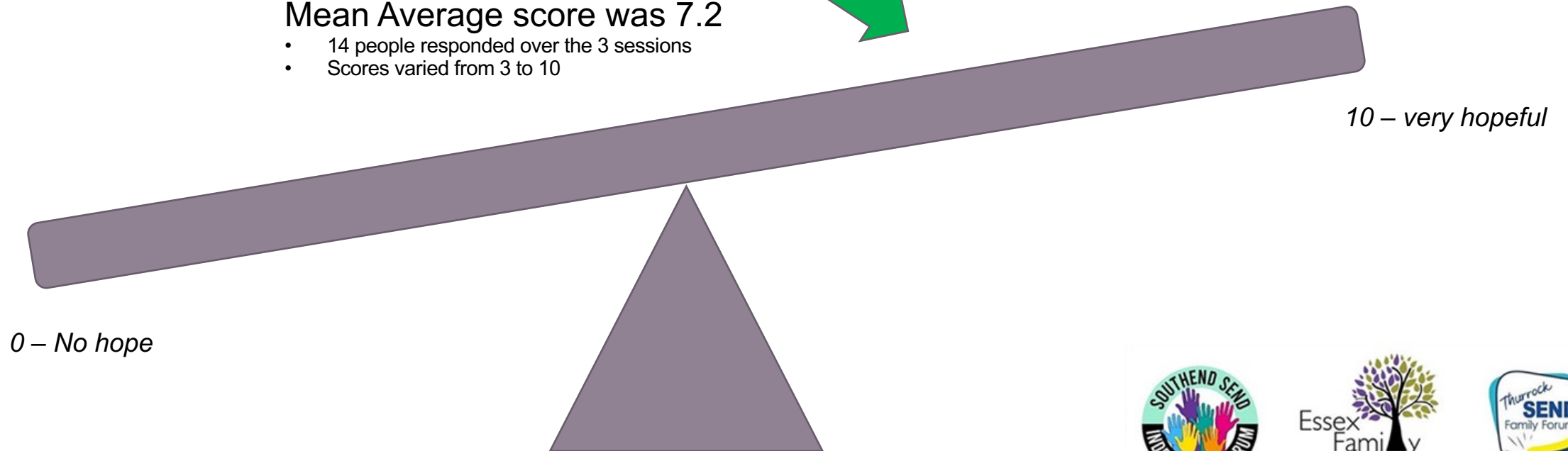
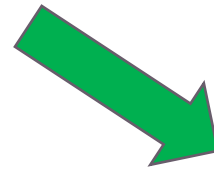
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Now that you have heard about Keyworkers, we are interested to know if you think it will make a difference?

Mean Average score was 7.2

- 14 people responded over the 3 sessions
- Scores varied from 3 to 10



I feel hopeful that it will make a difference



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What we will do now

The data will be presented to the Keyworker steering group.

The presentation will be shared with the parents and carers that attended*.

The views will be used by Essex Alliance when working with the steering group to develop the service specification and beyond.

All views gained through this engagement process will be provided **verbatim** (exact wording) to the keyworker steering group.

Views gathered will also be used by Essex Alliance within their local areas (Southend, Essex and Thurrock) with an aim to improving SEND Provision.

Essex Alliance will continue to engage with parents and carers as the service develops over the coming year.

** The public presentation shared with parents and carers will have the verbatim comments removed due to respect the privacy of those who contributed and shared their experience.*



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THANK YOU



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