

JOINT PARENT  
CARER FORUMS

# Lived experience shaping the Keyworker role

A joint report by South Glos  
Parent Carers and North  
Somerset Parent Carers  
Working Together

MARCH 2022



**Working together  
for SEND families**

BRISTOL, NORTH SOMERSET &  
SOUTH GLOS PARENT CARER FORUMS



# Introduction

Parent Carer Forums exist to champion the voices of SEND families in their local area to ensure that local services meet the needs of disabled children. Listening to the lived experiences of families and working co-productively is paramount during service design, development and review processes to ensure services meet the needs of the people they serve.

The Keyworker Project presents the opportunity to embed this approach from the very start of the development of this service, meaning the best chances for service providers to get it right for families from the get-go whilst working towards meeting commitments set out within the NHS Long Term Plan:

*By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker, implementing the recommendation made by Dame Christine Lenehan. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital. Keyworker support will also be extended to the most vulnerable children with a learning disability and/or autism, including those who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services.*

The Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (BNSSG CCG) spans several local authority areas, so it is necessary to capture the voices and lived experiences of families and young people from each locale. With this shared goal, South Glos Parent Carers (SGPC), North Somerset Parent Carers Working Together (NSPCWT) and Bristol Parent Carer Forum representatives have worked collaboratively to represent the parent carer voice. SGPC and NSPCWT sit on the Keyworker Project Steering Group and jointly facilitate Keyworker focused engagement events.

This report includes the learning from the engagement events and captures the voices of families and young people detailing 11 considerations and recommendations for developing the Keyworker role and service. Accompanying recommendations are foreseen challenges and difficulties that may impede the impact of the Keyworker role and prevent achieving outcomes.





# Voices and lived experience: whom we engaged and how.

The challenges and trauma experienced by families in crisis are often consuming and overwhelming. In capturing the experiences of young people and parent carers, we ask families, across Bristol; North Somerset and South Gloucestershire, to revisit some of the most distressing moments of their lives, so it is critical to acknowledge the value of what families who engaged with us gave.

Families gave their energy, time, courage and voice in the hope of making the experiences of those who follow their journey less challenging. SGPC and NSPCWT extend our thanks and gratitude to these young people and families for placing their trust in us to champion your voices.



# Who and how?

Families and young people in immediate and current crises do not have the time or capacity to feed into engagement processes. With this in mind, SGPC and NSPCWT engaged with families and young people with recent or comparable experience, speaking with:

- Parent carers with a child with autism and or learning disability admitted to a mental health hospital.
  - Parent carers who have experience of Care Education Treatment Reviews (CETRs).
  - Young people with autism and experience of having a support worker or mentor in a role similar to the Keyworker role
- .....
- Five young adults with autism/learning disabilities and mental health needs supported by Child Adult Mental Health Service (CAMHS), three of these young people required independent specialist school placements, two of which were residential placements.

In addition, we spoke with some professionals about their thoughts on the Keyworker role which are included here as quotes.





# Engaging parent carers; key considerations



- The nature of the issues discussed called for a sensitive engagement approach that built-in time and space for parent carers to share their stories, support one another and compare their experiences. Group numbers were purposefully small yet representative of the different experiences of families across local authority areas.

# Engaging young people; key considerations



- Being sensitive to the needs of the young people who feed into the engagement processes is paramount to avoid feelings of being pressured and allow time and space to process questions asked and their thoughts. Young people need to feel safe within the engagement process.

# Methods of engagement; key considerations



- It is necessary to use a variety of methods to gather feedback; approaches taken were:
  - Social media
  - Telephone conversations
  - Online meeting engagement sessions and discussion groups
  - One-to-one online meeting
- At an appropriate time, the discussions moved to focus on the following questions
  - What helped you and your family?
  - How might a Keyworker help?
  - What might have helped?
  - What should a Keyworker do?
- The result is a series of recommendations for developing the Keyworker role based on common themes.





# Planning informed by lived experience: Our recommendations

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## Link, coordinate, advocate and organise

Keyworkers need to function as the family point of contact and coordinate input from other services for effective joined-up working. Families reported feeling overwhelmed by the amount of time they spend chasing professionals whilst attempting to get information. This burden impacts their ability to focus on supporting their child.

Families find that they repeat information and their stories to many professionals involved. Joined up working approaches between services that facilitate appropriate information sharing and a joined-up approach in identifying and achieving outcomes is needed.

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*Having someone who can work with my son is important but I also want that one person to work with instead of being passed to various different professionals or teams. The chasing I have to do has to stop so that I can focus on being there to support my son who needs me. I do not want to be the coordinator of my son's support across education, health and social care when actually this is what services should be doing. If I can say to the key worker this is an issue it would be so very helpful if they could help or take my views back.*

**Parent carer**

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SHAPING THE KEYWORKER ROLE**



# Planning informed by lived experience: Our recommendations

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## Creative and flexible community support alongside information and advice

Keyworkers need to think creatively to personalise support through opportunities within the community if CAMHs or other services cannot offer what the young person needs. Such an approach will enable the young person to receive timely interventions when needed.

Families reported feeling overwhelmed when asked their thoughts on what might help. Involving families fully in the process is essential; families need professionals to be knowledgeable and present them with the options that might be available and suitable.

## A note here on the community-based services; a foreseen challenge

Families expressed how they felt positively about the Keyworker role but had concerns that community-based therapy and support options will also have issues with capacity and lengthy waiting lists External support that may be more personalised than what CAMHs can offer is positive, but is what is out there known and has availability and capacity been fully scoped and explored? .

## A note here on education; a foreseen challenge

Keyworkers should think broadly and creatively in supporting the young person in engaging with education, exploring what options may work and liaising with education settings to broker arrangements and opportunities. As one young person explained: "the reason I cannot go to school is much wider than needing help to get in. It's the lack of support the whole day and how school and the environment make me feel".



*When you ask "what do you feel you need?" I might not always know the help I need. So please think about that when you ask me what support do you think I need, I don't always know. Sometimes it takes me a while to get used to being with someone else maybe over time we will work out what is needed together at a later date.*

**Young person**

*I don't know what is out there, I have researched a lot and I have met people and have found things out but we need guidance on what is out there.*

**Parent carer**



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# Planning informed by lived experience: Our recommendations

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### Suitably experienced and trained

Families spoke of how important it is for professionals to understand autism, learning disabilities and mental health needs. This understanding should be current, up-to-date and gender-informed. Families shared their experience of needing to educate those working with their children.

In addition to understanding needs in general, Keyworkers must recognise the individuality of the young people they support and the understanding that families have of the needs of their children. Families must be listened to and not dismissed.

Families shared concerns that autistic behaviours and traits were incorrectly attributed as trauma or parenting related. Misunderstandings of this nature undermine the ability for services to build a relationship of trust with families, leaving families feeling as though the service did not truly understand their child or autism as a spectrum and its various gender presentations.

### A note here on training; a foreseen challenge

For keyworkers to have a rounded and gender-informed understanding of autism and learning disabilities, extensive and regular training is required. Training sessions with parent carers to hear of their experiences could be an invaluable part of the induction process.



To bed-in, a culture where Keyworkers are up-to-date with the latest information, available services and creative options capacity must be built-in to the service to allow a regular sharing of learning, reflection on reviews and reports and best practice sharing.







# Planning informed by lived experience: Our recommendations

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### Be their advocate

Families and young people spoke of the need for the Keyworker to advocate for the needs and desired outcomes for young people and families. Knowing that there is a professional on your side who will

broker discussions and provide a means of accessing and negotiating services is a way of building trust with families.



*Please remember we may have autism, but we are all different. A flexible bespoke approach is what we need.*



**Young person**

*When my son was in a special school I was gob-smacked when I felt I was trying to explain my son has Autism and this is why he has behaved in this way. I don't have the energy to educate and explain it to another person. A good understanding would be helpful.*

**Parent carer**

*I have taken research about what I think the thing is that we are missing – and the CAMHS professional had not even heard of the research – why am I having to be an expert. There isn't an understanding of what is new, current and out there.*

**Parent carer**



*Trust? It would take a long time, the person would need to understand the child's individual needs – after a year my child's mentor can now see when there is something a bit hidden, my child can't figure out the triggers herself and the professionals get blinkered. Professionals need to be able to shine a light on the bigger picture to give a holistic view. Our children are very complex and if you don't know them, they can be very misunderstood.*

**Parent carer**

*My child looks to me to see if they are saying the right thing, because of (their) anxiety and that is taken by CAMHS as me manipulating her.*

**Parent carer**



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# Planning informed by lived experience: Our recommendations

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## Processes and applications

Families in crisis are often overwhelmed and find themselves navigating several services and processes at once, such as education, disability benefits and health services, and may even require a Care Education Treatment Review (CETR). Each service will have its bureaucracy, paperwork and processes.

Families told us that to take this administrative burden off during times of crisis would make a huge difference. To this end, Keyworkers must understand the various processes and entitlement/eligibility thresholds for different services and benefits. Keyworkers could support families by contributing towards applications such as Education Health Care Plans (EHCPs) and Personal Independence Payments (PIP), reducing the administrative and bureaucratic burdens families face.



*I don't want to do the job of the professionals. I am finding I have to write my child's EHCP as what I had didn't reflect my child's needs, I have to book therapy sessions on the CETR, when you add this to everything else I have to do, I'm exhausted. I need to focus on helping my child.*

**Parent carer**

*Someone to help families navigate our complex systems across health, education and social care. Most families I meet are close to crisis point when I meet them; worn out, disenchanted and struggling. They are crying out for support to help them carry on in fighting for the rights of their child. When I meet them, there is usually some tension, anxiety and barriers within the system that parents need support to unblock.*

**Professional**



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**BNSSG PCF LIVED EXPERIENCE  
SHAPING THE KEYWORKER ROLE**



# Planning informed by lived experience: Our recommendations

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### Planning to prevent admissions and support discharge

Families and young people shared their thoughts on the importance of a support timeline and graduated exit. Young people and their families need to anticipate how long support is available or will last with the graduated conclusion of support communicated, discussed and reviewed regularly.

Arbitrary time targets and support length limits could be detrimental to the young person in achieving their identified outcomes or engaging with activities or resources they find helpful. Concluding support after a time-limited period could undo progress and prevent steps forward in engagement. If a Keyworker can only offer six sessions and the young person is ready to engage further on the seventh, progress and opportunity are lost.

Families raised questions on the regularity and method used to review the dynamic risk register. Questions include:

- Will there be robust triage processes in place to catch families heading towards crisis?
- Which services will be involved? For example, will GPs be able to feed into the process?
- Will families be involved in reviewing their rating on the register?
- If a family communicates urgent needs, how can it be ensured these are recognised?
- Is there a fast route to the register for families suddenly in crisis?
- How will the crisis be triaged?



**Keyworkers need to  
ensure manageable  
timelines for  
discharge plans**




# Planning informed by lived experience: Our recommendations

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## Available, contactable, flexible and reliable

Our discussions highlighted the necessity that services be personalised and adapted to meet individual needs. Presently, young people need to ‘fit in’ with how services operate or are delivered, flexibility is required in how and when the Keyworker works with young people. This could mean Keyworkers being available outside of typical office hours to enable young people to engage with education without regular disruption or access community opportunities in the evening.

How the Keyworker communicates with families or their young person needs to be flexible and convenient and could perhaps use text or apps alongside more traditional email, phone calls and letters. Technology has changed the way young people communicate, as such services designed to meet the needs of young people need to reflect these habits and communication styles.



*It's horrible when I keep being taken out of lessons I don't want to keep telling my friends why I was pulled out. I didn't want to draw any more attention to myself as I just get asked more questions from my friends or others in the class. Others think I have got into trouble or am being told off.*

*A young person*



# Planning informed by lived experience: Our recommendations


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## Soft skills; empathy, patience and understanding

It can take some time for a young person to build trust in a professional. Keyworkers need to be patient and move at a pace guided by the young person, not expecting full engagement or long sessions straight away.

A successful session for the young person may be a 5-minute text message exchange or talking through their bedroom door. Families felt that patience is vital and that pressuring young people to make 'progress' or meet targets in a non-personalised plan when they are not ready would be detrimental. Pressure to engage could overwhelm a young person and lead them to agree to things to bring the conversation to an end, which in all likelihood would cause further anxiety.

Young people also expressed how they felt it is important for the Keyworker to be someone that they can gel with and perhaps someone who has knowledge of or shares a passion for their interests.



*Someone to get alongside the young person. Most young people I meet 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.*

**A professional**

*Think about how you would assign an individual a key worker If you simply say you have a key worker or a mentor my first reaction would be oh no not another effing babysitter.*

**A young person**

*Having people with a variety of needs/interests would be helpful because we might not get on with someone in the team. It's more important the person can connect with us.*

**A young person**

*Please remember we may have autism but we are all different. A flexible bespoke approach is what we need.*

**A young person**



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# Planning informed by lived experience: Our recommendations

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### Wholistic and robust support for families

Families spoke of how important it is to recognise that a child or young person in crisis is also a family in crisis. Children and young people exist within a family dynamic, where there could be a sibling or carer with a disability or clinical health needs.

Families need to be understood as a whole, concentrating on one part of what can be a much bigger and more complex picture may not form the foundations required for successful outcomes for the child or young person. Support for the whole family is often necessary.

### An important note on parent blame and viewing families primarily through a safeguarding lens

Some of the families who engaged with us to share their experiences shared how their lives had been made more difficult for reaching out to services for help. How can it be that services intended to support children and young people leave families feeling broken and traumatised?

Parents experienced blame and found the time in front of professionals was spent analysing them, rather than focusing on the help sought. Safeguarding should (of course) always be a consideration, however, families felt interactions with services were being viewed through a safeguarding lens, interpreting common autistic traits as evidence of parental coercion and control or other malfeasance.

To share further examples here could inadvertently reveal identifiable information, every effort is made to protect and uphold the confidentiality agreement of our engagement and discussion events with families and as such, supporting quotes are not included here. For further understanding of the experiences of parent blame, one can hardly recommend more the 2021 report written by Luke Clements and Ana Laura Aiello for Cerebra and the University of Leeds; [Institutionalising parent carer blame The experiences of families with disabled children in their interactions with English local authority children's services departments.](#)



# Planning informed by lived experience: Our recommendations

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## Accountability; monitoring actions and outcomes

Families shared feeling frustrated that there is no accountability or consequences for services when they fail to follow up and complete actions agreed in meetings. Holding services to account may not be an appropriate aspect of the Keyworker role, however, it does highlight a concern born out of the experience of families that there is currently no consequence for not meeting outcomes and completing actions, for not carrying out simple tasks such as communicating with families or researching options and liaising with services.

Not doing what is promised and agreed in working towards identified outcomes for a young person undermines trust. Families we spoke with agree there should be an appointed independent person to review processes and ensure actions are completed and outcomes are met; a person whose role has the purpose of ensuring accountability without prejudice.

## A note; on monitoring the KPIs and outcomes of the Keyworker project.

Alongside the outcomes at the individual level, there is a real need for transparent KPI and outcome monitoring at the project level. Regular reviews involving the three parent carer forums to monitor how the service develops and whether it achieves its aims is necessary.

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*It feels like there are too many people involved, no accountability, sloping shoulders. Not much gets done beyond arranging meetings. Needs to be more targeted and have the right people with accountability (at meetings). Most of the outstanding actions remain with CAMHS. I can never seem to get them to do their job.*

**Parent carer**

*It can seem like no accountability as so many people involved.*

**Parent carer**

*Why is there not an independent CETR chair?*

**Parent carer**

*It is down to the parent when their plate is already full and if I don't do it, it doesn't get done. I don't get minutes from meetings, they are not shared so actions are rarely kept on top of. Social care is the worst, go to a meeting and get handed the minutes from the previous meeting at the next meeting.*

**Parent carer**





# Planning informed by lived experience: Our recommendations

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## Ensuring the triage process does not fail to recognise the needs of young people with high-functioning autism

Families raised concerns about the Keyworker service setting a threshold for eligibility that does not meet the need of young people with high-functioning autism.

Families told us that these young people; seemingly having less complex and immediate needs, on paper, often struggle the most with their mental health. Young people, particularly girls as recognised by the DSM-5 “perhaps because of subtler manifestation of social and communication difficulties” can experience missed diagnosis and misdiagnosis. Families discussed the emotional and mental drain of masking and more subtle manifestations of autism traits. It takes its toll on mental health and can result in crisis if not recognised for what it is. Families have described how hard it is to find support in these scenarios.



*No one should assume that just because someone is ‘high functioning’ that they are able to cope well in life and have little difficulties. ‘High functioning’ academically along with being articulate does not reflect on the complex mental health difficulties which can be extremely debilitating and escalate very fast...My 17-year-old son who has only recently been diagnosed with ASC (‘High Functioning’) has been struggling with his mental health for most of his life, but has been able to ‘mask’ because until he went into crisis, he thought everything he was experiencing was ‘normal’ ... He ended up being an inpatient for nearly 8 months due to his complex needs, and whilst it was the only place to keep him safe at the time, and provide him with intense therapy required , the environment itself was not suitable for his ASC needs ...Since being in recovery at home , he has been able to have an environment which is much more suitable for his needs. However, having had a relapse and going into crisis again, his levels of anxiety were increased by the thought that he might need admitting again. Luckily, being on the dynamic register and the ability to have an emergency CETR , meant that all professionals were involved, working together to put as much as possible into place to be able to keep him at home and support him and us all as a family through an incredibly difficult time....All of this has been extremely stressful to navigate...Having a keyworker to support my son and us as a family would make so much difference to us all.*

Parent carer



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# In conclusion

## The potential positive impact of the Keyworker role for families, children and young people



• The potential for the Keyworker project to have a positive impact on the lives of autistic children and young people experiencing mental health difficulties; can not be underestimated. Working closely with the young people and families who require Keyworker support has the potential; for a very personalised response to needs.

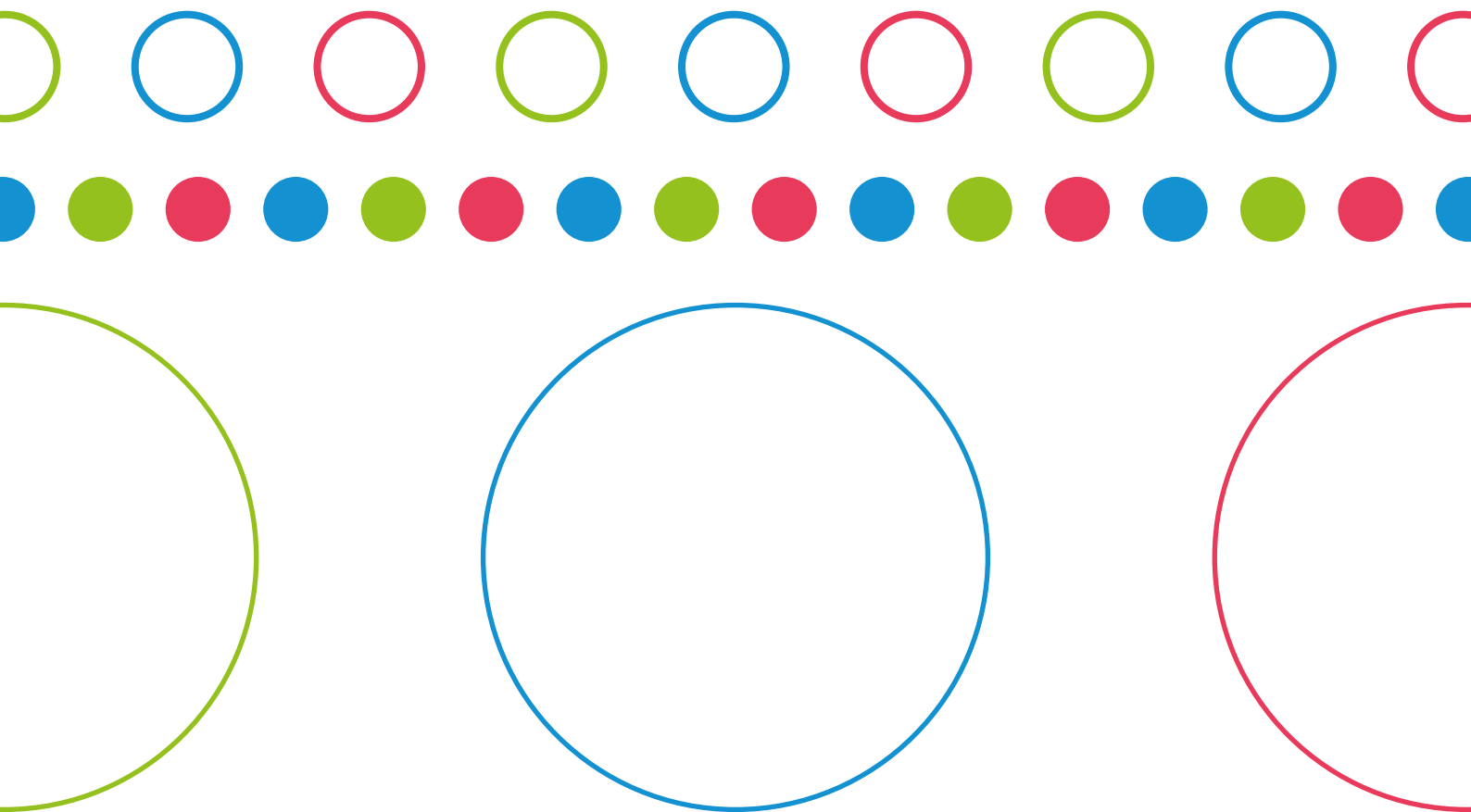


• Coordinating the provision and working in a joined-up manner across services and voluntary sector organisations (once availability and capacity have been scoped) could mean timely support within the community and presents families with support options rather than merely thresholds unreachd, facing a void, or lengthy waiting lists. This is vital to getting help to prevent crisis and assessment units admission.



• Through careful development, review and coproduction, listening to the voices of young people and family carers alike, this project can give, as Dame Lenehan put it, *'the necessary outcomes for this group of children'*.





**Bristol Parent Carers**

E: [info@bristolparentcarers.org.uk](mailto:info@bristolparentcarers.org.uk)  
T: 07306 650 222  
W: [www.bristolparentcarers.org.uk](http://www.bristolparentcarers.org.uk)

**North Somerset Parent Carers  
Working Together**

E: [admin@nspcwt.org](mailto:admin@nspcwt.org)  
T: 01934 440 844  
W: [www.nspcwt.org](http://www.nspcwt.org)

**South Glos Parent Carers**

E: [team@sglospc.org.uk](mailto:team@sglospc.org.uk)  
T: 01454 501 009  
W: [www.sglospc.org.uk](http://www.sglospc.org.uk)



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