

NO TIMEOUTS: UNDERSTANDING THE IMPACT OF BEHAVIOURAL DIFFICULTIES ON CHILDREN AND FAMILIES

Impact
on Urban
Health



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Foreword

Impact on Urban Health

All children should have the same opportunities to be healthy and to thrive, no matter where they grow up. That applies to mental health as much as physical health.

When children have strong, positive mental health, they are more able to deal with challenges, adapt to change, and to build healthy relationships throughout their lives. But their ability to do this depends far more on where they live than it should.

Children growing up in inner-city areas like the London boroughs of Lambeth and Southwark, particularly in families living with financial insecurity, are more likely to have mental health issues by the time they hit adolescence. NHS data tells us that children from families living on low incomes are over three times as likely to experience behavioural difficulties¹, but we know that a lot of research perpetuates stigma and inequity. Current data often focuses on ‘types of families’, for example, their income, whether or not they are nuclear – rather than the inequalities and discrimination they are subjected to, that put such a huge burden on their mental and physical health.

It is not unusual for young people to express their fear, sadness, frustration, or other strong emotions through their behaviour and interactions with others. This is especially true for younger children who don’t yet have the language to communicate in any other way. Experiencing a range of emotions and behaviours throughout childhood is healthy; feeling helpless and out of control is not.

Behavioural difficulties like those experienced by the children in this report are hugely distressing for both the child and those around them, and can have a significant, long-term impact on their lives. They can affect children’s friendships, family relationships and education, as well as their physical health. For these children, early support is vital and can prevent difficulties from becoming more severe as they get older. But children and families living in areas with the highest levels of inequality and poverty are not only more likely to need this support, they’re also less likely to get the early support that they need.

At Impact on Urban Health, we want to tackle inequality in urban areas that makes it more difficult for some children to thrive. Our Children’s Mental Health Programme will work with a wide range of partners to focus on reducing inequalities and inconsistencies in support that many families face when a child experiences behavioural difficulties.

As we developed the programme, we were struck by how little research looks at behavioural difficulties from the perspective of children or their families. That’s why in early 2021, we commissioned Renaisi and Close-Up Research to help us better understand the reality of life for those affected by behavioural difficulties. Over several months, Renaisi and Close Up talked to 18 families living in the London boroughs of Lambeth and Southwark about how behavioural difficulties were impacting the whole family.

What is clear from interviewing families is that many of us who are working to improve children’s mental health are failing to really listen to the experiences of young people or those who know them best. Families say they find the de-personalised, often clinical way of thinking and talking about behavioural difficulties extremely alienating and stigmatising.

Parents consistently reported a feeling of being judged and labelled, which often left them isolated from friends, family, and other community support networks. And for many families, the fear of having children taken away from them can make it feel impossible to seek formal support.

Those who do seek formal support report that it is often hard to navigate, inconsistent, and comes too late. It's evident that much of the available support doesn't currently work for families. It doesn't take into account their context – cultural, financial, familial – or importantly their own expertise. A recurring theme across the interviews was families describing not being listened to or believed, not feeling that their knowledge or understanding of their child is recognised or respected.

One stark if not surprising insight from families is that those with less disposable income and resources find things even tougher. Not being able to afford childcare, have time or money to spend on their own wellbeing, or live in a secure home with enough space all adds to the huge stress faced every day.

Our programme on children's mental health is just getting going and insights from the research raise as many questions as answers. But three of the main areas I think it's vital to explore, both here at Impact on Urban Health and with others, are:

- **How do we increase understanding of, and reduce stigma around behavioural difficulties?**
- **How can we ensure that all families get the support that they need when their children start to experience behavioural difficulties (including support for parents' mental health)?**
- **How do we make sure parents and communities play a role in designing and providing support?**

We cannot hope to make meaningful, lasting change to children's mental health without centring the expert voices of those with most experience. I hope the insights shared by the young people and families in this report start a different kind of conversation about behavioural difficulties and children's mental health, and look forward to working with partners to tackle this complex issue.



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This report sits alongside several other outputs from the research:

- Family portraits that tell the individual stories of the 18 families who took part, click [here](#).
- A podcast featuring a mum and her son who talk about their experience with behavioural difficulties and the impact it has on their lives, click [here](#).
- A video case study in which we see first-hand the daily life of a family impacted by behavioural difficulties, click [here](#).

Content warning

The issues raised and experiences shared in this report are upsetting and potentially triggering. They include domestic abuse, violence, racism, extreme emotional distress, and trauma.

Executive summary

Impact on Urban Health

Introduction

Mental health problems affect around one in six children and young people aged 5-16 in England as found in research conducted by NHS Digital in 2020.² Around half of all lifetime mental health problems start by age 14. These figures are likely to increase as the long-term impact of the pandemic becomes clearer, made worse still by the cost-of-living crisis.

Too few young people get the right support for their mental health when they need it. This is especially true for those children from families dealing with falling household incomes and systemic inequities, who are more likely to experience behavioural difficulties.

By better understanding these young people's lives, rather than reducing them to a clinical diagnosis or statistic, we start to understand more of the complexity, underlying issues, and societal factors, as well as the impact on the whole family. We can also begin to think about how we can intervene early to prevent children's behavioural difficulties becoming more severe as they get older.

What do we mean by behavioural difficulties?

Children and young people often communicate their distress through their actions. During childhood and early adolescence, mental health problems can present through behavioural difficulties. The language around behavioural difficulties is sometimes hard to navigate. All children's behaviour can be challenging at times, but some children experience persistent and more extreme behavioural difficulties that have a significant impact on their lives. These young people may be diagnosed with a conduct disorder – an overarching term to describe both conduct disorder (CD) and oppositional defiant disorder (ODD).³ The prevalence of conduct disorders across England is estimated to be 5.6% in 5–16-year olds⁴, but limitations in data mean this could be much higher. They are more common in boys than girls⁵ and evidence suggests they are more of an issue in inner-city areas where families experience greater inequality and discrimination.⁶

Oppositional defiant disorder (ODD):

'This involves markedly defiant, disobedient, and disruptive behaviour that takes place frequently and has been going on for a while. It is more common in younger children, and examples include losing their temper, being defiant, angry, and resentful, argumentative, and spiteful. The child generally struggles to comply with adult requests, instructions and family, school, and social rules.'⁷

Conduct disorder (CD):

'This involves behaviour that is much more severe than normative adolescent rebelliousness. It is more common in teenagers and is characterised by frequent defiant, intimidating and/or aggressive behaviour. It involves limited compliance with instructions and serious breaking of family, school, and social rules. Examples can include fighting, cruelty to others, destruction of property and theft. The young person might be absent from school and/or home. In general, the young person may not show remorse, guilt or concern about their behaviour.'⁸

Research context

The clinical definitions of behavioural or conduct disorders can feel very stark and dehumanising. They completely miss the complexity of each child's life and the experiences (often traumas) families have been through, both at a personal and societal level. As part of this ethnographical research, Renaisi and Close-Up Research spoke to 18 families living in the London boroughs of Lambeth and Southwark. As well as being where we are based, Lambeth and Southwark are also representative of inner-city areas across the country, where poverty and affluence exist side by side and inequality has a huge impact on individuals and families.

The researchers attempted to capture a range of experiences including different family sizes, ages, ethnicities, and family structures, as well as differences in the nature of the behavioural difficulties themselves. We were particularly keen to hear from families who were already accessing some form of support, as we need a clearer understanding of what is currently working for the people in the boroughs, and what isn't.

We know that those who took part are not representative of all types of families living in the boroughs, or the UK more widely. The programme does not define families by any heteronormative standard and we hope to work alongside many kinds of families as we build a more equitable evidence base. It is nevertheless the case that lots of the experiences shared in this ethnography will apply to a diverse range of people and families living in inner-city London.

More details on the sample criteria and characteristics of the families can be found in the [appendix](#). This research prioritises the experiences of families. They are best placed to talk about the realities of day-to-day life when a child has behavioural difficulties and are the experts on what they need. Because so many families feel judged or shamed, there can be a reluctance to share their stories. The emotional labour or trauma of talking about your experience might also feel pointless if you do not believe it will lead to any positive change.

Renaisi and Close Up Research focused on creating safe and inclusive spaces where families could feel confident to share their experiences, at a time and in a format that worked best for them. Those conducting the interviews made it clear that this kind of in-depth research is rare, particularly in the context of behavioural difficulties, that the family's insights would help inform our Children's Mental Health Programme, and hopefully the work of others, in coming months and years. You can read more about the research methodology [here](#).

Key considerations

Behavioural difficulties are hugely distressing for families – but especially for those already facing inequality

Behavioural difficulties have a huge impact on the whole family and can take a particular toll on mums. Though lots of families were anxious for their child not to be labelled or stigmatised, they also wanted people to understand how difficult and extreme things could be at home. Many talked about their own mental health issues, including being signed off work due to stress and anxiety.

Some mums reported having to give up work all together, to home school and care for children with behavioural difficulties full-time. Those that are unemployed or on lower incomes described struggling to pay for things the family might do together, making the situation even harder to cope with. Home schooling combined with limited access to disposable income meant some parents had no opportunity or space to get away or calm down when things were very stressful.

Among the families on lower incomes, poor housing conditions were far too common – including damp, disrepair and not having enough space. Many parents and children felt this exacerbated behavioural difficulties, as it could be hard to maintain a comfortable home.

Feeling judged or mistrusted has a huge impact on families getting support – especially for those who are already labelled

Fear of judgement or even punishment can leave families feeling as though they have to get through this alone. Without the respect or trust of those in a position to support, like schools or social workers, many parents feel that their children are being written off, that they aren't really listened to, and that support is not as effective as it could be.

Lots of families felt that the way they and their children were talked about meant they became defined by the behavioural difficulties. Reducing a child to a label or diagnosis, often ignores that they are also kind, loving, funny young people with just as much potential to thrive with the right support. Parents were proud and excited to talk about their children's strengths and positive traits, as well as those that were challenging but were equally anxious about their child being labelled, given up on or treated differently. That isn't to say that some of the behaviours described in interviews weren't extreme and don't have a huge impact on the mental health and wellbeing of the whole family. Many of the parents who took part in the research talked about how hard day to day life is, and how they wished the severity of their situation could be understood without the judgement.

Parents talked a lot about how isolated they have become – feelings of embarrassment, shame and anxiety are common, as well as fear about being judged as a 'bad' parent. This was exacerbated by other labels families felt they'd been given, like 'single parent' or 'low-income'. They described play dates, social activities and peer networks as feeling inaccessible because of the challenges of children's behaviour, and said they often avoid public spaces when their child is distressed. There were some examples where mums felt that other family members were avoiding them or not inviting them over because they were worried about the impact on their own children, or it was too much for them to handle.

Although there were some positive examples of support from schools, many families felt that their child had been labelled as 'naughty,' and that schools didn't recognise or accommodate their specific needs. Where schools were described as more supportive, this was often down to an individual teacher being proactive, or children attending specialist settings that could more effectively support with the behavioural difficulties. Several children had been excluded and parents were struggling to find new schools, and home schooling in the meantime. There was a definite sense from parents that schools don't want to deal with children experiencing behavioural difficulties, or mental health issues that are seen as 'disruptive'.

A lot of existing support isn't fit for purpose – especially for those who can't pay for it

Many parents talked about how daunting it is to access support, not knowing where or how to start. Besides the fear of judgement, permanently labelling their child, or even having children removed from the home, some parents felt they had to convince professionals that their child needed help in the first place. They described complicated and slow systems that required them to piece support together, going through the same steps with multiple people, and a sense that they'd be able to access help more quickly if they could pay for it. While attempting to navigate all this over months and even years, lots of children's mental health continued to get worse.

Most families interviewed were accessing support from different sources – for example, Child and Adolescent Mental Health Services (CAMHS), parenting programmes, schools, or voluntary and community sector (VCS) orgs. Support did not follow a linear journey and tended to be short-term.

Families who had higher incomes were generally more confident to navigate the system and advocate for their children's needs.

The main criticism of services such as CAMHS and support through schools was the time it took for support to start. Many families said they didn't feel believed or trusted by institutions, and described questioning that seemed to doubt their account of the situation.

There were mixed experiences of parenting programmes, and most of the positive feedback from families focused on the peer support available in between meetings. Many felt that more 'formal' support placed parents in a position of blame, rather than focusing on how to manage the behaviours within the context families live in.

It's important to note that some of the families who received earlier and more empathetic support felt relieved, positive, and hopeful. Though this wasn't the case for many it is clearly possible.

ETHNOGRAPHIC RESEARCH

The following write up is provided by Renaisi, who worked with Close Up Research, to hold interviews and capture insights from families over several months.

Understanding of the behavioural difficulties

Most children will display challenging behaviours at some point in their lives. However, the behaviours associated with CD and ODD are more extreme, frequent and persist over time. One of the aims of the research was to explore parents and children's own interpretations of the behavioural difficulties and the ways they navigate daily life.

Research questions covered in this section:

- » What is the lived experience of families where one child or more has a behavioural difficulty?
- » What does the behavioural difficulty entail – what are the signs?
- » How do parents and children describe the behaviour?
- » What triggers the behaviour?
- » What do families understand about possible causes?
- » How do families cope on a daily basis?

The nature of the behavioural difficulties

Families' descriptions of their children's behaviour revealed the extent of the challenges they were facing. The most commonly occurring behaviours were:

- **Physical:** banging head against the wall, running across the street, kicking doors and walls, throwing things.
- **Verbal:** screaming, shouting, swearing, using rude, abusive or racist language.
- **Aggressive or violent acts towards other family members:** hitting, punching, biting, kicking, pinching.
- **Controlling and manipulative behaviour:** towards other family members.
- **Breaking possessions or things inside the house:** furniture, tyres on a car, smashing TVs or tablets.
- **Aggressive acts towards teachers and classmates:** biting, hitting, fighting, threatening to severely hurt others.
- **Poor behaviour at school:** disrupting class, refusing to stay in class, leaving school during the day.



"She'd call them black this, black that, she was really bad. Saying she'd kill them, saying that she'll bring a knife to school." (Family 12)

"Once you get to know him, he can be very rude. I don't know how to describe it... You can see the difference even physically between when he's in one of them rages to when he is not." (Family 6)

"He can be argumentative, loud and rude, violent and he can smash things up." (Family 18)

"He was running in and out of each room, throwing anything that was in his way." (Family 16)

There was no noticeable correlation between the severity or frequency of the behaviour and having a diagnosis. Four of the families had experienced police involvement (for incidents at school and home, and in one case for common assault and robbery). These were all young people aged 11 or over and had either a suspected ODD diagnosis and/or an existing ADHD diagnosis.

There were a number of themes across the families:

- Uncontrollable anger and not being able to regulate emotions:** parents used words such as 'outburst', 'tantrum' and 'meltdown' to describe their children's behaviour, particularly among younger children. The behaviour of older children tended to be described as more confrontational and aggressive, though still involving 'flare-ups'.

"I don't think he can control anything he does at the moment. I don't know if it's anger, I don't know if it's something mentally. But I know he can't control it." (Family 6)

- Children having two sides:** several families explicitly referred to their children having 'Jekyll and Hyde' type qualities where they could be good one moment and then suddenly switch. Situations could quickly escalate, and in some cases last for a prolonged period of time.

- The behaviour being worse at home:** there were four families where school was the sole focus for the behaviour and two where it only took place at home. However, the majority of families reported that home and school were both sites for challenging behaviour. Parents in at least four of the families felt their children could be more controlled in other contexts outside of the home.

There were two families that talked about how their children often showed little awareness or no regret or remorse after an outburst. One of these had no diagnosis, and the other suspected ODD.

"When he wakes up the next day, he will act like nothing has happened and does not acknowledge his behaviour." (Family 13)

It was more common for children to apologise after or explain that they could not help their actions in the moment.

"She says she doesn't mean to act the way she does in those flare-up instances. She 'can't help it' and feels bad afterwards." (Family 12)

Others felt that their children could apologise but did not really understand what they'd done.



"I've got an angry head and you upset me, you telling me to do stuff I don't want to do."

(Child, Family 4)

"Sometimes I get mad and it feels like I'm shaking."

(Child, Family 6)

"It's just my mind that tells me to become angry."

(Child, Family 18)

Triggers for the behavioural difficulties

Identifying triggers for their child's behaviour was sometimes hard for families because the situation could be unpredictable with no obvious pattern. However, the majority of parents in the cohort had been living with their children's behavioural difficulties for many years (at least four or more) and could cite multiple triggers. There were some common themes:

- Not getting their own way and subsequently feeling things are out of their control.**
- Resisting doing something they had been asked to or refusing to follow instructions.**
- Being told off or having access to something restricted:** this could trigger further or extended outbursts in many families.
- Other less frequent triggers included:** children being tired (particularly at the end of a school day), anxiety around changes (for example, transition to secondary school or being asked to do something new), lacking confidence or getting easily bored.

In the families where researchers spoke to children, they tended to pinpoint feelings of anger at being denied something (for example, phones or remote controls being taken away or access to the internet restricted); reacting to being told off by their parents; or being provoked by siblings or situations at school.

"What makes you angry?"
CHILDREN IN THEIR OWN WORDS

Q **Researcher:** When there are certain things that you won't be able to get that week – how does it make you feel when your mum says that to you?

A **Child:** I actually get quite angry.

Q **Researcher:** What do you do if you're getting angrier... what might then happen?

A **Child:** I might sometimes shout.

Q **Researcher:** When you're at home, why might people be shouting at you? What's normally happened when people shout at you?

A **Child:** I've done something bad.
(Family 2)

"I get angry when my brothers annoy me. It makes me even angrier when they punch me. I am the angriest when I don't get to see my favourite movie. When I'm at my angriest, I feel like throwing things. I sometimes throw things when I'm angry. I feel like hitting or pushing."

(Child, Family 6)

Parents' views on initial causes and explanations for the behaviour

There is no single cause for behavioural difficulties, and the risk factors are often complex and interrelated. They can be individual (for example, related to gender, co-occurring conditions); within the family environment (for example, abusive situations, relationship breakdown, parenting styles, living in poverty); and outside the home (for example, being bullied, negative peer influence).¹⁰

In the interviews, we explored parents' views on what might have caused the behavioural difficulties in the first place, encouraging them to think about their family circumstances at the time.

Trauma

Five of the families disclosed that they were survivors of domestic and/or emotional abuse from ex-partners, and felt certain that even though their children were young at the time, they would have seen some of what was happening.

"There was a lot of domestic violence, verbally, mentally, physically. And my son witnessed quite a lot of abuse as a really tiny baby... I had special measures on my property because my ex-partner threatened to take my son, kidnap him and throw acid in my face... So I had to cut him from our lives completely. More so for our safety, and my other two kids." (Family 6)

In the group of families with an ODD diagnosis (confirmed or suspected), one family had experienced the sudden death of the father, and mum subsequently saw her son's behaviour worsen afterwards. Another was adopted as a baby and had witnessed trauma in the early months of her life with her birth mum.

There were also concerns that mums could see traits from dads (and themselves) in their children.

"I see his dad in the anger and realistically in the craziness. I've got screws loose. So that combined in my son, he's going to have a toolbox full of loose screws up there." (Family 14)

Family environment

Thirteen families in the cohort were single parent households. In some of these cases, the changes in family dynamics were associated with seeing their children's behaviour alter. This could include relationships that had ended badly, mums working full time, childminders looking after children during the day, and fathers moving elsewhere.

"He wasn't happy about me leaving them, and their dad going abroad. So at that time, his behaviour started changing." (Family 15)

Several of the families talked about housing instability at the time that the behavioural difficulties first started – often linked to the aftermath of a relationship breakdown. One family had to move around a lot in the early years of her son's life, including periods of time in refuges. Another was homeless for a while, and one family was in shared accommodation until eventually moving into a flat which had no furniture.

Sibling jealousy

Three of the families had seen their child's behavioural difficulties escalate when a younger sibling arrived on the scene and their mum's attention went elsewhere (these were all children with either no/another diagnosis). This often led to jealousy and in some cases, aggressive behaviour towards the sibling.

Other health issues

Several of the children had health issues early in their lives which parents felt contributed to their behaviour. Examples included: a stammer which caused frustrations in communicating; being premature and having sepsis; anaemia and scarlet fever; and bad asthma.

This often meant periods of time in and out of hospital, and mums then reflecting that they could be overly protective towards their children in recognition of them going through a difficult experience.

For children who had other diagnoses (for example, dyspraxia, autism, ADHD) frustrations such as poor motor skills and struggling to concentrate or learn to read and write, were also seen as possible causes for subsequent behavioural difficulties.

There were also examples of anxiety, low self-esteem, and attachment issues in about a third of the families. Several families mentioned that their children had been bullied at school and felt this was another contributing factor to behavioural difficulties.

There were some families in the cohort who acknowledged they had different parenting styles with the child with behavioural difficulties compared with other siblings – normally around setting fewer boundaries or spoiling them (for example, if they were the youngest child).

"We put in boundaries where I didn't do with my youngest son, I do feel like it has affected him where now he's so used to getting away with it... It's very hard for him. It's got to the point now where I feel like he's just confused with what are the rules and what are not the rules." (Family 16)

Coping strategies

A key area of focus in the interviews was how parents react and deal with outbursts. The aim was to understand whether there were strategies or coping mechanisms at home (and elsewhere) to try and manage the situation both in the short-term and long-term.

The strategies that parents used broadly divided into the following categories:

1) Let the episode run its course

A third of the families explicitly said that they try to ignore the behaviour when it is happening, and even walk away from the situation.

"I let him have his tantrum, ignore him, and let him deal with it in his own way." (Family 18)

Parents (and siblings) often felt that the behaviour was demanding attention so staying calm meant the child would eventually get bored and stop.

2) Asserting authority

There were many examples where parents did intervene:

- Several mums admitted that they would be more likely to intervene around family at home as other family members were used to the behaviour.
- In public, parents were often more likely to intervene to quickly deflect the situation – for example, by buying their children something, or trying to talk them down.

- Removing or restricting items was a common strategy although, as outlined earlier, this could sometimes then aggravate the situation.
- One family had a designated 'naughty corner' for her son and would get him to write lines.

3) Using different tips and tricks

There was a middle ground between the two extremes of standing back or taking a more authoritative role. For example, at home, one mum would take her child into another room where others were not around so he did not get any extra attention and she could deal with him calmly.

Many of the parents had been on parenting courses (discussed further on page 33) and they referred to specific techniques they had tried out. These generally involved acknowledging what was happening while maintaining boundaries. These included:

- Doing breathing techniques together to try and calm down (but this became less successful as the child got older).
- Having more frequent and smaller punishments rather than one severe one.
- Allocating special time where they can focus on giving their children their full attention.
- Learning to reward good behaviour.
- A pyramid tool called 'Ignore, Distract and Redirect' which has helped set boundaries.
- Keeping a clear structure at home – for example, around mealtimes or homework etc.

The complexity of finding the right approach

It was apparent that parents worry constantly about how to manage different situations, particularly for younger children. In some cases, they had been advised by professionals to ignore their children's behaviour, and they could end up feeling bad if they engaged rather than ignored. It was common to fear being criticised by professionals if they reacted badly to their child's behaviour.

Many of the parents were aware that they could be inconsistent in their approach – for example, they would be pushed to a point where they reacted out of sheer frustration or when their patience had run out. Several mums felt that their children knew exactly where their trigger points might be and could use these to their advantage.

"Sometimes I get angry and I threaten him. I say you know what, there will be a time I'll leave you when I can't take it anymore." (Family 6)

Some mums were aware their own mental health conditions could impact on their responses and lead to emotional highs and lows in the way they communicated with their children. One mum had Emotionally Unstable Personality Disorder (EUPD) and had experienced a breakdown:

"My responses to things are either too little, that make it look like I don't care; or they are completely extreme and make it look like I'm just a psycho." (Family 14)

Things children do to calm themselves down

In the families where we interviewed children, we asked them what kinds of things helped calm them down when they were feeling angry or upset. The main strategies children used were watching TV or playing games. Often this would be alone in the room where they could have some peace and take themselves out of the situation that had triggered their anger.

Other calming strategies that children identified including drawing being outside and listening to music.



"My room is a peaceful place. Closing your eyes and just forgetting about what's happening. Rest your eyes, and then you just rest. And then you might not feel so angry."

(Child, Family 2)

"I feel calm when I have peace. When I go somewhere alone like in the bedroom. I play games there."

(Child, Family 6)

Impact on family life

Living with a child who has a behavioural difficulty has an undeniable negative effect on life at home and on the wider family. The stories that the families shared demonstrate how much changes for families – in terms of what ‘home’ means and how it is experienced on a daily basis, but also the individual toll and impact on parents and other family members.

Research questions covered in this section:

- » What impact does the behavioural difficulty have on home life?
- » What are the main challenges families experience in managing their home life?
- » What impact does the behavioural difficulty have on parents?
- » What impact does the behavioural difficult have on other family relationships – siblings, and wider family members?
- » What impact did lockdown have on home life?

Home life

There was an overriding sense across all the families that home was not a happy place and could be tense or strained.

Although there were examples of things that families liked to do at home (watching TV, or playing games), home life often involved:

- **Not spending time together inside their houses:** sometimes this could be because the children were older, but also because time together could risk provoking arguments.

“We’ll all just be on our devices.” (Family 11)

- **A constant battle:** the behaviour that families described happens regularly – sometimes on a daily basis. Even when the more aggressive and violent elements are absent, there can be constant negotiations and resistance, resulting in a self-perpetuating cycle of winding each other up.

“Every tiny thing is a struggle.” (Family 2)

- **The child with the behavioural difficulties dominating home life:** Either by controlling situations or demanding a lot of attention.

- **Challenges around mealtimes:** these were frequently cited as another battleground – families with younger children often mentioned that their children were fussy about their food and would only eat certain things.

Nearly half of the families specifically highlighted struggles around maintaining a nice home because their children could break things around the house. For those on low incomes, replacing items was not always feasible. Household chores could also lead to further disputes. Many of the mums felt their children did not care what the home looked like and would refuse to clear up or do any housework.

“We have a rota to share the housework. The children comply apart from my son.” (Family 7)

“She won’t help around the house unless she gets a reward.” (Family 5)

Wider housing circumstances could also contribute to homes not being safe or nice spaces. Ten of the families reported issues with their housing. Unsurprisingly, this was most pronounced among the families on lower incomes. Poor housing conditions included structural issues such as damp or disrepair, but also not having enough space, and having to share bedrooms (between siblings, or in some cases, between the mum and their child).

Low quality, cramped housing is undoubtedly an ongoing risk factor. The main impact of this lack of space is that family members have nowhere to go for privacy or if they need to be alone. Where the home environment is uncomfortable, then the families' wellbeing suffers, which in turn contributes to the ongoing behavioural difficulties.

"It would probably be like easier if we had like a proper house because we live in this really small nasty flat at the moment. If we could all have our own space we could go to, where we could actually shut the door. Because if we shut the door here, it gets too damp. So a place we can lock the doors and like shut the world out. If that makes sense." (Sibling, Family 4)

The impact on parents

Wellbeing

The impact on parents was most noticeable on their mental wellbeing:

- Half of the mums interviewed described feelings of anxiety, stress, exhaustion and frequently feeling drained, upset and unable to concentrate. Some had sought help for anxiety and depression and were on medication.
- Where dads were involved, they also reported not being able to cope well with the situation.

"I feel I am constantly on edge and worn out."
(Family 13)

- Some parents had existing health conditions (for example, arthritis, lung conditions, post-natal depression, multiple sclerosis, anaemia, asthma, migraines, EUPD) which contributed to an already stressful situation and could leave them feeling even less able to cope.

Three of the families raised specific issues with sleep – either because their child was often up late (which then had a knock-on effect on their own sleep patterns) or parents' own challenges with sleeping due to the overall stress of the situation.

"I don't always sleep properly. So I always wake up really tired and recently because we had a bad patch I'd been awake tossing and turning till 3am. So I feel really, really, really tired." (Family 2)

The main overriding theme was the sense of loneliness and isolation parents could feel. This is linked to reduced social circles (see page 26) but also feeling responsible, misunderstood and blaming themselves for their child's behaviour. This could then become another contributing factor in making the situation worse as it is harder to parent consistently and effectively when resilience is low and multiple issues are being balanced.

Impact on daily life

About a third of the families reported that their child's behavioural difficulties had an impact on their working lives.

- In two families, parents had been signed off work for periods of time due to the overall anxiety of the situation.
- One mum had ended up out of work for three years after her daughter was expelled and then home schooled.
- Morning struggles with their children could mean mums turning up to work either late or already exhausted.

"I actually need to be emotionally ready for work. Whereas some days I'm not, and I've had to say to people, I just need five minutes. I just need a time out." (Family 16)

It was also apparent that parents could have very few opportunities to do something for themselves at home or to relax. For those whose jobs had been disrupted by the pandemic, this was also linked to finances.

"I miss going to swimming lessons, yoga, gym, sauna, and so many other things, out with friends but it does cost and once I get a good income I can start back that again." (Family 1)

Impact on family relationships

The interviews with the families revealed the impact that a child with a behavioural difficulty can have on different family relationships.

Mum and the child with the behavioural difficulty

These relationships were often very complex. In the interviews, many mums described the close, loving bonds they had with their children, and their many good qualities.

"He is my baby. I love him so much." (Family 1)

"He's very, very cuddly and can be incredibly cute and sweet." (Family 2)

"She is very lively, very funny. She used to be like the nursery rhyme, you know, when she's good, she's very, very good." (Family 5)

However, mums were often the main focus of their child's anger and frustrations, dealing with personal and hurtful insults.

"It makes me feel like it's a personal vendetta, like he's personally out to get me. And I've said this so many times: like he's six years old, He is so vindictive and manipulative it is shocking." (Family 14)

"He will tell me I'm the worst person in the world, he hates me and doesn't want me around." (Family 8)

Mums could often fear their children especially as they were getting physically bigger, and it could be harder to manage or constrain the behaviour.

Contrasting Perspectives

Communication: In one family, a teenage daughter talked about the trauma she now knew her mum had experienced, and how this combined with cultural differences to make communication challenging between them:

Managing Emotions: In one family, a mum talked about her reactions after a family fight and the frustrations she can feel towards her young son. She internalises these emotions to try and protect her son. Their bond is close, as evidenced by the son talking about his love for his mum:

"Because the way she grew up in Africa, back then they were more tough love...If I look at it from an outside point of view, there are certain traumas that she hasn't worked through... because she wasn't given the space to emotionally work through them, or the emotional support from that parent."

(Daughter)

"I leave her alone. The only time I speak is when I absolutely need to. The hostility from her is just... just give her the space."

(Mum)

[after a fight between the siblings] "**I felt drained and like 'oh this again.' It was a bit of frustration and I'd say a bit of anger. I do get upset. I don't cry or anything or if I do, I don't do it in front of him but I do kind of get disheartened and I feel bad for him as well.**

(Mum)

My mum is important because she does everything for me. She does everything that's good... My favourite thing to do with my mum is getting a hug."

(Son)

Relationships with dads

This was another complex area in the interviews. In the majority of single parent households, fathers were not actively involved in their children's lives. One was in prison, another lived outside of London, and others were simply not around consistently.

In two families, the children also spend time at their dad's house which could help give mums some time out from the situation.

These different arrangements appear to have the following impact on the child:

- **Children idolising their dads:** as the parent they get to spend time with doing enjoyable things in a different setting.
- **Feelings of rejection:** where dads have let down their children by not being around or breaking arrangements for time together.

Where parents were together, the behavioural difficulties could also have an impact on the relationship between mum and dad:

- In three of the families, dads worked long hours and were not around much. This meant mums were dealing with most of the practicalities and emotional labour alone, and dads did not always directly witness the worst of the behaviour.
- Mums reported that it could be hard to spend any time together as a couple if no-one would look after the children.

- Three families were very aware of their inconsistent parenting styles which could lead to their children playing them off against each other – for example, with mum being strict, but dad deciding not to intervene.

Sibling relationships

Most of the families that participated in the research had more than one child. In at least seven of the families, siblings were often the focus of the challenging behaviour on an ongoing basis. Siblings experienced taunting, deliberately provoking fights, taking their possessions, verbal insults, and being physically attacked.

"He wants her phone for instance, and she wants it at that particular time. So he'll go up and punch her in the face." (Family 4)

The Impact on siblings

- Feeling like they don't get any attention from their parents.
- Feeling embarrassed by the behaviour of their sibling.
- Feeling scared of their sibling.
- Not getting any time to themselves that is free from interruptions.
- Getting into trouble themselves with parents for things that they did not do.
- Arguing with parents because they perceive they are unfairly treated.

"Sometimes I'm like embarrassed because he can be really loud and we live close to a lot of people and they can all hear it and everything."

(Sibling, Family 2)

Siblings can react in different ways to the behavioural difficulties. Sometimes they fight back, withdraw entirely, or if possible go elsewhere. Elder siblings could occasionally play an active role in trying to mitigate the effects.

"His elder brother will be the one who often goes looking for him, or helps him calm down by doing an activity together such as playing on the PS4 or going to the swings." (Family 13)

It was apparent that there could be a ripple effect through sibling relationships. Five of the families expressed concerns that siblings were beginning to emulate the challenging behaviour 'following in their footsteps' or pushing the boundaries of what they could get away with.

While this was not explored in great depth, at least two of the families had siblings with ADHD diagnoses (though not displaying the CD and ODD type behaviours alongside).

Several mums were very aware that their children really did not like each other as a result of the behavioural difficulties.

"They hate each other. And no matter how many people we get involved to try and mediate a relationship between them two, it's just not working... And the fighting is getting so violent between them." (Family 14)

In five of the families, siblings lived apart for at least some of the time, either because their brother/sister was at a specialist residential school, they themselves were at boarding school, or they spent time with another family member.

Other family relationships

The role of other family members can be important in terms of informal support but can also cause parents additional issues when the family members have opinions or judgement on the behaviour and overall situation. While seven of the families had no immediate family nearby, at least six talked about how close they were to their own parents and that they played an active role in supporting them – either looking after their children at points, or being a source of advice when needed.

There were a few isolated cases where extended family members had close relationships with the children – for example, an uncle who enjoyed coaching football and did this regularly with his nephew to help out. Where family members were helping out, this could become less frequent as the child got older as they could struggle to manage the behaviour.

"Granny would like to look after more but it's the case of being scared of being overpowered. Because he has pulled my mum down in the kitchen and she has a dodgy hip." (Family 4)

Both close and extended family could cause additional problems for parents. They do not see day-to-day examples of the behaviour and can downplay the severity, or even question the diagnosis as a result. Extended family members can often say things that contribute to feelings of shame and guilt, or give parenting advice that is not helpful such as "needing to be more firm".

"They just see him as a bad child. He's not a bad child, he's just – it's been difficult for him. And being a teenager is difficult in itself." (Family 17)

There were some examples where mums felt that other family members were avoiding them or not inviting them over because they were worried about the impact on their own kids, or it was too much for them to handle.

"Some of the family members, they have kids. They don't even invite us because of him." (Family 7)

Other family members can also have views on parenting styles. This was most apparent around generational differences – two of the grandmothers interviewed talked about having stricter disciplinary techniques and questioning some of the advice their daughters had been given on how to manage the behaviour.

Impact of COVID-19 lockdown on home life

Most families reported additional pressures during lockdown on life at home. With everyone under one roof, experiences could be even more intense with no outlet for their children's anger or frustrations.

Mums felt this pushed their patience to the limit, alongside having to deal with their own anxieties about the pandemic.

"I didn't have patience and strengths to be able to cope with him. And so I probably shouted at him and told him off when he was upsetting me because I couldn't cope with it myself." (Family 2)

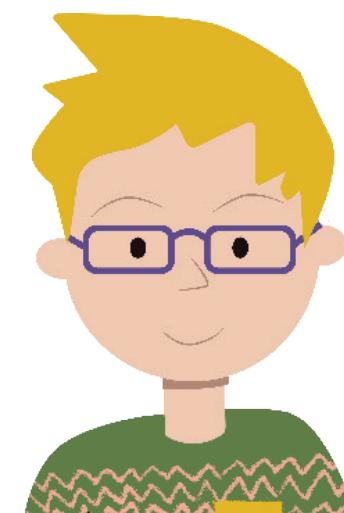
For several of the families, lockdown took away the structure they were working hard to instil. It also made it harder to maintain boundaries and rules – for example, around going to school.

"It's such a battle getting him into school then all of a sudden there was no school. He was like 'why are we not going to school, you tell me you get in trouble if I don't go to school and I get in trouble'." (Family 4)

Final observations

The majority of the fieldwork discussions focused on experiences of life at home, and the findings in this section illustrate the extent of the challenges being faced – both on a personal level for parents, and on different, wider family relationships.

However, it is important to recognise that many of the mums had aspirations and goals for themselves – for example, using lockdown to do online courses; gaining qualifications to start new careers; setting up businesses from home; and volunteering in the local area. This could be hard to fit in around the stress of managing home life, but serves as a good reminder about the importance of not making assumptions about parents' desires to improve their circumstances for the benefit of themselves and their children.



Experiences at school

The research explored the experiences of children and young people at school, recognising the important role these settings play in shaping their lives. The children we spoke to told us a little about school, and parents had their own perspectives too.

Research questions covered in this section:

- » What impact does the behavioural difficulty have on relationships and interactions at school?
- » What impact does the behavioural difficult have on engagement with learning?
- » What impact did lockdown have on experiences at school?

Across the 18 families there were a variety of different schooling arrangements in place:

- Nine children were in mainstream schools (mainly those with no diagnosis, but also the two with a CD diagnosis).
- Two were at specialist residential schools (two of the girls with an ODD diagnosis).
- Two were attending mainstream schools but only for part of the day (one had a suspected ODD diagnosis and the other no diagnosis).
- Two were in local Special Educational Needs (SEN) schools (both had an ADHD diagnosis).
- One was at Summerhouse (Southwark's primary behavioural support service) for part of the week.
- One was at Southwark Inclusive Learning Service (SILS) (and had a suspected ODD diagnosis).
- One was at a private school outside London which had more tailored support for special educational needs (SEN).

Negative experiences at school

Those attending mainstream schools were having fewer positive experiences overall. Getting to school in the first place was often problematic — a third of the families explicitly talked about the difficulty of getting their children up and out to school in the morning. For younger children this often involved incidents in the playground when dropping them off.

"Every day is a fight for him to go through the door."
(Family 16)

Other issues included:

- **Being told off or singled out:** in several cases, schools were perceived by parents as targeting their children in blunt ways with warnings and punishments, or drawing attention to them by being sent out of class for additional support. This could then contribute to anxiety and the behavioural difficulties, and make it harder for children to fit in.

"Measures such as strict detentions with 24 hour isolation is challenging for anyone let alone a child with behavioural problems." (Family 3)

- **Inadequate learning support:** nearly half of the families were aware that their children were behind expected levels of progress at school. One mum speculated that the school did not push her son with his schoolwork as they wanted to avoid conflict. Another child had experienced multiple criticisms for her spelling and writing even though she was diagnosed with dyslexia. In these cases, parents generally felt that teachers were ill-equipped to deal with large class sizes with competing needs, and support from teaching assistants could be inconsistent.

- **Being excluded or on reduced hours:** in both cases where the children were in school for part of the day, parents identified that they were falling further behind. For one child, this was leading to disengagement from learning. For the other, it was feeding into a cycle where he lacked the confidence to ask for help, and would then misbehave, and end up missing more school.

Six of the families reported that their children had been excluded at different points. In two cases, parents struggled to find new schools — one was home schooled for three years instead, and another was out of school for 10 months. His mother speculated that a report from his old school which outlined his behaviour was a major barrier in getting a place elsewhere.

"A lot of schools don't want to deal with children like him." (Family 17)



Positive experiences at school

Life at school was not all bad for children. Some were thriving in subjects they liked, and school was not the focal point for their challenging behaviour.

Positive experiences were linked to:

- **Individual teachers:** who would adapt their approaches – for example, being patient and helpful, rewarding good behaviour and progress, and not always expecting children to follow instructions at the same pace as the rest of the class. However, this could be the luck of the draw and vary between year groups.

"She would say – just sit there quietly. Don't disrupt the rest of your class mates... then in 5-10 mins you'd see him start to pick up the pencil and start doing the work. She'd ask him to tell her the answers – so just doing it in a different way." (Family 4)

- **Specialist settings:** the four young people who were attending SEN schools locally or out of London were all in their teenage years. All of them had negative experiences in their previous schools and were generally happier in their current settings.

Parent's views on specialist and SEN settings

The main benefits that parents reported were:

- Having smaller class sizes.
- More hands-on learning.
- More relaxed structures.
- Being around others experiencing similar challenges.
- Access to additional support such as therapy.

"At first, I didn't really want him to go to a special school, but once he did I could see why they have it like that. Because most schools have bigger classes, so there's more distractions. In special schools, their classes are smaller and then you have the teaching assistants working with them." (Family 17)

A major difference in a SEN setting was that when the children have a bad day it is not held against them the next day – they are not labelled as naughty, the school understand their needs and can help meet these. These approaches were viewed as helping to build resilience, confidence and re-engage children with their learning.

Several families were keen for their children to attend SEN schools in the future because they felt that their children would benefit from more specialist support.


"The school has highly trained staff, vocational learning, and it's customised to the child."

(Parent, Family 9)

"He's never been in trouble in school. He's always getting stickers, always on the rainbow, always getting pupil of the day."

(Parent, Family 14)

The impact of lockdown on education

Around a quarter of the families talked about the challenge of engaging their children in learning online during lockdown. In some cases, this was because an online platform was unsuitable to their learning needs, and no additional support was put in place. One of the families (with a higher income) paid for additional 1-2-1 support online to help their child with remote learning. One family had no devices and the school refused to post materials to them.

By the second and third lockdown the children of keyworkers were back in school. In one case, the school offered the child a place as they knew that it would be better for the family to have some time apart.

Four of the families spoke about lockdown having a more positive effect on their children's education. For one teenager, online learning was actually more accessible. Others found that removing the daily struggle to get to school meant that they could engage in a more relaxed way. Where children were able to go into school, class sizes were much smaller than normal which could also be beneficial.

Final observations

Overall, the fieldwork covered experiences of school life in less detail than home life, but the findings still show the extent to which experiences at school were mixed across the cohort. Some schools were proactive in their approach to the behavioural difficulties and working positively with parents to try and support children well. On the flipside, in several cases, mainstream schools were clearly struggling with how to manage the situation, with the actions taken not helping children or their families. SEN and specialist schools had a tangibly different way of working and interacting with children and there was an overall sense of reassurance and relief among parents (where this applied) that more appropriate support structures were in place.



Impact on wider networks in the community

The family interviews were an opportunity to find out more about their wider networks and how these could be affected by their children's behaviour. We also explored families' interactions with their local area and the things they felt more or less able to do.

Research questions covered in this section:

- » What impact does the behavioural difficulty have on friendships – for parents, and for children and young people?
- » What impact does the behavioural difficulty have on how families interact with their local community? Where do families go? Which places are important to them?
- » How do others react to the behavioural difficulty when out in public?

Children and young people's friendships

Friendships with peers could suffer as a result of the behavioural difficulty. Nearly half of the parents felt that their children did not have many friends and were reluctant to socialise much out of the house. Themes included:

- A few had been bullied at school and found it hard to maintain friendships.
- Some children had a 'flippant' attitude towards friendships and struggled to value them.
- Those who had been excluded or were not often in school had fewer chances to develop friendships.
- Teenage friendships were often close but also volatile.

Rejection by their peers was a common experience – with other children avoiding them at school to stay clear of trouble, or because they had been on the receiving end of aggressive behaviour. Some of the mums feared that other parents had told their children to avoid hanging out with the 'naughty' child. There were three examples given where children were rarely invited to other parties or play dates.

"He's only ever been, in his seven years of life, to three birthday parties. And we know there have been birthday parties, people being given out invitations and he's come home and said my friend's having a party, but I didn't get invited." (Family 4)

Where children had stronger friendships, these tended to be with a few close individuals with a high degree of loyalty and protectiveness, or friends they had made outside of school (for example, at a church group, or through participating in a local hobby). Two of the parents of older teenagers questioned their judgement in their choices of friends – with one feeling strongly that her son's group of friends had influenced his criminal activities.

Several mums talked about trying particularly hard to make sure their children saw their friends – setting up play dates with smaller group of friends and seeking out families who understood the behavioural difficulties. At the other end of the scale, there were some mums who said they often end up restricting their children's friendships because they feared how they might react at someone else's house.

Parents' friendships

Many mums found that their worlds had become smaller, often for practical reasons such as lacking time to socialise, or having to make sure they were around or back to look after their children.

Around half of the mums interviewed felt they had lost friends due to their children's behaviour. This often related to feeling shame/embarrassment about their circumstances and being reluctant to invite people over. It was also common to feel that their friends did not fully understand their circumstances.

"With my friends, I feel like they don't always understand and I feel like I just want to go home. But yeah, it impacts my relationships." (Family 6)

However, a small number of parents talked about particularly close friends who were supportive – either through talking on the phone, offering to help out with childcare, or being non-judgemental.

"Sometimes you just want to have someone empathise with you, say to you... I understand." (Family 10)

Generally, friends were less likely to help out directly with childcare, but a few parents mentioned close friends who had at points taken their children out for activities. In two families, new partners were helping with family dynamics – for example, going out on day trips all together.

"I wouldn't expect my friends to help look after him – they have other commitments, and they don't want responsibility for his behaviour." (Family 13)

Spending time in the local area

All of the families live in inner-city environments, and the majority liked being in London (even if they were experiencing problems with the quality of their housing). Some were on good terms with neighbours who could keep an eye on children when they were playing out on the estate.

Four families identified issues with crime on their estate or local area which they feared could pose risks for their children (for example, being influenced by gangs in the future), and one was keen to move out of London at some point to the coast.

Taking into account the research took place against the backdrop of lockdown, many families mentioned that they appreciated local parks. When open, sports centres, local youth groups, and sports clubs were all examples of things they tried to do with their children, although there were also several mums who acknowledged the reluctance of their children to try things outside the home.

Living on a low income could be a major barrier to accessing things locally. Two parents in particular found it very upsetting that they could not afford to spend anything extra on their children and do things that 'other families do'.

"I'm not working and dad's working, but he's not earning much to help... it's getting expensive as, you know, as they grow. He was like, 'mum, can we do something like just going up somewhere for holidays?' And we never do that. We never did it in our life. And it's really hard to get the money together." (Family 8)

Issues in public spaces

Trips outside the house were not without their challenges. On a more day-to-day basis, navigating public spaces could be problematic:

- Several families had younger children who were prone to running away, putting themselves in danger (for example, crossing a road without looking).
- Public transport and buses could be triggers for outbursts.
- Children being reluctant to leave once they had got somewhere.

This could mean that undertaking ordinary tasks like going to the shops could be fraught with anxiety. Three mums in the interviews talked about the constant process in their minds of playing through different scenarios of what might happen, and trying to head off any difficult situations in advance.

One of the major barriers to being out in public related to the reactions of other people. There were six families that discussed this issue at length and felt passionately that there was a lack of understanding in the wider population about behavioural difficulties. All of these were common experiences of stranger reactions:

- Questioning mothers about not being able to control their children.
- Directly addressing the children and asking them why they are behaving in that way.
- Staring and giving the behaviour an audience.
- Suggesting parents should try different things to try and address the situation.
- Showing visible signs of disapproval such as muttering or commenting under their breath.

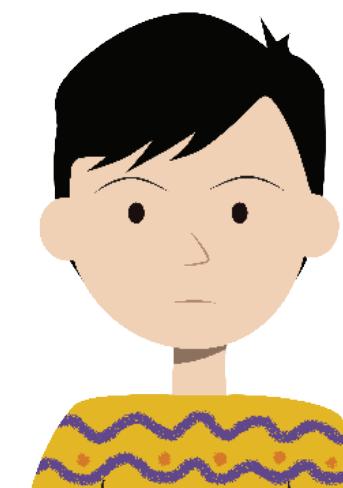
"There are good people out there but a lot of time people just look and mutter under their breaths like 'oh that woman doesn't have control over her kid, look at the way he's talking to her." (Family 6)

Many of these reactions could exacerbate the behaviour, and leave parents feeling even more judged. Several mums felt they did not want to have to explain why their children were behaving in that way and that people should keep their opinions to themselves.

"When he's acting like that in the back of my mind, all I'm thinking of is oh, that person thinks you can't handle it, that person thinks this, that person thinks that... I'm very, very aware of my surroundings when he's having a meltdown because of, I know, especially the area that I live in as well. Everyone is a gossip and everyone is a nosy parker." (Family 14)

"Sometimes we can get asked to get off the transport if he's being too much."

(Sibling, Family 4)



Experiences of support

This section explores families' experiences of support and what was more or less effective at various points in their journeys. There are also recommendations for how to improve support in the future. For the purposes of the research, we defined 'formal' support as anything families were accessing through a professional or community provider beyond more 'informal' support, such as that from friends and family.

Research questions covered in this section:

- » What types of informal and formal support were families accessing?
- » What are their experiences across different stages: first seeking help, beginning to access support, and receiving a diagnosis?
- » At each stage – what has worked well and less well?

Support on offer to families generally falls into one of the following categories:

- **Specialist support:** for example, Child and Adolescent Mental Health Services (CAMHS) who can provide group or individual therapy for children and young people and their families.
- **Support for parents to manage home life:** for example, parenting programmes and groups that help parents with strategies to handle the behaviour.
- **School-based support:** for example, individual support in class, help to focus on positive behaviours.
- **VCS organisations:** for example, running a peer support group for parents, providing activities for young people adapted to their needs.

Overall experiences

The majority of families were already accessing support from a variety of sources for their children and themselves.¹¹ One was yet to seek out formal support, and another two were at the early stages of referrals. Several families had children whose behaviour had stabilised in their teenage years, but ongoing support was vital to maintain the progress that had been made.

Support is not a linear process (for example, where one intervention then leads to another) and it was very apparent across the families how most were piecing together what they could. This could be frustrating for families if they had to repeatedly tell their story to different professionals and organisations.

Overall, the families had mixed experiences of support, but this was not all negative.

First steps: seeking help

As outlined earlier, families could identify the point where they knew something was different about their child's behaviour. However, it was often harder for them to remember when they started to realise they might need help. For most of the families, this was a gradual process involving different sources of information, other people in their lives (personal and professional) and multiple steps.

The main barriers to starting to look for support or talk to others included:

- Fear of being judged as a parent by professionals, and that their children might be taken away.
- Concerns about labelling the behaviour, and that this would then stick with their child for their entire childhood. However, it is important to note that not all families felt this way.
- Not knowing where to go to for help, or what might be available. It could be overwhelming having a lot of information spread across multiple sources, and hard to understand what is authoritative or not.
- The ongoing stress of managing daily life and not necessarily knowing where to start to get support.

A few parents also mentioned needing to feel ready to deal with seeking support as this step would be a public acknowledgement that there was a problem. They needed to feel resilient enough to be ready to hear what professionals might say.

"It's a very slow process as a parent to get your head around having a special needs child." (Family 9)

"Anything out of the norm gets labelled as it's not the right thing. It's not very open.... I'm not ready to hear what they have to say yet." (Family 16)

The first steps that parents took were:

- **Talking to someone at their child's school:** this was the most common first step. For some families, this involved the school encouraging them to seek further help having recognised signs of challenging behaviour. In a few cases, mums had gone to the school because they were feeling overwhelmed by the situation and wanted advice on next steps. Schools could play a role in making referrals to other services (for example, CAMHS, early help, support workers).

However, where children did not display challenging behaviour at school, it could be more of a struggle for families to engage in these initial conversations, unless the school had witnessed the behaviour first hand.

- **GPs:** two families had approached their GP initially who then arranged assessments in both cases for more specialist support. Others commented that they had not approached their GP first as they felt the school might be a quicker route.
- **Doing their own research:** this often overlapped with talking to schools or a GP. Nearly half of the parents interviewed talked about looking into different behavioural conditions online to improve their understanding, reading about support and their rights.
- **Social workers:** three families said that social workers were their first contact for help. For two of them, this was because they were already in contact with social services (for example, because of adopting their child, or being a survivor of domestic abuse).
- **Talking to family members:** where parents had family they were close to, talking to them about the first signs of the behavioural difficulty was often helpful.

Experiences of different forms of support

Experiences of CAMHS

The majority of families had engagement with CAMHS – the only exceptions being three families who were nearer the start of their support journey. Most of the referrals to CAMHS came via contact with the school, or another service, such as Sunshine House (Southwark's Child Development Centre).

Criticisms of CAMHS focused on long waiting times for assessments and support, with the pandemic causing further delays. However, once support did start, many families were positive about what they had received (which tended to be sessions for the children and young people, but also some with parents too). Examples included:

- CAMHS involvement providing more clarity over diagnosis and a treatment plan.
- Helpful and supportive professionals – who were also willing to answer parents' questions.
- Useful and focussed psychotherapy and counselling sessions for children.

The main negatives were that sessions tended to run for a set period of time and it was not always apparent what help would then follow.

"If they get to a wall and they can't go no further, they'd shut your case." (Family 4)

Sometimes support could feel quite generic and fail to take into account wider circumstances – for example, advising one mum to deal with sleep issues by giving the child their own room, which was not possible due to living in an over-crowded flat.

School support

Support in school was the other area that featured prominently in families' support journeys:

- Some children had additional support in place in the classroom – through a teaching assistant, Special Educational Needs Coordinator (SENCO), Emotional Literacy Support Assistant (ELSA) as well as educational psychologists helping to set goals and explore disengagement from learning.
- One family referenced having an Education, Health and Care Plan (EHCP) in place (her son was now a teenager) and two were in the process of formulating them and were hopeful that this would help support better decision making around their children's education.

As outlined earlier in the report, individuals in schools could make a difference to children's engagement with learning. There were also examples of staff (both teaching and those in other roles) being supportive and caring towards parents too.

"They always take me seriously because they saw his behaviour in the school. So they know what kind of behaviour he does develop when he gets angry."
(Family 7)

Support could work well when schools and parents were aligned, and if there had been incidents during the day teachers updating mum on those and working out the next steps together.

School support could also make parents' struggles worse. Unhelpful practices could include:

- Getting involved too late when problems were already quite severe.
- Staff being judgemental or too rigid – for example, reception staff repeatedly marking children as late despite special arrangements being in place.
- Lacking time to adhere to agreed support plans – for example, agreeing a routine, but then giving up on these after a week.
- Poor communication with parents – not keeping them up to date on what is going on.
- Telling parents that they wanted to see the child moved to a SEN school – this could leave parents feeling that schools were giving up on their children.

Experiences with social workers and family support workers

Half of the families had some involvement with social workers or family support workers (for example, through Keeping Families Together or Early Help). Helpful experiences were linked with the personal attributes and an empathetic approach of individual workers.

Positive involvement from social workers and support workers involved:

- A senior social worker coordinating wider meetings with other professionals involved in the child's case. This could be intensive but was seen as useful in making sure actions were followed through.
- Giving practical advice and things to try next accepting that some suggestions might not have worked.
- Doing activities with the children.
- Establishing plans and targets with children.

Less positive experiences included:

- Support coming to an end due to the pandemic.
- Social services setting out 45 days of support and the family feeling this would not be long enough.

- Cases being closed suddenly without an explanation.
- Being judgemental and not seeing beyond the surface.
- Support workers not following through with what they had promised – for example, wider family support such as items for the flat.

"Their attitude was that they are higher than me. They are better qualified. I'm just a single mum with two kids and one is playing up." (Family 4)

Other forms of support

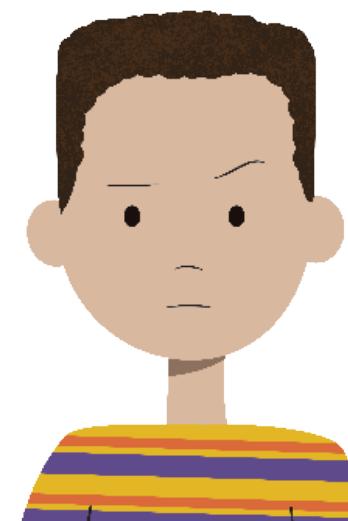
A few other forms of support were mentioned for children and young people although these did appear to be fewer. Two young people had a mentor provided by a charity. One was positive about this as her daughter enjoyed spending time away from home, but the other mum found the support to be inflexible. She wanted to be able to spend the time with her other child but the mentoring sessions had to start and end at home, so in practice, the time was not freed up in the way she would have liked.

Several families also referenced local charities who had good provision or were understanding about children with behavioural needs – examples included Oasis farm, and a photography course arranged by the Baytree Centre in Brixton.

Two siblings also had help – one from a mentor, and another from a charity that arranged annual residential breaks for young carers.

A third of the children in the cohort were on medication for ADHD and this included three who had an ODD diagnosis alongside. This could be a difficult area for families. Most felt that medication had helped their children be calmer. However, there were side effects as it meant that children could come home at the end of school with the medication having worn off which could then trigger an outburst. Several children found it hard to sleep on the medication.

"He has calmed down quite a lot. Sometimes he wants to stop the medication because he wants to be like other children, but he also sees the benefits for himself." (Family 18)



Experiences of support for parents

Parenting programmes

Eleven of the parents had been on a parenting course at some point in their support journey. Some had been on multiple courses from different providers, and one mum had accessed a more intense form of support through CAMHS on a 1-2-1 basis so she could really understand the conditions her child had been diagnosed with. Referrals tended to be through CAMHS, Early Help and schools.

The majority of parenting courses were over a number of weeks and delivered in a group setting (online during the pandemic). Helpful courses included these features:

- Calm and kind facilitators.
- Support in between the group meetings where the facilitator could talk to each parent individually to discuss their experiences of trying out different strategies and provide more tailored advice.
- Space for open discussions where parents were invited to share their experiences, and given the opportunity to talk about how to adapt strategies and ideas to meet the family's individual needs.
- The opportunity to meet other parents in similar situations.
- Supporting parents to understand the reasons behind the behaviour.
- Specific tools and strategies to try out building confidence in managing the behaviour.
- The chance to reflect on what they might have been doing 'wrong' in the past.

"The last one I did was helpful because there were things I used to do and through that I learnt was wrong. Like doing a star chart and when he was misbehaving, taking away the stars. And silly things like that. It was quite intense, it was 13 weeks but I put myself on that." (Family 6)

Although most parents were broadly positive about parenting courses that they had attended, there were some more negative experiences. These included:

- Facilitators not listening to parents or giving them time to speak.
- No arrangements in place for childcare or a creche making it practically hard to attend.
- Providing materials in printed format when a mum had explained she was dyslexic.
- Going through a textbook and having a formulaic approach.

Overall, parents emphasised the importance of courses that placed the parent as an expert (in their family) rather than a problem. They also felt that courses could be provided too late in their journey where it became about parenting skills, rather than earlier on and how to support their children to prevent things getting worse.

"I've done the course now for 5-6 weeks now... I've taken this opportunity to learn as much as possible...they're amazing people that have been able to get on this group.

(Parent, Family 18)

Other support for parents

A few families highlighted how parent support groups could be a useful form of peer support. The Lambeth ADHD parent support group was highlighted as the organisers brought in doctors and psychologists to talk more about different conditions.¹²

However, other families were less positive about peer support more generally having tried these out in the early stages of looking for help for the behavioural difficulty.

"I've never been part of any of those groups again because it just makes you feel more helpless rather than in control of the situation." (Family 9)

There were very few examples of dedicated therapeutic support focusing on parents' own wellbeing. One had accessed talking therapy through Lambeth, and another counselling via work. Some were already in touch with GPs about their own health conditions and being prescribed anti-depressants that was sometimes accompanied with the offer of counselling.

Support during lockdown

Lockdown did have an impact on support, but not as profoundly as might have been anticipated. Although some courses and appointments stopped or were delayed, others moved online. Several families in the cohort were assessed and referred to CAMHS during this period. This could be more problematic for children who did not necessarily want to sit still for an hour during an online call, but where parenting courses moved online, this could actually make it easier for parents to participate, as they did not need to arrange childcare.



Receiving a diagnosis

There were mixed views about the role a formal diagnosis could play in support. Some families felt it was important as they linked it to the possibility of being able to access more appropriate support. For those who had a diagnosis, they often felt it had not led to any tailored help with the pathways of support remaining unclear.

CD and ODD diagnoses: the children and young people who had a CD or ODD diagnosis mostly had other diagnoses alongside, ADHD being most common, that had been diagnosed earlier. Families were not convinced the CD/ODD diagnosis made any difference in practice to the support they received and was 'just another label'. One mother had been referred to a parenting programme (*Incredible Years*) after the ODD diagnosis, but there did not appear to be any CD/ODD specific strategies or advice for families.

Two families were unsure as to whether the CD had been correctly diagnosed and were still pursuing other diagnoses alongside. For example, one mum felt certain that her son had autism and wanted this to be confirmed one way or the other to help understand the different aspects of his behaviour.

Families who were awaiting the outcome of an ODD diagnosis had a more positive perspective as they felt it would be helpful to have it more explicitly laid out that their children needed behavioural support to manage emotions and anger.

Other diagnoses: where children had ADHD diagnoses, this seemed to have given some parents more clarity on what they were dealing with which could be a relief.

"I knew there was something wrong. And for me it was just, ah, right. So this is what it is now we know what it is. Now we can help her. Now we know what we have to read up on. So it kicked me into action."
(Family 9)

Several families had experiences of being told their children were 'borderline'. This was viewed unfavourably as it leaves parents in limbo and unsure of their next steps.

One of the biggest criticisms of the assessment process was that it could only be effective if professionals went to different settings to see how children behaved differently.

Overall experiences of support:

What works less well

Across the families, it was clear that:

- Support often starts with parents having to convince others that they need help.
- Support is laden with stigma for parents – placing them in a deficit position where they feel blamed for their parenting style, rather than receiving help to address the behaviour.

The main criticisms were:

- **Not being holistic:** overlooking other wider issues that contribute to the behaviour such as education, housing, and health.
- **People lacking warmth in their interactions:** many families are at the end of their tether, and can take criticism more acutely and notice 'jobsworth' attitudes.
- **Focusing too much on negative behaviour:** discussions being framed through their children's worst qualities rather than their positive attributes.
- **Not being listened to:** many families raised this in different contexts (sometimes at schools, sometimes from CAMHS, or social workers). This could sometimes change when people directly saw what was going on and stopped doubting parents' accounts.

- **Inconsistency:** many of the children already struggle to build rapport with others and could find it hard to engage with support if workers changed.
- **Timebound support:** interventions not being designed for more sustainable changes to family life. Most felt that the sessions were delivered over a long enough period to develop an understanding of what was really happening, but also that there is a high risk of 'going off track' as soon as that ending happens.
- **Poor communication:** not being kept updated on progress or next steps was frequently cited. For example, when parenting courses, or a block of counselling sessions come to an end it is not always clear what will happen next, and this can cause parents considerable anxiety.

Overall experiences of support: What makes a difference

Where support was considered more effective, it involved:

- **Good coordination:** involving elements that focused on the wider context and family circumstances. This included examples of Sunshine House helping a mum write letters to get housing support.
- **Availability out of hours:** one family referenced a crisis line they were able to ring in the middle of the night where a professional was able to speak to their son and calm him down.
- **Where parents had done their own research:** it could be empowering to know what the options are and use this when negotiating with professionals.

Turning points

In the interviews, we explored where a turning point might have been that really made a positive difference. This seemed to vary considerably between families. Examples included:

- » Where this was applicable, children being in a specialist school was transformational.
- » Having a good support worker who could help with the whole families' needs.
- » For those nearer the start of their support journey – parenting courses were helpful in starting to get exposure to different strategies and approaches.
- » An individual in a particular setting who was almost fulfilling an advocacy role and able to help parents make progress or unlock barriers. In schools these were sometimes class teachers, or specialist workers such as the SENCO or ELSA.
- » In one case, getting legal support unlocked a financial blockage at the council over paying for a place at a specialist residential school.

Other observations: Injustices in the system

There were two other themes that emerged in the fieldwork that are worth briefly outlining.

Discrimination: some parents felt that they wanted to protect their child and give them the best chance, but had to really push for this to happen. Sometimes this could be related to racism and class.

"Even though that I am not from the white background... I know how to protect my child, you know, and I was really clear about that. Even though we don't have a wealth, even though we don't have anything, but she is in that school and she should be treated equally." (Family 11)

Income: there were three families in the cohort who had higher incomes. Their children all had an ODD diagnosis (alongside other diagnoses). It was very apparent that they had the tools (such as confidence and knowledge) to navigate different forms of support more effectively and work their way through the system. Ultimately, they also had the financial resources to deploy where needed:

- In one case, the family were paying for a school outside London with smaller class sizes.
- Another was confident in her rights because of her professional experience (and that of her husband who worked in a local authority).
- The family that accessed legal support acknowledged their privilege in being able to pay for this and how it had meant a massive increase in the financial package from the council for their daughter.

"What does a family do that cannot justify this expense and doesn't have someone to recommend a great lawyer to them? The vast majority of people really don't have this access and it makes me sick. It just makes me feel guilty and wonder how many children go with far less support than my daughter has."
(Family 9)

The overriding sense from the families on lower income was that they had few options for any respite as these would all come with a financial cost.

"If you've got money, you get a nanny, you send them to boarding school... you can walk away and you can actually get a rest of your mind back... If you haven't got the money, basically, it just feels like, get stuffed."
(Family 13)



Conclusion

Impact on Urban Health

We were incredibly moved by the insights and experiences captured by Renaisi and Close-Up, and struck once again by how little we had read previously from family's perspectives. Listening to children and their families has demonstrated the huge impact that behavioural difficulties can have on people's lives. This is in addition to the better known impact on a child's school attainment, future employability, and links to crime, which without the broader context reduces children to statistics and feels extremely deterministic. Through these interviews, we learned about distressed children isolated from friends, singled out or excluded from school; brothers and sisters scared of what to say and do, not living at home or spending as much time with their families; and the massive impact on parents — often anxious, lonely, and trying their best with limited or no support.

It's clear that this is an issue of inequality, and that things are even harder for those with fewer resources and more limited time and money. Insecure, cramped, low-quality housing, the likes of which is so common in inner-city areas like Lambeth and Southwark, can make managing the family's needs feel impossible, with no privacy, no space, and no guarantee they'll be able to stay in that home long-term. And lack of disposable income means many can't plan fun or relaxing activities outside the home either, which is so important for quality family time and rest for parents. This is not to mention the huge mental and physical toll living with financial insecurity brings in itself. Families with more money are sometimes able to access

specialist support quicker and in a more personalised way, but this inequality is framed as a failing on the part of less wealthy parents.

The feeling of being judged and stigmatised for having a child with a behavioural difficulty, and the lack of understanding and empathy so many families face means that even if the right support was available, many wouldn't feel safe or able to access it. In reality, families have to fight for support, which is inconsistent and very short-term, with parents piecing together any help they can find.

As a result of the invaluable and incredibly honest insights shared with us by children and families, we are working with partners to tackle the inequalities, biases and discriminatory systems that make behavioural difficulties worse and leave so many without the support they deserve. We hope that by improving understanding of behavioural difficulties and the distress they cause we can reduce some of the stigma experienced by families, and challenge the unfair, often prejudiced judgements that are so damaging. We want to work with others to build nurturing, safe and compassionate models of support across schools, community-led services and any other system that plays a role in protecting the mental health of families and young people.

APPENDIX

HOW WE APPROACHED THE RESEARCH

The research involved engaging with 18 families living in Lambeth and Southwark between March and June 2021.

Identifying families to participate in the research

We aimed to recruit a range of families to allow us to explore different lived experiences of families where one or more children was experiencing a behavioural difficulty from across Lambeth and Southwark's diverse communities. Recruitment took place via two routes:

- A specialist agency (Plus4) recruited the majority of families by contacting a range of relevant organisations, agencies and local authority departments.
- The research team used some of Impact on Urban Health's existing contacts to help find families who might be interested.¹³

We sampled families across a range of criteria, including the nature of the behavioural difficulty, age of the child, family size, ethnicity, gender and family circumstances. An overarching criteria was that ideally families should be already accessing some form of support. The sample criteria and characteristics of families in the final sample are laid out in the following table.

Main criteria

Families with one or more child with a behavioural difficulty

Focusing on CD and ODD, but also including those who are not yet diagnosed, or with other diagnoses and showing signs of CD/ODD behaviours

Final sample:

- Conduct disorder: 2
- Oppositional defiant disorder: 3
- Note that two families had been told suspected ODD and were awaiting confirmation
- Other diagnosis (e.g. ADHD, autism): 8
- No diagnosis: 8

Age of the child

Equal split between primary and secondary age

Final sample:

- Aged 3-10: 9
- Aged 11-18: 9

Living in Lambeth or Southwark

Equal split between both boroughs

Final sample:

- Lambeth: 7
- Southwark: 11

Other criteria

Family size

Balance of lone parent households and different family sizes

Final sample:

- Single parent household: 13 (includes one where the dad was the primary carer)
- Two parent household: 5
- Three or more children: 8
- Two children: 7
- Only child: 3

Demographics

Balance of different ethnicities

Final sample:

- White British: 8
- White other: 2
- Black/African/Caribbean/Black British: 5
- Asian/Asian British: 3

Gender

Include some females whilst being aware prevalence greater amongst males

Final sample:

- Male: 13
- Female: 5

Family circumstances

Likely to be mainly low income families (£26k per annum and below), but include some average and high income.

Final sample:

- £15,99 or less: 8
- £15,600-25,999: 5
- £26,00-35,999: 3
- £36,500-£51,99: 1
- Above £52,000: 1

An inclusive approach

We were mindful of the importance of creating safe spaces where families felt confident and supported to discuss their experiences. We recognised that finding the time to participate might be challenging, and that their circumstances could change over the research period, particularly against the backdrop of the pandemic.

Our approach included:

- Ongoing informed consent:** consent was not just a one-off at the start of the project. Before each research engagement, the researchers checked with the family whether they wanted to continue, and reminded them of their rights. Parents were required to give consent for any young people participating, but we also sought this directly from children and young people, regardless of their age.
- Choice over how to participate:** the researchers talked through what the research entailed and agreed with each family on how they would like to participate. This included considering preferred times of the day and length of interviews (for example, when their children might not be around), preferences for talking over the phone or on Zoom, and how they like to receive information.
- Incentive payments:** in recognition of the time and emotional cost, we wanted to recognise families' commitment. Every family received an initial payment after their first interview, with a final payment at the end of their participation.

We emphasised to families that participating in the research would not impact on their current engagement with support or influence support they might access in the near future. We stressed that this kind of in-depth research is rare and their insights would help inform Impact on Urban Health's decision making and improve things for families in similar circumstances in the longer term.

Information about the research

This is a quick re-cap of what is involved

What is the research project about?

 Impact on Urban Health (part of Guy's and St Thomas' Charity) is committed to helping urban areas become healthier places for everyone to live. One of their programmes focusses on adolescent mental health and they are in the process of exploring what some of the big issues are at a local level.

This research aims to explore the experiences of families with children with behavioural difficulties.

We know that living with a child who has a behavioural difficulty and trying to get support can be really challenging.

This research is all about the voices of families and making sure these are not overlooked. You know the most about what day-to-day life is really like and the impact the behavioural difficulties can have on your child and your family as a whole.

The research will help Impact on Urban Health to know where best to target their funding – aiming to help more families in the future have more positive experiences and much-needed support.

Useful to know:

Will this influence support for me and my family now? The researchers are not social workers or support workers. They're independent and their job is to help you share your experiences. They can't influence any decisions about services you currently receive or are waiting for.

What do you do with my information? All information we gather will be stored securely and only accessed by the research team. It will be destroyed six months after the project.

Can I change my mind? If you change your mind after an interview you can ask us to remove all of your responses before we analyse the findings (by 1st May).

What does the research involve?

 What kind of things will we be asking you? We will ask you about your day-to-day experiences, the impact that the behavioural difficulty has on your child, your family and other relationships outside the family, and your experiences of support and what could be improved.

 When and how do we want to speak to your family? The research will take place in March and April 2021. It will involve meetings over Zoom or the phone, some short diary tasks to do in between, and activities to engage children and young people. For those who are keen, there are also options to be supported to tell their stories in different ways through a short film or podcast.

 The research will be published in the future – but your family will not be identified or named individually. For those families that take part in the short film or podcast, can choose whether to use a different name and whether they would like their faces shown or blurred.

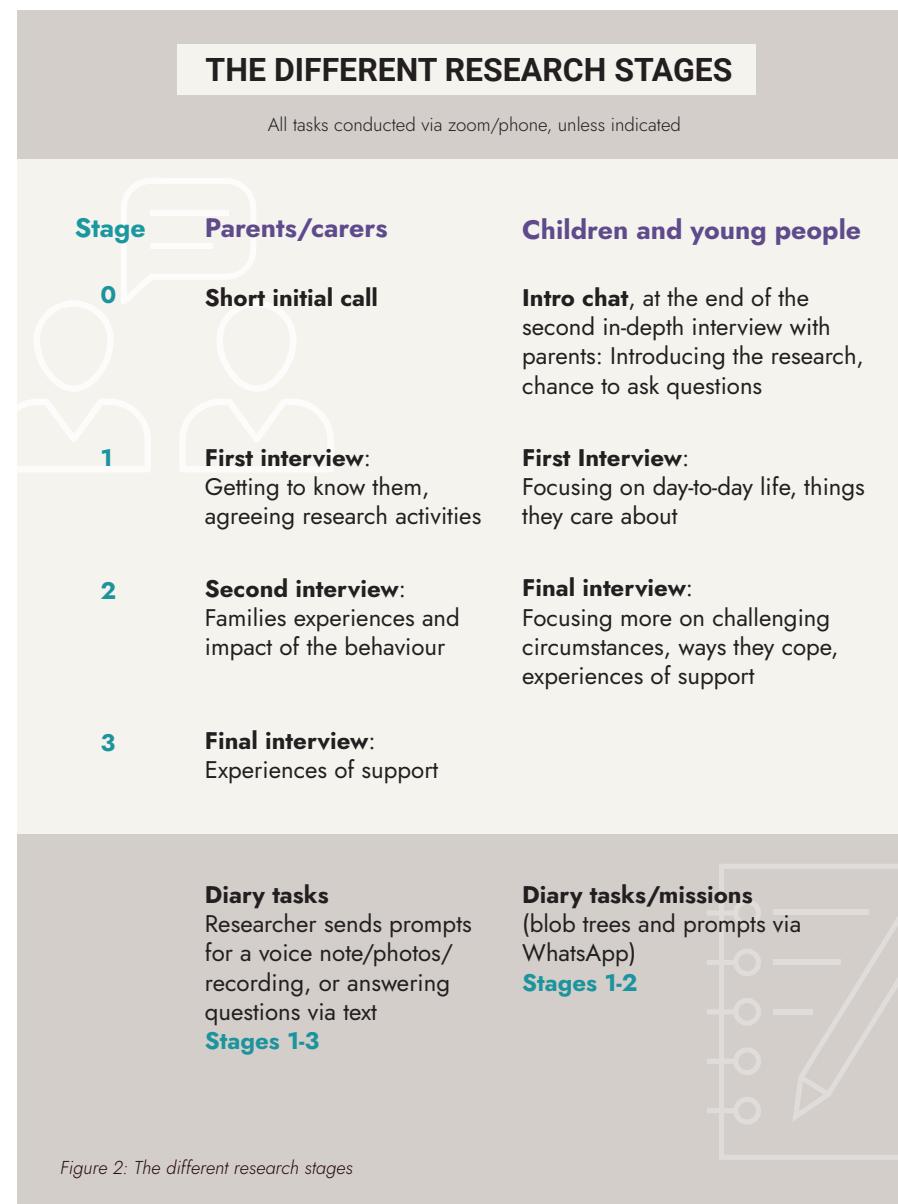
Figure 1: Example of an information sheet from the project

The ethnographic fieldwork

The families shared their experiences over three to four weeks (and in some cases longer) through remote interviews, in-person visits, diary tasks and other interactive exercises. This gave the researchers time to understand families' day-to-day lives and contexts, before introducing the main research themes.

Figure 2 gives an overview of the different research stages. In practice, each family participated in different ways – for example, some preferred to speak on the phone, others used Zoom, and some families met up with researchers to go for walks together in local parks as COVID-19 government restrictions eased in Spring 2021.

Nearly all of the families tried out different diary tasks at various points. *Figures 3* and *4* give some examples of the materials and prompts used to stimulate discussions and explore different themes with parents and children.



INTERACTIVE EXERCISES AND DIARY TASKS WITH PARENTS

Using WhatsApp prompts

Parents were asked to share their thoughts on what had happened that week responding in any way they liked (for example, a voice note, photo, video, text). Questions included:

What has been the most challenging part of your week and why; What has been the best part of your week and why; and: How has the mood amongst the family been this week?



Ways to respond

- Remember if you prefer not to use photos, videos or voice messages, you can just reply to us with a WhatsApp text – that is OK as well!
- Use the voice note option on WhatsApp (by pressing the microphone icon as seen in the image below) – to talk through how you feel or explain your response to a prompt or question we send you.
- Take a photo of something on WhatsApp (by pressing the camera icon as seen in the image below) or attaching a photo you have taken already on your phone – which represents something significant that has happened that day or represents your response to a prompt or question we send you. You may want to accompany your photo with a voice note or a written message that explains a bit about why you took that picture.

For example - that could just be a photo of your coffee mug. because perhaps you had not slept well and you were feeling very tired that day so coffee was super important today.

Your experiences

To help prompt parents to think about the nature of the behaviour, their responses and how others react.

Examples of the behaviour	How I normally respond	What helps about how others respond	What can make it worse about how others respond
?	?	?	?

Your support journey

To prompt a discussion with parents about each stage of seeking support and what this entailed.



The support journey for your family

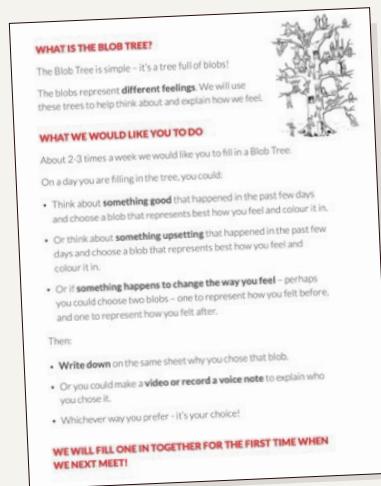
Seeking support → Accessing support → Getting a diagnosis → Future support
 School support → Community support → Friends & family support → COVID-19

Figure 3: Interactive exercises and diary tasks for parents

INTERACTIVE EXERCISES AND DIARY TASKS WITH CHILDREN & YOUNG PEOPLE

Blob tree

A visual that represents different feelings. We asked children to choose a blob that represented something good from the past few days, and a blob that represented something upsetting.



Anger volcano

To help children and young people explore what makes them angry or upset, and the kinds of things that can help calm them down.



Storyboard

With two different scenarios at home and school. Children were encouraged to think about what the characters were feeling, how they were reacting and to decide how they wanted the story to end.



Figure 4: Interactive exercises and diary tasks for children and young people

OVERALL ENGAGEMENT WITH THE RESEARCH

We spoke to parents in the first instance and then explored with them how to involve their children in the research if possible.

The overall number of research engagements was as follows:

- **Interviews with mums:**
 - 53 (not including introductory calls) across 17 families. 12 of these families were single parent households where mums were the primary carer.
- **Interviews with dads:**
 - Six across three families. This included one family where dad was the primary carer, one family where the parents were still together, and one where they were separated but co-parenting.
- **Interviews with the child or young person with the behavioural difficulty:**
 - 16 across nine families. In six of these families, children participated independently, and in three others, we interviewed children with their mum or a sibling present.
- **Interviews with siblings:**
 - Five across six families.
- **Interviews with other family members:**
 - Three grandmothers in three different families and one aunt.
- **Diary tasks:**
 - 44 in total from mums, children with behavioural difficulties and siblings across 14 of the families.

CONSIDERATIONS TO TAKE INTO ACCOUNT WHEN READING THIS REPORT

Understanding behavioural difficulties among the cohort

The families who engaged with the research included some children with a CD or ODD diagnosis, other diagnoses (such as ADHD or autism) or no formal diagnosis. When looking at common trends and patterns across the families, and where appropriate, we analysed the families as follows:

- The seven families that have a CD diagnosis, an ODD diagnosis, or a suspected ODD diagnosis awaiting confirmation.
- The four families that have other diagnoses.
- The seven families that have no formal diagnosis.¹⁴

At the beginning of the project, we were aware that locating families where children had CD or ODD would be challenging given many are not known to existing services. Focusing on CD and ODD was built into the original sample because these are the closest clinical diagnoses to the types of children and young people that Impact on Urban Health want to prioritise for support (for example, those who are at risk of developing severe behavioural disorders in adolescence given the impact on their life chances more broadly).

However, as outlined earlier, CD and ODD can co-occur with neurodevelopmental conditions such as ADHD and autism. In these cases, we had to try and establish if behavioural difficulties were associated with the neurodevelopmental condition (for example, sensory issues, difficulty concentrating) or were the kinds of behaviours associated to CD and ODD (for example, the more aggressive and vindictive behaviours).

This sometimes took us into problematic territory. These diagnoses are labels that can change over time in response to the environment. It can be hard to establish what came first – for example, is the more challenging behaviour triggered by the other condition such as autism or ADHD and the stress of handling particular situations?

Awareness of CD and ODD is higher now among health professionals. In retrospect, it is likely that some of the secondary school aged children in the cohort might have received an ODD diagnosis when they were younger due to the extreme nature of some of their behaviour. Instead, they either have no diagnosis, or another one such as ADHD.

Methodological limitations

As with all social research, there are some limitations that must be taken into account. The study involves a small sample of families, which means that the findings are illustrative of these particular experiences and should not be generalised to a wider population or taken out of context. Families chose to participate, and their experiences will be different to those who we could not reach or chose not to participate.

In this overall report, we have drawn out commonalities and differences from across the families, but these themes should be treated in an exploratory way rather than a robust statement about particular trends.

Fieldwork reflections

Ideally we would have liked to have spent more time meeting families in their own homes as this helps to understand their contexts and observe first-hand the nuances of reported behaviours. This was not possible due to the national lockdown in 2021.

There were challenges for parents to find time away from their children and, in some cases, interviews took place with children in the room or nearby. Researchers were mindful of the sensitivities of some of the questions being asked and adapted accordingly.

The children and siblings we spoke to tended to be older (aged 11 and above). While we engaged with younger children in five families, our reflections are that we probably would have been able to speak to more younger children if it had been possible to meet in person.

Overall, this project provides considerable insight into the lives of the 18 families which can be used to inform future priorities and research. Every family approved their family portrait (see accompanying pdf) and we have done our best to represent their experiences as faithfully as possible.

OVERVIEW OF THE 18 FAMILIES

The individual stories of each family are in an accompanying report. *Table 1* below summarises their circumstances.

The accompanying family portrait pdf has more detailed descriptions of each child's behavioural difficulties.

Family	Description of the behavioural difficulties	Number of years since the behavioural difficulties first started	Household circumstances¹⁵	Schooling	Support accessed based on what families shared in the interviews
FAMILY 1 Carlos (9) Other family members: One sibling Grandmother	CD	6	Single parent Low income	Mainstream	<ul style="list-style-type: none"> — Mary Sheridan Centre for help with speech and language — Sunshine House — Mentor at school
FAMILY 2 Stephen (Note age not provided at the request of the family) Other family members: One sibling	ODD, ADHD, dyspraxia	4	Two parent High income	Mainstream private school	<ul style="list-style-type: none"> — CAMHS, — Social services — Parenting programme — ADHD parent support group — Talking therapy for mum
FAMILY 3 Johnny (11) Other family members: Two siblings	No diagnosis – but referred for ODD, ADHD and dyslexia assessment	3	Single parent Low income	SILS	<ul style="list-style-type: none"> — Social services – Keeping Families Together
FAMILY 4 Zack (7) Other family members: One sibling Grandmother	No diagnosis – behaviour being monitored	5	Single parent Average income	Mainstream primary	<ul style="list-style-type: none"> — Four different parenting programmes — Southwark Family Support — CAMHS
FAMILY 5 Hannah (16) Only child	ODD, ADHD, PDA	13	Two parent Average income	Residential SEN college	<ul style="list-style-type: none"> — ADHD parenting support group — Post adoption support group — CAMHS — Mary Sheridan Centre — Parenting programmes

Family	Description of the behavioural difficulties	Number of years since the behavioural difficulties first started	Household circumstances¹⁵	Schooling	Support accessed based on what families shared in the interviews
FAMILY 6 Colin (8) Other family members: Two siblings	CD, depression	5	Single parent Low income	Mainstream primary	<ul style="list-style-type: none"> – ELSA and SENCO at school – CAMHS counselling – Parenting programme
FAMILY 7 Yusuuf (10) Other family members: Four siblings	No diagnosis	6	Single parent Average income	Summerhouse twice a week	<ul style="list-style-type: none"> – Summerhouse twice a week – CAMHS – Early Help team – Key worker support
FAMILY 8 Emmad (10) Other family members: Three siblings	No diagnosis	6	Two parent Low income	Mainstream primary	<ul style="list-style-type: none"> – Counsellor and ELSA at school – Parenting programme
FAMILY 9 Lisa (9) Other family members: Two siblings	ODD, autism, anxiety, DMDD	9	Single parent High income	Residential SEN school	<ul style="list-style-type: none"> – CAMHS – weekly support for parents over a year – Family therapy – Social care funding for the residential school and carers
FAMILY 10 Raina (18) and Audrey (14)	No diagnosis	6	Single parent Low income	Mainstream secondary	<ul style="list-style-type: none"> – CAMHS – Private therapy – Parenting programme
FAMILY 11 Mahreen (11) Only child	Depression	4	Two parent (divorcing) Low income	Mainstream	<ul style="list-style-type: none"> – CAMHS – psychology sessions – Early Help Southwark – Mentoring – Parenting programme
FAMILY 12 Rosie (11) Other family members: Four siblings	ADHD	8	Single parent Low income	Summerhouse then SEN school	<ul style="list-style-type: none"> – CAMHS – for speech therapy

Family	Description of the behavioural difficulties	Number of years since the behavioural difficulties first started	Household circumstances¹⁵	Schooling	Support accessed based on what families shared in the interviews
FAMILY 13 Oscar (12) Other family members: Dad (co-parenting) Two siblings	ADHD with suspected ODD	5	Single parent Low income	Mainstream but mornings only	<ul style="list-style-type: none"> — 1-2-1 literacy support at school — Early Help support — Social worker — Educational psychologist — CAMHS
FAMILY 14 Jaxon (6) Other family members: One sibling	No diagnosis	2	Single parent Low income	Mainstream	<ul style="list-style-type: none"> — Social worker
FAMILY 15 Nicholas (8) Other family members: Two siblings	No diagnosis	2	Single parent Low income	Mainstream but only half days	<ul style="list-style-type: none"> — Mental health support and a mentor in school — Support worker — Mum on waiting list for therapy — Parenting programme
FAMILY 16 Kyle (3) Other family members: One sibling	No diagnosis	1	Two parent Low income	Mainstream nursery	<ul style="list-style-type: none"> — None at present
FAMILY 17 Joshua (17) Only child	ADHD	14	Single parent Low income	SEN school	<ul style="list-style-type: none"> — Social worker — YOT involvement — Parenting programme
FAMILY 18 Jaydan (11) Other family members: Grandmother, Aunt, One sibling	ADHD	6	Single parent Low income	Mainstream	<ul style="list-style-type: none"> — Teaching assistant, weekly group sessions at school — Dad doing two parenting programmes

RENAISI AND CLOSE-UP RESEARCH RECOMMENDATIONS FOR DESIGNING EFFECTIVE SUPPORT

This section summarises how support for families with children with behavioural difficulties might be improved in the future.

Support should ideally address three main areas:

- **Support for parents' mental health and to build their own resilience** – to help parents cope with stress and improve their own mental wellbeing.
- **Support to help parents with their children** – to validate the concerns of parents and helping them understand the reasons behind the behaviour.
- **Wider holistic support** – to address interconnected causes and issues such as poor housing conditions, unemployment, and engagement at school.

Overall, the experiences of the families that took part in the research suggest that there is a need for:

- **Earlier intervention** – before the behaviour worsens and reaches a crisis point.
- **More accessible information** – support should not be dependent on families' own abilities to research different options and navigate the system, or finding out about different programmes by chance.
- **Faster responses** – to avoid long delays which can then lead to more acute needs. This is particularly the case for schools who are often the first port of call for parents. They need to be proactive from the outset.

- **Clearer pathways and signposting between services** – support tends to be in isolated packages with little sense of what the next steps are, or how different interventions might connect. This can leave families feeling adrift.

- **Sustained support** – support needs to be available over a longer period so parents really get the chance to understand what is going on with their children.
- **Guidance and advocacy** – parents need unbiased guidance through the process of getting appropriate support in place.

Effective formal support (regardless of whether it is provided by a health/local authority professional or voluntary sector organisation) should involve the following key principles which will improve parents' experiences:

- **Transparency** – being clear about what the support is aiming to do and what parents' options are.
- **Collaborative** – working with parents rather than against them. Those providing support need to be consistent, empathetic and caring in their interactions with parents.
- **Consistency** – where different agencies and organisations are involved, having a shared understanding and agreement about intervention strategies.
- **Supportive and empowering** – giving parents tools and techniques to try out with access to ongoing advice or 'low-level' support so that they can talk about what is working and what is not.

- **Reflective** – having a child with a behavioural difficulty is not a linear journey so it is important to learn and reflect as the situation evolves. This entails listening to parents and respecting what they are saying, rather than basing support on an assessment made on one particular day then not deviating from that initial plan.

Underpinning all forms of support (formal and informal) is the importance of trust. It is very easy for parents to feel judged or feel that they are to blame. Professionals and family members can all be guilty of questioning parents' accounts of the behavioural difficulties which can serve to further isolate the family from the support they need. Families need to feel heard and understood.

Based on the findings from this research project, the following areas could help make a difference to the lives of families in Lambeth and Southwark in the future. Areas to consider include:

- **Respite support** – for example, programmes that take children with behavioural difficulties on trips, or centres where children can go to take part in activities that help them control their anger and emotions, and meet other children experiencing similar things. This could help head off situations before they reach breaking point. These could be provided through schools and/or community groups.
- **Informal support for parents** – opportunities for parents to come together and talk. These are often volunteer run and would benefit from more infrastructure support to be more sustainable.

- **Refreshed approaches to parenting programmes** – learning from parent feedback and developing new approaches to programmes. This should incorporate elements that involve more sustained support in between sessions.
- **Mental health support for both children and parents** – waiting lists are too long, and some interventions offered are too short to have an impact. Mental health services need to be provided by a range of different organisations and in community settings to avoid over-reliance on already stretched services.
- **Training for teachers and other support staff in schools** – so they are better able to support parents in the early stages.
- **Information campaigns** – to provide families with impartial and useful advice on their rights, what is available locally, and what to expect at different stages of a support journey. This needs to avoid jargon and include different formats to help accessibility (such as YouTube or blogs).
- **Public awareness campaigns** – there is a need to reduce the stigma associated with behavioural difficulties and talk more openly about what the causes are and how it can be addressed.
- **Addressing wider urban inequalities** – these ultimately continue to present significant risk factors for behavioural difficulties, and then further exacerbate already challenging situations.

REFERENCES

- 1 NHS Digital (2017) Mental Health of Children and Young People in England: Behavioural disorders
- 2 NHS Digital (2020) Mental Health of Children and Young People Surveys: Mental Health of Children and Young People in England, 2020: Wave 1 follow up to the 2017 survey
- 3 National Institute for Health and Care Excellence (2018) Conduct Disorders in Children and Young People. See page 5 for a more detailed explanation of conduct disorder and oppositional defiant disorder
- 4 National Institute for Health and Care Excellence (2018) Conduct Disorders in Children and young people: How Common is it? (Drawing on PHE data on Children and Young People's Mental Health and Wellbeing)
- 5 National Institute for Health and Care Excellence (2017) Antisocial behaviour and conduct disorders in children and young people: recognition and management
- 6 Blakey, R. et al (2021) 'Prevalence of conduct problems and social risk factors in ethnically diverse inner-city schools' *Public Health* 21 (849)
- 7 Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013) Oppositional Defiant Disorder
- 8 Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013) Conduct Disorder
- 9 All quotes are from parents unless otherwise stated
- 10 National Institute for Health and Care Excellence (2018) Conduct Disorders in children and young people – when to suspect a conduct disorder
- 11 Refer to the family summary in the *Appendix* for an overview. A PDF file of the family portraits also has more detail on the support accessed by each family
- 12 This group helped with recruitment for the study
- 13 Examples of organisations that referred families included: Lambeth ADHD support group, Parents and Communities Together (PACT), Family Early Help, SLAM/CAMHS, individual schools, family support and child protection service, the Max Roach Centre. Several organisations also helped spread the word about the research by either directly putting families in touch with the research team or sending out information on their mailing lists
- 14 Please see *Appendix* for an overview of the families
- 15 For the purposes of this study, we classified household income as follows: low income £26k per annum and below; average income £27-36k, and high income £37k and above The family portraits pdf also has more detail on the support accessed by each family