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Summary

This report has been written to inform the development of an East Sussex children and young people's keyworker service, funded and specified by NHS England. As the introduction will clarify, national keyworking services are being developed to meet one of the recommendations in the review '[These are our children](#)' by the National Children's Bureau.

Our report sets out recommendations for the keyworker service based on feedback from East Sussex families, as well as considering information on what has worked well from areas already delivering the keyworker programme.

This report will be provided to the mental health commissioning team with the expectation that it will be used to help inform the tender and procurement process for the 2023/24 East Sussex keyworking service. The report will also be shared with Sussex ICB (Integrated Care Board) senior commissioners, and managers from the Learning Disability and Autism Programme, as well as those who have responsibility for children and young people more broadly.

ESPCF will also share this report with its members and the wider SEND (special educational needs and disabilities) parent carer community, and welcomes further feedback.

ESPCF would like to extend heartfelt thanks to the families who gave up their valuable time to tell us about their difficult and often overwhelming experiences. These families allowed their voices to be heard and we must ensure that the East Sussex keyworker programme is designed to reflect the feedback from those with lived experience.

Introduction and background

East Sussex Parent Carer Forum (ESPCF) is the recognised parent carer voice organisation for families with children and young people aged 0 to 25 with any special educational needs and disabilities in East Sussex. We engage with families in a variety of ways, and work to ensure that the voices of families are heard and contribute towards developing and improving services. It is vital that local services meet the needs of the families they serve, so working in co-production, where families have an equal voice, is of utmost importance, particularly during service design and development.

We are pleased therefore that the NHS children and young people's keyworker programme was developed at a national level by working closely with young people themselves as well as a parent carer co-production group, including the [National Network of Parent Carer Forums \(NNPCF\)](#) and [Contact](#). This work defined the scope, outcomes and what mattered to families and young people from their direct experiences through extensive consultation with young people, parent carers and

other stakeholders. The expectation is for this co-productive way of working to continue at a local level.

The keyworker programme dates back to 2017 when the Department of Health published a review into 'the care of disabled children and young people with challenging behaviour and complex mental health needs' carried out by the Director of the [Council for Disabled Children](#) (CDC) Dame Christine Lenehan. The review '[These are our children](#)' called for urgent action at a national level to prevent these children being institutionalised at an early age, at huge cost to the taxpayer and with low ambitions for improving their lives.

One of the ten recommendations from the review is now part of the [NHS Long Term Plan](#) which includes a commitment that 'by 2023/24 children and young people with a learning disability and/or who are autistic with the most complex needs will have a designated keyworker'.

The children and young people's keyworker programme is a four-year multi-million-pound investment by NHS England and NHS Improvement to provide keyworkers to support autistic children and young people and those with learning disabilities; to prevent admissions to mental health hospitals and settings and help inpatients to leave and access suitable support in communities when this is more appropriate.

After a decision-making process involving the NNPCF regional representatives and other families and young people, 13 pilot areas were appointed in various regions for 2020/21 and 14 early adopters were appointed for 2021/22. Sussex was not appointed at this stage but is now included in wave 3 services to be implemented in 2022/23. Being part of this final wave brings the benefits of being able to learn from other local areas who are further forwards with this work.

The NHS has created a Keyworking Communities of Practice platform to share information from areas which are already delivering the keyworking programme to share what is working well, what may not have worked so well, and to consider the benefits, challenges and actions needed. This has been helpful when considering the day-to-day aspects of the services, but also the more time-consuming aspects around data sharing/information governance for example, which some areas have reported caused delays whilst details were being ironed out.

Finding out how others are making the programme work has also been a key part of the research for this report.

ESPCF was allocated some funding to support engagement with families as part of a pan-Sussex co-production plan. ESPCF has attended several of the NHS Community of Practice events, as well as being part of the NHS keyworker project online platform with discussion boards for information and insights to be continually shared. These have helped us to become fully immersed in the project, and well versed in the outcomes it should achieve.

Initially, the scope for co-production in East Sussex was not clear. This is in part due to an existing service from local charity Aspens, which we understand had been given additional funding from local NHS commissioning to extend the age threshold of its Youth Engagement Worker service from 18 years up to 25 years, in line with the keyworker project. It is not clear whether this service fulfils all of the functions of the NHS keyworker service.

ESPCF reached out to families who have lived experience relevant to the support being offered by the keyworker programme. Their feedback forms the basis of this report and recommendations.

It is too early to consider in detail for this report, but it is of note that the new [Dynamic Support Register and Care \(Education\) and Treatment Review policy and guide](#) has recently been published and is due to be implemented by 1st May 2023. The new policy has been co-produced by people with lived experience and endorsed by parent carer Yvonne Newbold of [Newbold Hope](#) who notes that it will '[take time to get it completely right and to have the capacity for robust help and support](#)'.

This report is presented as a list of recommendations for the East Sussex keyworker programme. The lived experiences of the parent carers who provided feedback to ESPCF shows the alarming lack of support for families living with an unacceptable level of risk. The feedback from these families and their insights into what could help is especially significant as it demonstrates a direct correlation with the successful approaches from some of the early adopters of the scheme.

Engaging with parent carers

The keyworker programme is for children and young people who are autistic, and/or have a learning disability, who also have complex mental health needs. In January 2023, we (ESPCF) publicised a request for families to share their experiences with us. The first objective of the programme is to prevent hospital admission, so we asked for families to get in touch where the child/young person:

- has been admitted to, or is at risk of being admitted to, a **mental health hospital** or setting AND/OR
- has **visited A&E, or had contact with the police or SPOA (Single Point of Advice)** because of the risk of harm to the child or young person in distress and/or to others

We offered flexibility to collect the feedback and were contacted by 13 families. So far, we have been able to coordinate feedback from nine families who provided us with detailed information about their experiences. We collected this by phone calls, Zoom calls, home visits and email.

We believe that the number of families experiencing these extreme situations are relatively limited, and we appreciate that some of them are too exhausted or distressed to have the time and energy to share their views. The numbers responding to our request correlated with this, but were nonetheless extremely impactful, and the families that took part had similar experiences and views on how things need to improve.

Type of feedback collected

To assist us when speaking with families we created a prompt sheet. Sensitivity was the primary concern when collecting feedback, so we did not approach the exercise with a need to complete answers. The prompt sheet was purely guidance for us where it was helpful and appropriate:

- **General background** and situation. Current or historic. When started/how progressed
- **School/college/post 16** – attending/excluded etc. Any support offered/what/helpful or not. If relevant, why removed or excluded/ home schooling etc
- **What health services have been explored** – and availability/waiting lists etc
- **Any hospital admissions/visits to A&E/calls to police/SPOA** what happened/how supported
- **Impact on family**
- **What (if anything) has helped** – services, professionals. What **would** help/make a difference
- **Would keyworker service be best if third party (e.g. community/charity sector) or within the NHS or local authority**
- **Where to find info**/what did people search for/were they familiar with local offer/what would people want to know about the keyworker service/what format would be helpful - would videos, booklets be useful

The following questions were suggestions from the NHS Keyworking Communities of Practice platform:

- **Keyworker service**
 - Is keyworker the right name? Care coordinator, navigator – any ideas
 - What matters most about the actual worker? What sort of person - personality traits, personal or work background, skills etc?
 - Best way to get in touch with keyworker – text/calls/apps/face to face
 - One person or two/more to build relationship with/provide continuity and cover?
- **If historical situation** – how to manage withdrawal of support/what if anything needed as follow-up

Child/young person data

Of the nine families we spoke to:

- 8 of the young people are teenagers aged between 12 years and 17 years. One is very young aged only 5 years
- 5 of the young people are male, 4 female (including one transgender)
- All have a diagnosis of Autistic Spectrum Condition (ASC), four with Pathological Demand Avoidance (PDA). Some of the other additional needs include: sensory processing, hemiplegic migraine, dyslexia, anxiety and depression
- All of the children and young people are currently self-harming and/or display violence towards others
- 5 of the 9 young people have suicidal ideations and have attempted suicide on more than one occasion

Before a keyworker can begin to support a child or young person and their family they need to have a clear understanding of the young person's story, how they have arrived at crisis point, and the impact this has had on the family.

We feel therefore that those responsible for commissioning and providing services should have a detailed example of the lived experience, and so we have provided a more detailed case study of one family.

Using all of the feedback we received has determined the nature of this report and the recommendations within. However, case studies show more clearly the detail behind the feedback and illustrate the complex and difficult battles people go through in their attempts to get support; they show the devastating impact on children, young people and their families. We are sad to say this case study is representative of the feedback from all of the families who spoke to us.

Case Study - Alex (not real name)

**Alex is 16 years old with formal diagnoses of autism, learning difficulties, anxiety, clinical depression, self-harm/suicide ideation and emetophobia.
Alex lives at home with parents and has one sibling.**

During the nursery and primary years Alex suffered from separation anxiety. Alex found academic life very challenging, had very poor spelling. School suggested Alex would 'grow out of it'.

Alex's junior years started well with a teacher offering help for Alex, who was simply 'behind'. However, year 4 was a large class with a newly qualified teacher and Alex's anxiety worsened. At the end of year 5, Alex was referred to the SENCO. In year 6, the SENCO reported no need for assessment as Alex's behaviour in school was seen to be fine.

During preparation for secondary school, Alex was treated as a special educational needs (SEN) child and had extra transition sessions. Year 7 was a difficult time, but Alex was well supported by pastoral care staff. During year 8 Alex had increased issues with eating and anxiety and lost a lot of weight. Following two weeks off school when unwell, Alex was unable to fully return. A reduced timetable was put in place but this was not successful and Alex began self-harming and had suicide attempts at school.

A CAMHS (Child and Adolescent Mental Health Services) Tier 2 worker arranged Teaching and Learning Provision (TLP) but even when reduced to one lesson, Alex was not able to cope. The self-harm which started in year 8 got progressively worse over time with the intervention of CBT (cognitive behavioural therapy). Self-harm escalated with Alex trying to jump out of windows, in front of moving cars, off bridges. There were multiple assaults to parents as they tried to protect Alex.

CBT was provided but Alex continued to self-harm. Parents challenged the CAMHS worker that CBT was clearly not working. The handouts being given to Alex were of no use as Alex was not able to read or process or use the information provided.

Autism experts, SALT (Speech and Language Therapists) and OTs (Occupational Therapists) working with the family have since acknowledged the CBT was not appropriate. The expectation of CBT with Alex's learning difficulties and autism exacerbated the anxiety levels because Alex couldn't understand what was required and how to respond.

A referral was made to Tier 3 and Alex was put on the 'pathway'. They were left in 'limbo' for 2.5 months whilst waiting to see a psychiatrist and Alex deteriorated during this wait. Alex was then diagnosed with depression, anxiety and suicidal ideation and offered CBT again even though Alex's parents had already highlighted Alex had been provided with CBT with no positive effect.

From the breakdown of the school placement (2018 - 2020) there were multiple calls to the police and ambulance service, and multiple attendances to A&E.

In 2021, Alex was admitted to Hastings hospital for one month. On discharge a Tier 4 worker advised that parents should lock the windows and doors and see how Alex is in a month.

Over the next five months there were daily/weekly calls to the police/ambulance service and the parents continually contacted CAMHS asking for urgent help. They were told they had been referred to a parenting course and on a waiting list (at the time of writing this course has just come up for February 2023).

After an incident where Alex ran into traffic, the police took Alex to hospital. At this stage the parents were absolutely desperate and left Alex in police care at the hospital as they just couldn't

keep Alex safe anymore. Alex was then an inpatient at Hastings for 16 days under Section 2 (of the Mental Health Act), where Alex was eventually diagnosed with ASC, and then transferred to Chalk Hill under a Section 3.

Alex was at Chalk Hill for ten months. As an inpatient, Alex's behaviour worsened and Alex learned destructive behaviours, for example ligature ties, head banging, scratching holes in cheeks. Alex stopped eating for five weeks and ended up in Brighton Hospital with an NG tube for feeding.

A consultant in hospital stated that Chalk Hill was not the right place for Alex but that there was nothing else available.

It took seven months from the start of discharge discussions before Alex was able to return home as there were disagreements about who would fund post-discharge support. That was six months ago, and they are still not receiving the full support stated in the Section 117 aftercare plan.

Just recently, funding for 25 hours of support per week from Aspens has been agreed, but at the time of interview, the resources were not available to provide this in full. Parents have asked for a more personalised approach but told that anything that does not follow the policies etc has to go back to the commissioner for approval. Parents report that interventions are too prescriptive and not everyone fits the boxes.

They have not been offered anything to help all of the family members to cope with the trauma.

Impact on family

Mum

- Continually exhausted as she sleeps on a mattress in Alex's room every night to ensure safety.
- Had to give up her business to be with Alex 24/7.
- Feels stuck in a system that she doesn't understand and doesn't know how to fight for Alex; she doesn't feel listened to; is angry and frustrated that she has asked for help since Alex was 4 and feels all this could have been avoided if there had been suitable early intervention.
- Has been proactive in finding support groups and joined an online group which has six parents from around the world that chat and support for two hours a week. Mum voiced that this was her lifeline in some of the darkest hours.
- About to complete a 'partnering not parenting' eight-week course but feels that siblings and dads get forgotten about.

Dad

- Also exhausted and feels helpless as out at work all day.
- Parents 'tag team', each sitting with a child in the evenings.
- Helps when he can and leaves work if Alex has run off to help find Alex, but aware that he needs to bring in an income for the family so has different pressures to mum.

Brother

- Regularly having to go to friend's house in the night if crisis.

- Struggling with the dramatic changes witnessed with sibling and misses who they used to be.
- Traumatized but not able to be supported by Care for the Carers as most of the children there are much younger.

What would have helped

- An advocate who would get all the services to work together so that exhausted parents do not have to do this.
- Someone who would know and understand all the terminologies, documentation, legal issues that these young people and families face.
- A more creative and joined-up service that could provide support for the young person and their family.
- Improved support for autistic young people or with learning disabilities and mental health issues instead of being told “its autism so we can’t intervene”.

Addendum Shortly before completing this report we heard from the family that Alex has again been admitted to hospital after spending 6 days in an A&E cubicle. A parent is now looking after Alex on the ward 24/7 as Alex cannot be left alone safely.

A keyworker service would have stepped in when Alex was 12/13 years old and was self-harming, attempting suicide and therefore at risk of hospital admission. That would have been about four years ago and could have potentially prevented significant increased illness for Alex and an enormous amount of stress and distress to the whole family.

The keyworker provision would probably have been heavy on cost at the beginning but would have gradually reduced and would certainly have a reduced financial impact than the hospital admissions, the many calls to police, ambulance services and visits to A&E, which the intervention would probably have prevented.

Recommendations for the East Sussex keyworker programme

The following list of recommendations is not exhaustive and is not presented in order of priority.

The quotes and examples used (in purple italics) are exactly as provided by East Sussex parent carers, unless otherwise indicated. The use of CYP (children/young people) has been used to maintain anonymity.

Recommendation 1

The East Sussex keyworker service needs to be co-produced; to take note of the NHS community keyworking model; and to learn from existing schemes.

Co-production

As identified in the introduction to this report, national co-production was embedded right from the very start of developing the community keyworking model. In co-production, NHS England and NHS Improvement have made clear the vision and mission of the keyworking service.

The vision:

- Every area in England will have a keyworking service by the end of 22/23.
- Autistic children and young people, and children and young people with a learning disability, with the most complex needs, at risk of admission or in hospital will have a designated keyworker.
- Keyworkers will work with young people and their families to make sure they are fully involved in their plans, feel listened to and informed, plans are personalised, and they have the support they need at the right time, in a co-ordinated way.

The mission:

- Plan and implement keyworking services at a local level, with the strategic involvement of young people, parent carers and system partners.
- Ensure sustainable host arrangements which build relationships and link across system partners.
- Improve dynamic support registers to ensure timely identification of young people for support.
- Recruit people with the right skills and capabilities.
- Support the outcomes young people and families have described so they can remain in their community.

It is vital that this co-production continues at a local level and is embedded as soon as possible so that the East Sussex provision is developed to meet local need.

Feedback from existing services agree that the aim of the keyworking service is to do something unique, to provide a different angle rather than just another professional parachuting into families' lives. Co-producing the keyworker service relies on hearing about lived experiences and the impact on the whole family; finding out what would have helped, and what could help in the future. Allowing parent carers and young people be a major part of co-production is the only way to develop a service that is truly effective. As one young person from the Community of Keyworking Practice says:

"Decision making in a pilot like this needs co-production at the forefront because it is such a new way of thinking and working. No one knows autistic people or people with a learning disability like autistic people and people with a learning disability do – no matter how much training you do, you'll never experience the world exactly as we experience it. We know our needs, what could have changed our journeys, the support that is lacking, the changes that need to be made."

Feedback from existing keyworker schemes shows that East Sussex is among other areas where parent carers have lost faith with the system, including the NHS and local authorities. Transparent co-production is key to developing a service that families can begin to trust.

At the time of this report, ESPCF has 670 parent carer members representing 740 children and young people with SEND, and further reach into the parent carer community via other support groups and community organisations. Previous workstreams have clearly shown how the involvement of parent carer representatives not only identifies where things are not going well but can help to offer innovative and practical solutions. Their views, experiences, and expertise are invaluable and must be allowed to shape the improvement and development of the keyworker service.

The NHS community keyworking model

The Council for Disabled Children together with NHS England and Health Education England produced two documents: a Keyworking Function Guidance and Keyworking Workforce Competency Framework. These have been based on a review of existing models and designed through extensive consultation and co-production with key stakeholders including parents, young people, Learning Disability and Autism commissioners and service leads.

These documents describe how the overall vision has moved towards a keyworking function - an overall keyworking workforce with required competencies. This describes a service model as opposed to keyworkers working almost in isolation; a service where the whole workforce requires the same core competencies.

Keyworking Function Guidance

This sets out function characteristics highlighted by existing models:

- Delivery of flexible, personalised and child-centred support, to ensure the complex and often varying needs of children, young people and their families are met.
- Flexible duration of keyworking function involvement and step-down process, to ensure continuity of the right system of community services and support to meet the child/young person's needs once keyworking involvement ceases.
- Supporting families to access Personal Budgets, to enable greater choice and control over their child or young person's care.
- Cross-system function with an ability to build relationships and support co-ordination across the system.
- Role seniority and holding services across the system to account.
- Flexible service hours and sufficient out of hours provision, to support the flexible, personalised nature of keyworking support provided.

Keyworking Function – a workforce competency framework

This framework sets out and defines the core competences required by workers or team members to deliver the keyworking function and notes the following key components:

- Placing the child, young person, and family at the centre
- Effective communication
- Achieving change and unblocking the system
- Bridging and working across the system

The framework goes on to describe the core competencies in detail.

In November 2022, a further document was produced as an addendum to the Keyworking Workforce Competency Framework and Function Guidance. This addendum *'is based on 90-minute interviews with nine representatives from five pilot sites, a review of supporting documents and is informed by case study material from every pilot site.'* The addendum presents learning from the experience of the pilot sites of setting up and delivering their keyworking service model, organised into four sections:

- Setting up the keyworking service
- Getting up-and-running
- Delivering the service
- Key processes

This addendum provides useful information for developing services and the East Sussex keyworker system needs to take advantage of the guidance available.

Learning from existing schemes

The Keyworking Communities of Practice platform provides a wealth of information and lessons learned from the thirteen pilot schemes and fourteen early adopters that can help to inform developing services. The majority of the models in existence have teams with a similar structure:

- Service manager or team leader to oversee the service
- Specialist keyworkers for case allocation and clinical supervision
- Keyworkers providing the direct support to families
- A project support officer providing oversight of administrative functions and documentation

The service in South East London also has a separate Information Advice and Guidance Keyworker who can use the legislative framework to remind services of their statutory duties. As an example, they report that non-existent or inadequate EHCPs (Education, Health and Care Plans) have featured heavily in many of their cases. They also stated how the role has helped identify and support those children and young people who have been excluded or are off-roll.

Existing schemes report that the recruitment of keyworkers has come from all sectors: education, health, social care and the voluntary sector, and a number of services have recruited keyworkers with lived experience.

As new services offering a new type of support they report the need to test, learn and adjust. Being flexible in their approach and willing to change is essential to being effective as a service.

All report on how essential it is for keyworking services to have good relationships with clinical and social care leads so they are able to influence changes where needed.

One scheme describes keyworking as the ‘dynamic arm’ of the Dynamic Support Register (DSR) and the Care, Education and Treatment Reviews (CETRs), requiring a strong link with everyone around the table who understands that this is a crisis planning tool; with everyone actively participating; and everyone discussing cases back and forth – not just a single route to referral.

Recommendation 2

The keyworker service needs to include out of hours provision.

*“What would help is to have that missing emergency ‘blue light’ service in times of crisis. When a child or young person is telling professionals (multiple times) that they **will** take their own life, it would be really helpful to have direct, practical help or support with this rather than leaving it solely down to the parent to keep their child alive.”*

One parent interviewed told us that the previous week her CYP had punched her in the face and she was momentarily passed out on the floor. She feels “disposable” and that she and her family don't matter. A friend came over to help but there is no provision or service that is helping.

Families need a service that can respond as and when needed.

The North Central London scheme states: *‘Each keyworker looks at where the ‘pinch points’ are for the families they are working with, for example around night-time routines, mealtimes etc. and tailors intervention accordingly. This was felt to be crucial. We want to work with the family on the issues they have. Families do not operate nine-to-five Monday to Friday so neither can we.’*

A number of the pilot projects have offered an out of hours service and commented on how essential this is, noting that keyworkers need to be available outside of office hours. This availability does not always necessitate a home visit, with existing schemes stating that keyworkers communicate with families and the child/young person according to what is needed and convenient at the time, and includes text, apps, and phone calls.

This flexible approach is to help prevent problems escalating to the point of crisis. It is acknowledged by existing services that to be really effective, the support is usually intensive, particularly at the start. Keyworkers generally work with families for multiple hours, several times a week in the initial stages of relationship building.

Recommendation 3

Keyworkers need to be advocates and coordinators who have a breadth of knowledge about health and social care systems.

A keyworking service could:

“...relieve my stress levels to the point where I could concentrate on being the best parent I could be, instead of juggling so many struggles and carrying the weight of a system that is not supporting CYP.”

The keyworker role:

“...should not be prescriptive but personalised to the young person and their family. They must know and understand all the terminologies, documentation, legal issues that these young people and families face.”

The feedback from parent carers and the experiences of existing schemes tells us that families need a keyworker who will act as a strong advocate for the child/young person and their family. They want to know that the keyworker is 'on their side' and will have a sound knowledge of the system, knowing what *could* be available in terms of support, as well as where and how to seek out that support with an understanding of criteria and thresholds.

An essential part of the keyworking function therefore needs to be supporting families to navigate the system, and to work across those systems and services to ensure they are responding to the needs of families as and when required.

Pilot schemes have emphasised the importance of the keyworker being able to challenge services and hold them to account where needed. Some suggest this requires keyworkers to have a certain level of independence from health and social care but it is also essential for them to have the authority to access professionals and their teams. Some of the pilot schemes have keyworkers employed by charities with a memorandum of understanding or a service level agreement with health and/or social care. Some areas have their keyworking team as part of the local authority. However, a number of areas have employed keyworkers within the NHS. One service is embedded in health but is a joint partnership with the local authority, health and their local parent carer forum.

Wherever the keyworker sits in terms of employment, what is absolutely essential to the service being successful is a multi-agency commitment to the keyworking programme with effective strategic partnerships between health and social care.

The CDC keyworker addendum notes *'The Keyworking Service must build influential relationships with professionals across the system, securing buy-in and a shared, unified approach'*. For the keyworking function to work there will need to be a level of integration and/or links to a high level of influence. It cannot work if the service has no power to challenge and hold the system to account where necessary.

Recommendation 4

Keyworkers need to provide a highly personalised empathetic service based on the needs of individual children, young people and their families.

"Interventions are too prescriptive. Not everyone fits the boxes."

“CYP was provided with a series of behavioural intervention sessions which was a disaster. CYP was unable to engage with them. It was not a great approach from them and it just didn't work. They came in with an expectation around working with someone with an ASC diagnosis without understanding the severity of CYP's mental health. The approach was too wordy for CYP to be able to engage.”

The keyworking service must be child and young person centred and personalised. The children and young people referred to this service will be experiencing life in very different ways, and developing a relationship with an understanding of each person is essential. The support that each child or young person needs must be tailored to that individual; a 'blanket' approach is not the answer.

If the service is commissioned to sit within the third party sector such as a charity/community organisation, consideration should be given to the wider ethos of the organisation. For example, a number of families have expressed that they would not feel comfortable using an organisation which supports or uses an ABA (Applied Behaviour Analysis) or a PBS (Positive Behaviour Support) approach across their services, which would be a barrier for some to receiving support.

Parent carers in Bristol, North Somerset, and South Gloucestershire (BNSSG) have joined forces and worked collaboratively to represent the parent carer voice. They sit on the Keyworker Project Steering Group and jointly facilitate keyworker-focused engagement events.

BNSSG comment on the importance of a personalised service and remark that what is needed is 'someone to get alongside the young person'. They recognise that many children and young people 'are struggling to engage in educational relationships, friendships, and life in general. They are often isolated, lonely and have low self-esteem. They require someone to get to know them, with no pressure involved and help them to enjoy life again and have new experiences... slowly building their confidence and desire to come out of their comfort zone'.

“If a child was screaming and hanging on to the building when it was time to go home from school it would automatically raise concerns about home, and social services would be called. When my child behaves like that when we try to get her into school the blame is aimed at us and schools are often very harsh in regard to unauthorised absence.”

The ESPCF feedback from families supports the BNSSG findings that some families' lives have been made more difficult by reaching out to services. Parent carers have experienced blame, with autistic traits being interpreted as some kind of failure in parenting or even as evidence of parental coercion and control. Parent carer peer support and sharing information is a vital part of coping for

SEND families so it is important to create a culture of support rather than blame, in order that the negative experiences mentioned above do not discourage other families from seeking support.

It is essential for keyworkers to understand and acknowledge some of the more subtle manifestations of autism, particularly the relatively common trait of masking. This is often described as a 'social surviving strategy' and largely used to enable the child or young person to cope with educational settings. The mental and emotional energy it takes to mask often results in an unleashing of pent-up emotions when back in their safe place, most often at home.

Keyworkers will need to have good knowledge about what therapeutic approaches are available so they can facilitate the type of emotional and behavioural support that is most appropriate for each child/young person and their family.

As relationships with the child/young person and their family are established, the keyworker will need to develop a personalised plan that includes a set of key outcomes for the keyworker intervention. This will involve developing a plan of work around the child and family's needs with identified outcomes and delivering this with flexibility.

Pilot schemes have recognised the capacity requirements to provide such an intense service and acknowledge the early caseload limitations. There is also an understanding that most areas will have a backlog of families who need long and intensive engagement, but that as time goes on the team will be more able to engage in earlier and preventative work, allowing them to manage a larger caseload.

Recommendation 5

Keyworkers must be suitably trained and experienced and receive appropriate support.

A keyworker:

"...needs to have sound knowledge of neurodiversity, preferably previous experience or lived experience with ND/mental health. Excellent communication skills for children and parents, strong personality to be able to stand up for the families that they support."

The keyworker role should be:

“...to support the child in all aspects of care affecting their mental health, to communicate clearly and effectively with professionals and parents/carers, to chase up referrals or refer to services that should be involved in care. To hold others to account and ease the burden from the exhausted parents. To support the child and guide them to a place where they are able to use strategies to help cope with daily life.”

The keyworking competency framework recognises the importance of a personalised service, noting the need for a compassionate and empathetic approach. The framework states that keyworkers need the ability to communicate clearly, sensitively, and effectively with children/young people and their families, as well as the ability to listen.

E-learning has now been developed for the implementation of keyworking services and includes three sessions:

1. Foundations for keyworking
2. Human rights approaches
3. Understanding the system

It is mandatory for all appointed keyworkers to complete this resource as part of their induction, in addition to participating in local and national skills-based training programmes.

As mentioned already within recommendation one, guidance has been developed to identify a [workforce competency framework](#) for all those working within a keyworking team. The requirements are extensive but have been developed to incorporate the reviews from existing services and as such are a clear indication of what works.

The [keyworking function guidance](#) highlights the need for keyworkers to have a ‘*strong understanding of children’s mental health and human rights*’. This correlates to the feedback from ESPCF parent carers who told us that some of the approaches used to support autistic children and young people are not always suitable for those experiencing mental health difficulties.

Feedback from existing services has recognised that the keyworkers will require specialist skills when they are supporting children and young people with mental health needs and notes the necessity for keyworkers to have access to clinical supervision. Keyworkers will often be supporting families in very difficult and distressing circumstances which also has the potential for conflict with other professionals over the best course of action. Pilot sites have introduced a range of mechanisms including peer-to-peer support and reflective practice sessions to help keyworkers develop their practice and prevent burnout.

Recommendation 6

The keyworker service needs to offer manageable timelines and discharge plans.

East Sussex families have told us how inadequate time-limited support can be. While recognising that any service needs to consider a discharge process, the common six-to-ten week offers of support rarely work. This is particularly so for young people who have disengaged with the system and are generally struggling to interact. It takes time and patience to develop a meaningful relationship *before* the real ‘work’ can begin. The discharge of support therefore needs to be done with careful consideration.

As mentioned in the introduction, a new [Dynamic Support Register and Care \(Education\) and Treatment Review policy and guide](#) has recently been published and ESPCF is still learning what the significance of this new policy will mean and its effect on the keyworking function.

The comments from East Sussex families reflect national feedback that actions within CETRs are often not followed up and no one is held accountable. The new policy recognises this and has an increased focus on accountability and quality assurance. We will be keen to follow this up with families to see how it works in reality.

The NHS states:

‘DSRs and C(E)TRs are central to the NHS Long Term Plan commitments by 2024 to:

- *reduce the number of children and adults with a learning disability and autistic children and adults in mental health inpatient services*
- *avoid inappropriate admissions to mental health inpatient settings*
- *develop responsive, person-centred services in the community.’*

‘Early identification of people at risk of admission to a mental health hospital and their access to person-centred planning and support are essential for the prevention of avoidable admissions. If someone with a learning disability or an autistic person does need to be admitted, this should be for the shortest time possible and during their stay they should receive high standards of mental health and physical healthcare.’

The keyworking service needs to be fully involved in the local DSR and CETR systems and play a major part in assessing the progress of the child/young person they are supporting.

Most pilots have taken a major role in the oversight and ownership of the DSR, including establishing a clear criteria (and referrals process where this was not in place). Some pilots play a significant role in supporting CETRs to develop into more effective multi-disciplinary meetings and keyworkers have proved crucial in making sure recommendations from CETRS were actioned by services.

We are watching with interest the growing feedback from existing projects to learn more about how keyworkers manage the ending of support. The key elements need to be a graduated 'step-down' period; a clear handover and re-integration into provisions such as school and college; and an identified route back into the keyworker service should the need arise.

Recommendation 7

The keyworker service needs a fully accountable monitoring, evaluation, and review process.

ESPCF has heard from many families who are extremely frustrated by the lack of accountability or consequences when services do not provide support according to the legislative requirements, and when agreed actions are not followed through. This is one of the most important factors in the breakdown of trust between families and the local authorities/health providers.

It is essential for the new keyworker service to have transparent processes that can provide evidence of accountable monitoring, evaluation and review. As an evolving service, delivery will need to adapt in response to any identified gaps and problems.

Monitoring and evaluation need to show clear evidence of the impact of the keyworker service for the children/young people and families who have been supported. This must be very specific with evidence to demonstrate improvements using recognised evaluation tools such as those prescribed in the National Keyworking Evaluation Framework. Where families give their consent, ESPCF will collect a more detailed narrative of their experiences.

According to early adopter sites, evaluation should seek to answer the following questions:

- Does keyworking help reduce the risk of autistic CYP and CYP with learning disabilities going into mental health hospitals?
- Do CYP experience prompt, coordinated care, feel involved in their care and feel safe and happy?
- Do parents/carers feel listened to and informed and experience a reduction in stress and uncertainty?

There will need to be mixed methods of evaluation, analysing quantitative and qualitative data to understand the impact of keyworking.

Data collection must include monitoring outcomes. Pilot services have recommended creating a baseline from each child/young person and their family with a follow-up approximately four months later. Qualitative methods should cover how keyworking is being implemented; the context in which the service is being delivered; and what key factors are impacting on outcomes.

Conclusion

As stated, the purpose of this ESPCF report is to inform the development of an East Sussex keyworker service as specified by NHS England.

We have listened to families and heard about the overwhelming situations they find themselves in and the devastating impact these circumstances have on the children/young people and their families.

We have made use of the CDC jointly-produced documents and initial guidelines on setting up a keyworker service as well as noting the experiences of the early adopters and pilot schemes.

Our recommendations are a direct result of the feedback from families which has been correlated with the initial guidance and subsequent feedback from existing schemes to understand what a successful service looks like.

Regular meetings have just been initiated for ESPCF, the Sussex Learning Disability and Autism Programme and the Senior Commissioner for Children and Young People's Mental Health to look at the progress and development of an East Sussex service.

We look forward to working on this project to see how our recommendations can inform commissioning and how the feedback from those with lived experience can shape service development on an ongoing basis.

We will be keeping parent carers updated and will share what is working, as well as what needs to improve.