INQUEST

Truth Justice Accountability

Family Consultation Day Report on deaths of people with mental ill health, a learning disability or autism

April 2023

Unlocking the truth for 40 years

FOREWORD

DEBORAH COLES
Director of INQUEST

As the only charity working directly with the families of those who die in state detention, INQUEST works hard to ensure the voice and experience of bereaved families is at the heart of everything we do. That is why our Family Listening and Consultation[2] days are of such value: they provide dedicated time for families to share how they navigated the complex inquest process during one of the most difficult periods of their life.

Our last Family Listening Day, which focussed on families bereaved by a death involving mental health services, was commissioned by the Care Quality Commission in October 2016 to review investigations into deaths in NHS Trusts. Given the increase in cases we have received involving mental health services over recent years and the growing concern from the wider public on mental health deaths, we felt it timely and important to focus on hearing from bereaved families whose loved one died in circumstances involving mental ill health, a learning disability or autism.

During this year's Family Consultation Day, I was both saddened and angered to hear families discuss many of the same issues we heard over five years ago. As you will read in this report, families continue to face major challenges in accessing information about the inquest process and being properly included in investigations into the death of their loved one. The lack of independence in post-death investigations was also repeatedly

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[1] Family Listening Days refer to INQUEST reports published following events commissioned by external agencies to learn from the testimony of bereaved families, whereas Family Consultation Days refer to events organised by INQUEST itself to develop its own policy and campaigning work on key issues.

[2] Justice Select Committee, The Coroners Service, https://committees.parliament.uk/publications/6079/documents/75085/default/, May 2021

raised as an ongoing concern for families. The litany of issues left unchanged further adds to the distress families feel and risks making them disengage from investigatory processes entirely or being retraumatised by the process.

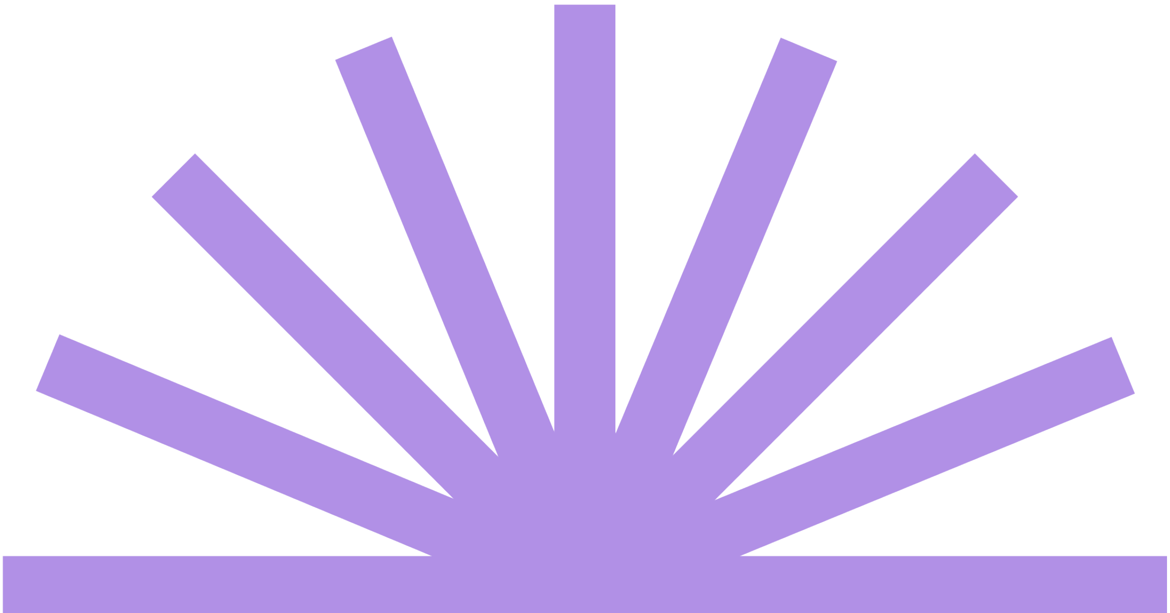
In 2021, the Justice Select Committee published a report following their inquiry on the coroners service.[1] In calling for “major reform” of the inquest system, the committee found much more needs to be done to put bereaved families at the heart of the process. Yet our Family Consultation Day report shows that bereaved families whose relatives died under the care of mental health services were often sidelined by authorities. Too many families told us they felt marginalised from before their loved one died, right up until the inquest hearing and after.

Poor communication with families following a death, inadequate information sharing and investigations that failed to properly include families were just some of the issues which families told us about. So too was the ongoing issue of a lack of access to automatic, non-means-tested legal aid for representation before and during inquest hearings. As one family member so aptly put it, “everything is a fight when you have the least fight in you”. Not only is this a damning indictment of the post-death investigation system for mental health deaths, but a clear indication that urgent change is needed.

In the face of these persistent challenges, bereaved families came together during the course of the Consultation Day to construct a series of strong recommendations to change the way in which deaths in mental health and learning disability settings are investigated, and on the treatment of bereaved people. The voices reflected in this report are too strong and their stories too compelling to be ignored. Families deserve nothing less than an investigation and inquest process that treats them with dignity and respect whilst uncovering dangerous practices and preventing future deaths. The time for fundamental change and a complete overhaul of the way these deaths are investigated is long overdue. As one family said, “nothing can bring your child back. All we can do is help them ensure it doesn’t happen again”.

This report was written for INQUEST by independent consultant Chris Tully. He assisted in designing the Family Listening Day model.

We are grateful to The Three Guineas Trust for funding this work.



CHAPTER ONE

INTRODUCTION

In recent years, INQUEST has dealt with a significant increase in the number of cases involving mental ill health, learning disability and autism. 29% of INQUEST's current cases involve individuals who died while in the care of mental health services. INQUEST is committed to monitoring these deaths and working alongside families to highlight the key thematic issues involved.

INQUEST is part way through delivering a Three Guineas-funded project which aims to deliver the following:

- high quality casework support to families
- establish a network of advocates
- utilise active research methodologies to better understand families' needs, the role of the investigation and inquest process and of oversight bodies like the Care Quality Commission (CQC) and the impact on families when engaging with these

As part of the project, INQUEST committed to holding a Family Consultation Day which took place on 19 May 2022 at NCVO in London. It was facilitated by INQUEST and involved 11 families, with 14 people in attendance. The structure of the day saw feedback from families outlining the processes and systems that frame investigations and inquests, with a particular emphasis on family recommendations for improving current practice on investigations and inquests into deaths of people with mental ill health, learning disabilities and autism.

The day was planned to focus on thematic strands such as on families' experiences of communicating with institutions prior to a death, the subsequent notification of a death and any information or support offered. Families were also encouraged to discuss their role in NHS Trust investigations, how they perceived the role of investigators and their impartiality or otherwise, and the impact of investigation reports both on the families themselves and as drivers of lasting change. The last part of the Consultation Day focussed on the inquest, the role of coroners, families' suggestions for improving the experience and the crucial role of Prevention of Future Deaths (PFD) reports.

CHAPTER TWO

METHODOLOGY

The family listening day model is a tried and tested methodology for seeking participant feedback and uses the following framework:

- **planned** – in conjunction with families and INQUEST staff
- **facilitated** – by experienced INQUEST staff, briefed and knowledgeable on the key issues, and with an understanding of the families' particular cases
- **thematic** – to provide focus
- **discursive** – by encouraging participants to discuss the issues in a safe and understanding environment, allowing a free flow of ideas and thoughts surrounding the review's themes
- **inclusive** – ensuring as wide a range of families affected by the issues under scrutiny felt able to attend and speak
- **confidential** – information shared during listening days is honest and heartfelt, and families recognise that what is shared within the group should not be disclosed outside the group
- **compassionate** – as an INQUEST caseworker pointed out, "families find it difficult and painful to talk through these things". Compassion and understanding are crucial to the success of the process and families should not feel isolated by judgemental attitudes.
- **reflective** – offering a chance to re-balance power structures and give participants the chance to reflect on the impact of events
- **archived** – the families' contributions are recorded and placed in the public domain

All quotes are anonymised to protect both the families and individuals involved.

CHAPTER THREE

COMMUNICATION

No family expects to hear about the death of their loved one who is in the care of the state due to mental ill health, learning difficulties or autism. For many families, it is their worst nightmare, and therefore the state's responsibility to alert the family to the death – sensitively and in a timely manner – is great. And yet a key finding from this Family Consultation Day was the inadequate levels of communication between families and the bodies responsible for caring for their family member.

What became abundantly clear as families spoke was how little advice, support or information they received from hospitals, police and NHS trusts prior to the death of their loved one. This lack of adequate communication often characterised families' experiences of notification following the death of a relative, as well as information about what would happen next. Families reported some of the following failures, especially around the notification of a death and in how and when they were informed: a lack of empathy; an abrogation of responsibility; and little or confused information as to the processes surrounding viewing the body, post-mortems and the initiation of the coronial process.

Reporting concerns and communication prior to death

A number of participants spoke about their anger and frustration at the inadequacy of systems and policies on information sharing prior to their relatives' death. Most commonly, families wanted to discuss medical needs, changes in health and well-being or broader concerns around their relatives' treatment. Some participants expressed guilt and remorse, suggesting they could have done more, but in fact faced an administrative system that was hostile to family input. Many tried to inform medical professionals about inappropriate treatment, deterioration in their relatives' mood and concerns about behaviour they knew to be indicative of unhappiness and isolation.

In many of these examples, mental ill health, learning disability and autism were seen by the health professionals as the cause of insularity, rather than a change in behaviour that required care and support. Families described how hospital staff didn't listen to those in their care:

I knew she was struggling; she couldn't cope with the therapy, they didn't listen.

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> I RAISED COMPLAINTS BUT FELT I WAS JUST SEEN AS TROUBLE.

Another parent was despairing in their frustration at what action might have prompted professional intervention:

Unless someone is in front of you trying to commit suicide, if it’s ideation, it goes to one side.

Another person knew their relative was not being listened to and feared for what might happen:

From the minute he got there he said [to me] this place is awful, they’re not listening.

It was agreed that in the end, “the patient knows more about their illness than their doctor”.

A mother had seen the positive impact of a collaborative approach to care with her son:

He had been in other good hospitals. One consultant said sometimes the patient knows more than the doctor, so in the good place they listened. Elsewhere they think they know best.

If failing to listen to patients was common, it appears that their families, friends and advocates also struggled to have their voices heard. There were barriers to reporting concerns regarding the quality of care, and many of the systems in place in mental health settings failed to either acknowledge or take action after repeated warnings from parents and siblings. In some cases, families were met with indifference; in others, hostility:

They did nothing, we warned them, because she was autistic, change is incredibly difficult for [relative] to deal with.

I begged day in day out for more information [when he was alive]. The doctors just ignored me and said this was the best place for him.

Doctors ignored me for weeks and said he was in the best care. At the end of five days he died, he committed suicide, he committed suicide on site, under their noses.

I raised complaints but felt I was just seen as trouble.

Some families spoke of their dismay at how a response from the care provider only came about following desperate measures:

He told the nurses “I wished I’d died” [and] from that moment he was given help.

Another participant felt that there was complete abrogation of responsibility from senior management when things weren’t working. He described how the ward manager in charge of placing a bully right next to his son on the ward was then promoted. After a complaint was made about her, she left.

As an outsider, I look at the people responsible for my son’s care, the lowest care workers got sacked, the ward manager and CAMHS manager were promoted and looking at that picture, the only accountability is rewarding people.

It was felt systems failures were not really addressed, and what families wanted was “someone physically held to account”; but another person reflected that when an individual is solely held to account, someone else will come and replace them. A family said that “the moment something happens, the capacity in the [mental health] system was not there”.

What we heard indicates a system that does not place patients or their families at the centre of a process and that is ill-equipped to manage individual needs. It appears to be under-resourced and marked by inconsistent levels of information, empathy, openness and sensitivity. As one participant explained:

My son was incarcerated for so long he’d rather kill himself than go back there [to the unit].

At a time when families needed support, advice and information, to feel empowered and included in decision-making processes before and after the death of their loved ones, they were mostly left to their own devices, and many we heard from felt they were cast adrift:

I used to think we’d have been better off if [our relative] was murdered. We would have had victim support.

Notification of death

Families described how they were informed about the death of their loved ones, highlighting how inconsistency, lack of empathy and the absence of information or facts impacted on them. Often the news was delivered by police officers who appeared ill-equipped or lacking the required skills and information to answer the inevitable questions that families had:

She died at 9pm. We were told the next morning at 8:30am – told by [redacted] police, they knew nothing about the circumstances of the case. The hospital wouldn’t talk to us until lunchtime.

We had an awful 4-5 hours where we could speak to no one.

They added:

I was so angry that I was allowed to go to bed when my daughter was dead.

This was common, with other families sharing similar stories:

We were told of her death by a policeman who was totally incompetent.

And in one particularly insensitive example, a father described how he heard about the death of his son:

The police told me over the phone while I was driving. There was traffic and so I just had to sit there after hearing the news.

Families felt that health care providers were unable or unwilling to take responsibility for what had happened and were already passing on responsibility:

There’s an over-reliance by the mental health services on the police: they don’t want to recognise what’s happening. The worst news [of the death] is then left to police.

If the police are to be tasked with informing families, then they need to be empathetic and, most crucially, prepared:

The police who come to tell you that your relative has died should take ownership of this part of the process and come to your house equipped with the information and details. They come to you to give you the news but can’t answer any of your questions.

As one person suggested, the absence of support heightened the sense of abandonment:

I would have liked someone to stay with me for those few hours.

Poor communication compounded the desperation of the situation, with families left unaware of where their relatives were or what would happen after notification:

We didn’t even know she had been sent to hospital […] communication in [redacted] was terrible.

We knew nothing, our son had to call every hospital in [redacted], they didn’t know where her body was.

As we heard from families, it became increasingly clear that the inability of care providers to coordinate notification with the next steps of the process wounded families terribly, with one woman angrily pointing out:

What gives them the right to pack my daughter off to the mortuary before I even know she’s dead?

Another family said:

We didn’t get her back for a month.

If much of the families’ frustration and anger was directed towards the police, there was also considerable criticism of hospital trusts, their lack of empathy and their insensitivity. Families described an institutional indifference, a sense that the care providers were already looking to protect their own reputations and positions. This was described as lacking respect for those that had died and for grieving families:

We were invited to the hospital, it was very corporate; a bunch of flowers, “we’re very sorry”, ”we have ordered a memorial bench”. I don’t want to hear this.

We had minimal contact, no one called […] I would expect the CEO of the hospital to come to your house.

Others shared similar experiences:

I was given a card saying, “sorry that [relative] has died today, here’s a support line, condolences from ‘the doctor’”. Then a booklet. I found it offensive. It literally had space to insert the name.

One family member detailed events that suggested the hospital knew their relative was dead, but had not contacted her about the seriousness of the situation prior to that moment:

They [the hospital] offered their condolences when I was told [my relative] was going for a brain scan. They already knew he was dead. Straight away I knew they were protecting themselves.

This lack of respect was not isolated. Other families described emails with incorrect spellings of the family name – “I got an email from them, and they didn’t even spell my name right” – or an incorrect date of birth, which felt like a personal slight for those reading them. One person described the mail they received:

They emailed me casually a few days after he died. They didn’t even offer condolences, they just said “Hi [name], is this your email?” There wasn’t anything about my brother dying, no condolences, nothing.

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> IT FEELS LIKE YOU NEED A FAMILY LIAISON OFFICER – ESPECIALLY IF THERE’S MULTIPLE AGENCIES.

Information and support

There appears to be a distinct failure to support families with information on what the processes following their family member’s death would be, such as counselling and advice or offers/sources of bereavement support, what to expect of investigations and inquests, and the coroner’s role. Some felt information was hard to take in the immediate aftermath of a bereavement and as such what is provided needs to be direct, simple and ideally supplied by one trusted source. For many of the families we spoke to, this role was filled by INQUEST, with families finding the organisation by word of mouth or online.

A number of families suggested that a specific point of contact, like a family liaison worker with specialist skills, should be appointed to work alongside families from the start of the process:

It feels like you need a family liaison officer – especially if there’s multiple agencies. We had to write five letters of complaint. We want someone to monitor impact of [the] whole process.

Others agreed:

Every hospital should have someone specifically designated to you during those early days to just listen to you and offer you support.

As with a great deal of the investigation and inquest process, it was left to families to find out for themselves; and in all too many cases, finding reliable resources was as much due to families’ good fortune as by design.

I was handed a leaflet and that was it.

We didn’t have much information to begin with, in fact, they did not give us any information whatsoever.

They said advice is unnecessary, just look at the coroner’s handbook.

After she died, I was given a booklet which had a list of organisations which could support me.

I found out about INQUEST through a BBC article, and I got in touch.

I had never heard of coroners etc, my son was ringing everyone, rang legal reps of another [redacted] death who mentioned INQUEST.

The failure to provide information at an early stage has the potential to impact on the rest of the process. Without prior knowledge of their rights, families are potentially denied insight into the cause of death.

One family member did not think they were ever advised. They were denied a post-mortem and the death was signed off as natural causes very quickly. The coroner didn’t want to grant a post-mortem and the family did not know they could ask for one. It was only when the family started asking questions that the coroner realised the seriousness of the case (her son was given no fluids or nutrition). Because there was no post-mortem, she was told they will never know exactly how her son died. They asked for help getting an inquest. The person doing the investigation at the hospital said, “this wasn’t his job”. The family phoned the coroner themselves and started asking questions. The coroner opened the inquest that day.

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> **IT WAS JUST SHOCK AFTER SHOCK AFTER SHOCK TRYING TO NAVIGATE ALL THIS STUFF YOU DON’T KNOW.**

Ultimately, families are faced with a completely alien system that has inconsistent levels of information, empathy, openness and sensitivity. As one participant explained:

Reflecting on how I was notified was all phone calls. I’d have appreciated a letter from the chief executive, with condolences on your son’s death in our care, which said “we are going to do a Serious Incident Review, led by … who will contact you. If you need anything else contact this liaison officer”. That would’ve set an expectation that they were taking it seriously. Even if it was no good at the end.

Another outlined the trauma of stepping into the unknown:

It was just shock after shock after shock […] trying to navigate all this stuff you don’t know.

What families recommended

Families made a number of recommendations as to what initial notification, communication and support should involve:

- Prompt notification of a death, delivered by the equivalent of a family liaison worker providing a single point of contact, who is independent of the hospital, trust or other involved state bodies and equipped with concise and independent information outlining families’ legal rights.
- The preference was for this not to be the police, but in that eventuality, they must be fully aware of the circumstances of the death, trained to be sympathetic and sensitive to families.
- Families want straightforward information regarding post-mortems, the role and contact details of the coroner and what investigations were underway and by whom.
- They want enough information, but not so much they are overwhelmed.
- Signposting to support agencies, bereavement organisations and in particular to INQUEST as a specialist organisation.
- Families should be encouraged to seek specialist legal advice, rather than the current situation whereby it is presented as an option or unnecessary.
- Interaction with state or trust staff should be empathetic, humane, respectful and informative.

CHAPTER FOUR

INVESTIGATIONS

If a person dies whilst an inpatient under the care of a mental health trust (whether detained or not), that trust should carry out an internal investigation into the death to find out what happened and if lessons can be learned. These investigations are often called Serious Incident Investigations or Root Cause Analysis, but they vary a lot from trust to trust. To be effective, an investigation into the death of a detained patient should be carried out reasonably speedily, with the involvement of the family and with an appropriate level of independence. Independent investigations are very rare, but if they do take place, they will usually be carried out by professionals not directly employed by the hospital trust.

As with much else in the process following a death, bereaved families are immediately put on the back foot due to a lack of knowledge and information, their expectations shaped more in hope than in actuality. For some, securing legal representation at the earliest possible opportunity made a difference, as did the knowledge and support provided by INQUEST. However, for many families, the hospitals and trusts control the process from the outset and from that point onwards dictate the tone, direction and scope of what follows. As such, the process is often shrouded in delay, secrecy and in some cases animosity towards families who simply wanted active participation and a truthful account of what caused their relatives' deaths.

The frustration at how opaque the institutions can be when conducting investigations was felt by many we heard from. This lack of clarity masked serious flaws in the independence, impartiality and quality of the investigations. As noted in the previous section, little information or guidance was provided to families, although there were exceptions which had a significantly positive impact on the overall experience for this part of the process. However, many families remain angry, suspicious and distressed at the ways investigations were conducted.

Terms of reference – defining the scope of an investigation

In keeping with initial contact, families felt ill-equipped to make informed decisions or plan their engagement with the investigations, which in turn made managing expectations difficult. For many, this lack of involvement at the outset meant the process was already flawed; it simply didn't involve families enough to elicit their observations, thoughts, concerns and recommendations in order to create a meaningful account of what happened. This wasted an opportunity to examine poor practices which, if addressed, could prevent future deaths.

Families felt they had little or in some cases no role in establishing the terms of reference for the investigatory process. This compounded existing concerns regarding the hospitals' and trusts' failures to recognise the complexity of care and support in cases involving mental health, learning disabilities and autism. As one person explained, family input can play a crucial role in defining the terms of reference in order to conduct a meaningful investigation:

We're not the enemy of the investigator. We are there to help them.

Families should be given an opportunity to feed into the terms of reference, and to be provided with timelines outlining the anticipated duration of the investigation and publication of the final report.[3] Unfortunately, this was not the case for the vast majority of families we heard from:

I kept saying what I wanted looked at and they kept saying what was or wasn't in remit.

The terms of reference are central. Families think they'll look at everything, but then they set the terms and they're just looking at a few days and say everything else is not their job.

Another family member agreed:

We hear investigation and we think they will investigate everything, to then be told "that's not in our terms of reference".

The opportunity to help shape the investigation was often blocked by trusts; and at a point in the process where families are struggling to cope, the last thing they wanted to do was engage in a drawn-out, confrontational battle:

You can try and control and set the terms of reference. That's the key when you look at the things around the death. You go in expecting a broad remit, the trust have a narrow one, then there's a dog fight of where to go and what's allowed. Much of that isn't in your control, the terms of reference is a judgement call.

There were examples where families had been granted input into the process, but even in these rare examples they were forced into a background role, in some instances facing hostility from the trust:

Our family were able to feed into the terms of reference. The trust had weeks of meetings setting these terms. What we wanted was them to just go in and look at the whole thing. We then had a company called [redacted] who did an awful investigation. We were told we'd have days with them to give our side of the story, but we only got one morning and were ignored

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[3] NHS England, Healthcare Safety Investigation Branch, Learn Together, Patient Safety Incident Response Framework supporting guidance Engaging and involving patients, families and staff following a patient safety incident, August 2022 https://www.england.nhs.uk/publication/patient-safety-incident-response-framework-and-supporting-guidance/

by them from then on. We were told the investigation was costing £60k and then there was no more money so we can't ask any more questions. When we asked where that money was coming from, we got referred to police for harassment and were told we couldn't contact them again.

One person felt the "internal investigation was honest but did not cover enough". Another explained that although the terms of reference were negotiated, their role was less about working with the investigators to shape them and more about a question of interpreting unnecessarily legalistic language:

We had terms of reference but needed lawyers to explain [them].

This highlights the disadvantage that families face during the early part of the investigation process and many felt this was an intentional strategy employed by trusts to delay, confuse and impede active participation, rather than find ways to encourage dynamic engagement.

One family member was able to pinpoint the positive impact of involvement from the outset and how that helped produce a more positive outcome for the family:

The Serious Incident Review was critical. They asked for my input.

The investigation

A number of factors influenced how effective families deemed the investigations. A majority of those who spoke doubted the independence and impartiality of those tasked with conducting the investigations. Similar numbers called into question the extent to which trusts welcomed or valued family involvement, even though they were often crucial witnesses to the care on offer and had become experts in supporting their relatives' mental health, learning disability and autism.

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> I KEPT SAYING WHAT I WANTED LOOKED AT AND THEY KEPT SAYING WHAT WAS OR WASN'T IN REMIT

Families felt the antipathy they were met with when their relatives were alive extended into the post-death experience. Families felt their knowledge and insight was met with at best displeasure and, in extreme cases, hostility. This rejection of the role families should and could play in the investigation was common. However, the success of an investigation process must be based on candour and integrity and if this was missing it felt like a futile endeavour. As one woman commented:

They came to my house and said trust us, we're going to change things but how can I trust you when you killed my son.

The family role

Families shared common experiences regarding their roles within the investigation, such as resistance, apathy and the view that, unless families fought for a role, the investigation tended to be something that happened to them, rather than something that happened with them. It became clear that families were not central to the process, and without grit, determination and perseverance, they could be excluded altogether. Whilst some had the means, time and skills to create engagement, it was pointed out that without those attributes, families would inevitably face investigations that were narrow in remit and couldn't possibly establish what happened and how future deaths could be avoided.

In extreme cases, families were not made aware that an investigation was happening, and trusts failed to communicate what would happen following a death:

My son died on Saturday; I got a call on the Sunday from someone on the ward my son was on. He rang and said, "we've looked at all the paperwork and everything seems to be in order". My son had been allowed leave and was let out the wrong side of the hospital and he was able to abscond. I didn't know there'd be an internal investigation; they wouldn't tell me. I rang corporate affairs to ask and they never got back to me.

She was eventually told that there would be an investigation, but only by asking was she informed. It was at this point she realised what she was facing: "you're playing the game, aren't you?"

It was also suggested that:

We don't get enough information, it's not timely, and nobody thinks of how we're feeling at the time.

It was common for families having to push for the investigation to happen at all, and this at a time when they were at their most vulnerable; grieving, exhausted and confused:

We were having to chase them for everything.

Another agreed:

We had to go to [our] MP to get an investigation.

This apparent evasion on the part of mental health trusts was highlighted by others:

We had to fight really hard to get safeguarding reviews opened. We were gaslit the whole way along.

It was pointed out that what families were seeking was not special treatment or anything beyond their rights as grieving relatives, but they soon realised they were required to become 'qualified' in the ways of the investigation to gain traction:

Families need to become experts and push for what they are entitled to.

Another participant noted:

If you as a family have the ability to advocate for yourself, speak to NHS people in their language, the mental stability at the time, and the time to push and press – you can push yourself into the investigation. But then the people shut down because they don't want to answer your questions. Or you become placid and just say "yes".

There were examples of families fighting hard to engage with investigators and then facing further obstacles when their input proved 'difficult' or 'inconvenient':

I had to force myself into the process. I sent four pages of questions. e.g. the blood potassium levels were shown to be very dangerously low, but their assessment was that it was fine when it wasn't. When they realised I knew what I was talking about they shut down and said I had to put questions in writing. So I did and sent many questions off.

Two days after the death there was a phone call mentioning there may have been issues with observations. Later they acknowledged issues with tests. The moment they mentioned it and I asked about more information, they shut up shop. One person at one level tries to be open, then lawyers get involved and *try to shut them up. I still get calls from staff involved telling me things. When trusts start to manage the process they try and silo people.*

The attitude of trusts were highlighted by other families:

God forbid you want to be part of the investigation. They block you every step of the way.

If you challenge them, you become the focus of their aggression. They never apologise for what they did.

For another participant, the investigation was only widened to include what the family saw as relevant after they had fought for it:

We had three investigators each looking at different bits. I only had contact with the chair who was an ex-trust employee who did these things as a consultant. Like these investigations were his side line. It felt they would frame it impartially but only look at what the trust wanted them to look at. In our trust we know there are three other similar deaths, and we had to push for an NHS England investigation. So now the trust have commissioned this investigation with NHS England separately setting the terms of reference.

This strategy on the part of the trusts was considered to be a well-practised and intentional way of delaying the process at best, or a deterrence to participation at worst. As one father explained:

They are there to gather information about what you know [in meetings], not to provide information.

He went on to say:

Resistance, obstruction and delays in recognising facts and evidence is often aggressive and part of a deliberate strategy to weaken family resolve.

Quality, independence and impartiality

Families were broadly in agreement that the fundamental principles that should underpin the investigation process – namely, quality, independence and impartiality – were too often absent. As one person said about the trusts, “they’re marking their own homework”. This leads to a lack of faith in how independent the system is and subsequently impacts on the families’ trust in the credibility of subsequent findings.

Various descriptions were given of difficulties with gathering statements, the quality of the investigators and their commitment to truthfully disclosing mistakes and/or shortcomings in resources and competence. It was felt by some that the investigation process was intended to place distance between trusts and families.

We had to tell the investigator what we knew. They wouldn’t say anything. When we viewed CCTV, they brought a director in to sit between [the] family and investigator so there was no direct contact.

A lack of experience on the part of their investigator was identified as problematic by one family:

The trust investigation experience was terrible. At first it was going to be an informal one, but when we sent our list of questions they upgraded it. We found out in the end it should’ve been a level 3 serious investigation, but the investigator said he’d struggled to get statements from people, and “it wasn’t his job” to chase them up.

This relationship then degenerated further:

He was rude to me. I said I’d spoken to my GP about the treatment, which she [the GP] said was so appalling, and she wondered what else was going on at that hospital.

I raised that with the investigator and he said it [the GP's observation] was a conflict [of interest] and bad practice.

Another relative felt the specialist knowledge needed to investigate deaths involving mental health, learning disability and autism required experience of current medical best practice:

[The investigator's] knowledge of the field dates back to the 1980s and she should retire basically.

One family encountered a claim that there were simply no resources to engage experts, but this seemed contradictory to them:

The worst thing was lack of money and ability to fund experts. There were two investigations so there [are] resources somewhere.

Families regarded the appointment of investigators with specific expertise of mental health, learning disability and autism as vital if the process was to be sufficiently rigorous and far-reaching.

For some, a more pressing concern was the pre-existing relationship between those tasked with investigations and the trusts that were commissioning them. Families felt that familiarity between the two meant investigators were unlikely to report in a way that went against the interests of the trusts.

One person observed:

Ours said she'd investigate and one of the things she assured us was of her impartiality. As far as was possible that was the case but [the investigator] was entirely enamoured with the consultant doctor and enthused in her report about how wonderful he was, so I do wonder about her impartiality in that sense.

Another person went further in their condemnation of the quality of investigators, suggesting:

They corrupt and subvert statements. They don't take statements; a nurse was allowed to emigrate to Australia.

One family was told by their investigator:

If I rock the boat too much I won't get asked to do reports again.

There was almost universal agreement that some investigators recognised their role was essentially curtailed by the trusts and what was said in person to families was not necessarily reflected in what appeared later in reports:

If I could catalogue the number of […] professionals who say, "look I can't say this publicly but …" and then make serious criticisms. They will go, "this is what the trust will allow me to say, I'll go right to the edge but I can't go further because there will be ramifications".

Families felt let down by the apparent failure to investigate independently, which in some cases impacted very profoundly on the final report findings – much of this centred on the absence of critical information relating to medical care, missed observations, mistakes in administering medicines and incompetent staff:

We knew what had gone on, we'd been there. One nurse retired and took herself off the register, and another has been given extra training. [The investigator] said "I haven't put this in the report but to be honest the nurse that was on when he died wasn't capable of being on a [redacted] ward and was also having problems, but I haven't put that in".

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> **INTERNAL INVESTIGATIONS ARE DIRECTED AND COACHED NOT TO FIND THE NEW LEARNING BUT TO SHAPE THEIR FINDINGS TOWARDS THE ESTABLISHED “ACCEPTABLE FAILINGS.**

Another person explained:

The carer left him all morning and found him dead. He hadn’t even been given his meds at 8.15. At first they told us he’d refused the meds. It wasn’t true.

There were some families who had a better experience of the investigation, and this mostly manifested in terms of proper engagement, a sense that they were being placed at the heart of the process and had a central role to play. One woman said her investigator had acknowledged that the problems are “systemic” and another was reassured based on the endeavours of the investigator:

I spoke to the investigator and he seems on the job, seems to be taking it seriously. He’s taking his time and he sounded sincere and said he wasn’t going to leave any stone unturned.

The lead investigator was formerly a nurse on a psychiatric unit and was a really nice guy. The final report did say things like “according to the mother”.

However, the group’s consensual view was that independence cannot be ensured if the investigators are selected and paid by the trusts:

If it’s paid for by the trust to investigate them, and you do multiple investigations for that trust, which one will get the job? The honest open one that causes problems, or the one who does it how they want it?

As experts by experience, families are well placed to function as reliable corroborators on matters relating to mental health, learning disability and autism, but are too often regarded with suspicion or irritation, thus missing valuable insight that could contribute to better care and the prevention of deaths in the future. This blemish on the system is compounded by the impact it has on families enduring the investigation:

The death wounded me, dealing with mental health services has broken me.

Everything is a fight when you have the least fight in you.

Nothing can bring your child back. All we can do is help them ensure it doesn’t happen again.

In the end, the handling of the process should include the full participation of relatives and loved ones; but without knowledge, families are placed in the unenviable position of not knowing what they are entitled to:

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THE CONCEPT OF FIGHTING FOR THE RIGHT OF YOUR CHILD OR WHOEVER IS QUITE WEIRD. WE’RE MEANT TO BE GRIEVING.

The concept of fighting for the right of your child or whoever is quite weird. We’re meant to be grieving. There are families where one person can fight, someone else can’t even speak about it. We’ve learnt you have lots more rights than you’re really told.

Without these rights, investigations will never fully uncover systemic flaws and simply result in findings that are deemed ‘tolerable’ or ‘tenable’ for the trusts. One family member summed up his assessment of the process:

Internal investigations are directed and coached not to find the new learning but to shape their findings towards the established “acceptable failings”.

Investigation reports

In keeping with the anger expressed by many of those we heard from regarding how investigations are conducted, families were often disappointed and angered by the subsequent reports. Concerns ranged from the time it took for these to be produced, a lack of opportunity to see drafts prior to publication, inaccurate or impartial findings, to dismay at the lack of impact or momentum for real change.

Families felt the trusts were ‘box-ticking’ or going through the motions for much of this process and saw the failure to consult with them on draft reports as insulting to them and the memory of their relatives. There were various examples given of poor practice, where families were not given a chance to respond to the final report or found out about the report after it had been published. Trusts seemed unwilling or unable to share their provisional findings with families:

We had to sit in a windowless room to read the draft and weren’t allowed to take it away.

Another woman felt the trust was hostile to her family’s needs:

We were just given two weeks to look at the investigation [report]. My husband ended up having a seizure. I wanted longer but they had no sympathy, they wouldn’t give us longer but then blocked my calls.

There is an expectation that families should be able to read draft reports in order to comment on their contents and challenge inaccuracies. One contribution from a participant, who was accidentally sent a copy of the draft report, may explain why some trusts are loathe to share with families:

The professionals were all sent a copy of the report to fact check. Then the professionals can correct and update it. When people realise what they have said they can change it, and make sure they don’t appear to bend the rules. When I compared draft one and the final [version], I can see whole paragraphs have gone.

One participant went further in his suggestions for how families should approach the lack of engagement:

Families are perfectly entitled to be part of the Serious Incident Review, go to the CCG [Clinical Commissioning Group] as they fund the trust. They're the ones, you can impress upon them your responsibility and entitlement as a named individual in that report. Checks on the report are meant to be about accuracy, you should be able to get the original and the altered version so you can see changes and contribute to the accuracy. You can't change the content but you can challenge.

Families were in unanimous agreement that prior to publication:

You should get a chance to respond to the trust report.

The denial of opportunities to comment on draft reports threw up a number of concerns for families – from the seemingly 'unimportant' to major omissions and mistakes. For some, the absence of attention to detail on basic information symbolised the lack of care and attention that was given to their relatives during treatment and care:

The basic errors are just horrendous.

Another relative agreed:

I think they copy and paste as key details like name and date of birth were wrong.

What angered families most was a perception that subjectivity takes the place of impartiality, that protection of reputation was of more importance than uncovering poor practices, a lack of resources and inadequacies in care. Some felt this meant reports were simply not credible:

The fact they tell you a pack of lies, you think it can't be true.

One family member outlined what they believed was a problem with shifting blame onto individual staff when resources were in fact the key issue:

So staffing levels for example. How can staff fulfil their roles if there's not capacity in the systems. Really important in terms of observations. Often it's "something kicked off on the ward so the staff were needed". So staff meant to protect one person are taken to help another. That's not that staff member's fault, it's the manager's.

One person had seen the differences between the initial draft report and that which was published:

The hospital's investigation said that there was a lack of co-ordination between the two consultants. This finding was overruled by the board as a "misquote".

Families also noted they had no way to challenge disputed findings and felt angry that their own observations regarding the behaviour of staff and treatment regimes, for example, were absent from final reports. As one family member stated about the trust:

[They exert] institutional control over what constitutes fact.

Some remained optimistic that their contribution would be honestly reflected and the truth would be revealed:

The local authority are running their own investigation. The council and CQC are also looking. The school have also decided to bring in their own independent investigator, which I found out via my friend who was communicating with them. So I spoke to that investigator, his report is coming soon. He seemed very open and transparent, and we'll see if the criticisms I made come out.

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> THE PROCESSES ARE MEANT TO PUT YOU AT THE CENTRE. THEY DON’T.

The role of private sector investigations

For some families, their investigations were conducted by private companies involved in care provision, in some cases running parallel to NHS investigations, in others independently. This caused some concern as families were unconvinced by the motives, independence or expertise of those involved. Some were sceptical about the financial arrangements involved:

Hospitals are biased in their own favour and the private sector is only in it for the money.

We were also told that by [redacted], their work is being paid for by the trust so they say they have to do a job they want. They need to give value for money.

This particular statement was not a commonplace occurrence for the majority in attendance, but it does raise a serious question as to how effective private investigations can be when there appears to be a conflict of interest.

For others, the concern centred much more on how independence could be measured, coming back to ideas of the trusts “marking their own homework”:

We had a level 3 report by a private sector firm which narrowed the trust’s report. I don’t think the private sector should be involved; it should be looked at by an independent board.

This suggestion was supported by another relative:

I don’t think the private sector should be involved in any medical investigations. There should be an investigator that’s independent of any trusts.

Resources and expertise may be one reason private investigations are commissioned; one woman’s experience was more positive:

[Redacted] did a review and got it done by a person who was specially trained on how to do the report after [my daughter’s] death.

However, the majority of those who spoke about this remained sceptical and felt trusts commissioning private investigations would inevitably select investigators who could be relied upon to tone down or dilute critical findings.

Investigations as drivers of change

Broadly speaking, it was felt that the investigations fulfilled a role that was more about compliance with an ineffective system than it was about enacting radical changes, or even committing to the idea of change.

There were concerns expressed as to how seriously the findings in investigation reports are treated by the trusts:

I don’t know why they even bother. I know I’ve got timelines on the investigation’s recommendations, and many still haven’t

> *been met. You see that it's a box-ticking. They say it's about learning, but it's not about learning it's about covering up. It's about justifying and saying, "we did what we were meant to".*

One mother said:

> *My son's place in [redacted] was paid for by [a] health authority elsewhere, but in the end they had to pay for that substandard investigation. Even today the commissioning authority have said nothing about what's going on because they don't want to get involved and open to criticism or criticise others.*

If the function of the investigation is to help ensure improved practice, understand the critical implications of under-resourcing and to prevent future deaths, then the families appeared unconvinced as to their effectiveness. Some did see them as useful from a personal point of view, but were sceptical about their lasting impact on change:

> *After [a] family have persisted, obtained evidence and forced acknowledgments, providers claim "common sense now prevails", for example, they've investigated, changed policies and implemented 'learning' and therefore no longer require being held to account.*

> *The [investigation] processes are meant to put you at the centre. They don't. Your questions should never be seen as argumentative, it should be about learning from the deaths of our loved ones.*

What families recommend

Families suggested the following for improving the experiences of investigation systems:

- Investigations should be independent, thorough and conducted by a body independent of the trusts, private care providers and other state agencies involved.
- Families must be made aware of their role within the investigation process, including setting the terms of reference.
- Investigations should be carried out in a timely fashion with a clear agenda as well as information on by whom, how and when the investigation is to be carried out.
- Families' evidence and expertise should help investigators rather than be seen as hostile or troublesome.
- Families must be given a draft copy of the investigation prior to its publication and given ample time to digest the findings and make their own comments.
- The language should be accessible wherever possible.
- Recommendations should be taken seriously, with commitments to and evidence of compliance.
- Investigators should have adequate expertise of mental health, learning disabilities and autism.

CHAPTER FIVE

THE INQUEST

The inquest is the only public hearing provided by the state that seeks to establish who died, where the death took place and how it happened. Unsurprisingly, families place a great deal of importance in the inquest as they seek the truth. This is particularly significant where there has not previously been an independent investigation into the death.

As was noted in INQUEST's 2007 report Unlocking the Truth,[4] inquests are the "forum for the struggle between bereaved families and those in authority to establish how someone died and whose 'truth' is finally put on public record". For the inquest to be effective, families argued for more information in advance, an equality of legal resources in the form of non-means-tested public funding, to be recognised as central to the process and for recommendations arising from inquests to be enforceable.

Information and support

Families were firm in their belief that the information and support they received prior to the inquest was inadequate and because of this they were utterly unprepared for what was to come. The onus of responsibility fell on families to ascertain their entitlements, their right to legal representation (some families were told it was unnecessary) and what to expect in the coroner's court once proceedings began. For most people who have not experienced formal legal proceedings, expectations are formed by popular culture, films and TV dramas, but bear little resemblance to what can be a traumatic and complex legal process:

We were told nothing [about the inquest]. The coroner told us we would not need legal advice.

Another relative agreed:

The coroner's office was cold, direct and gave me little information – they did not tell me how to get legal representation.

The absence of information places families at a disadvantage, particularly in the context of engaging with a legal process with its own rules, etiquette and jargon. It created the sense of being excluded from active involvement:

We were contained as we were not given much guidance on what we could and couldn't do.

In some cases, families were able to find out more, but this was often due to chance:

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[4] INQUEST, Unlocking the Truth:Families' Experience of the Investigation of Deaths in Custody, https://www.inquest.org.uk/Handlers/Download.ashx?IDMF=d700d323-2931-467a-882e-59e13bd2cf81

There was nothing from the coroner, there was a leaflet when I went in and I saw that myself.

The families that felt better equipped tended to be those that had contact with INQUEST and were empowered with information, knowledge and specialist legal representation:

INQUEST put me in contact with a lawyer who was lovely.

I read the [INQUEST] handbook cover to cover and it was so helpful.

Others mentioned the importance of finding the organisation, often online and in one case as a result of seeing the organisation on TV.

Legal representation and article 2 inquests

The importance of legal representation for families going through an inquest cannot be underestimated. Although the government recently improved the system for legal representation at inquests, families are still required to show their case meets the article 2 threshold to be granted non-means-tested legal aid.[5] There were a number of scenarios provided by families that highlighted how families are unable to 'take on' the state without experienced specialist lawyers who are well versed in such cases and can help families navigate a path before, during and after the inquest.

Much of the focus for this part of the Consultation Day was on families' struggles to fund representation and the obstacles faced when seeking an article 2 inquest which triggers the potential for legal aid. It also established that without honest information, families are led to believe the process is inquisitorial rather than adversarial when often the opposite is true.

They say it is an inquisitorial process not adversarial. That is the biggest misconception. You get into that court room and you are facing all of them.

One person described the dreadful impact and personal cost for some families in order to fund their legal costs:

Some families have had to pay and have lost houses, marriages and cars.

Others had crowdfunded their legal costs in an effort to challenge the coroner's original decisions not to grant article 2 status to the inquest.

Families discussed the importance of the pre-inquest review hearing (PIR or PIRH) in establishing the parameters for what particular issues are to be considered by the coroner and felt this was especially true following cases involving mental health, learning disability and autism:

Ours was a clear article 2 inquest, took us up to the PIRH to get a jury.

For one relative it was the PIR that highlighted the need for an article 2 inquest, having faced a resistant coroner:

From the PIR we decided we need representatives. I said it should be article 2, and the coroner makes you feel you shouldn't be saying this.

Another contributor encountered hostility:

We had to stop one PIR as [the] state lawyer was so obstructive, kept trying to blame someone else.

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[5] Justice Committee, The Coroner Service: Government Response to the Committee's First Report, https://committees.parliament.uk/publications/7221/documents/77640/default/, September 2021

In one case, the coroner applied overt pressure on the family's desire for an article 2 inquest:

We had to take the coroner to judicial review. The coroner threatened us with his legal costs.

It should be noted that in some cases families had to struggle to secure an inquest at all. In one example, a family were only granted an inquest after the BBC covered the case and raised it with the coroner directly; in another, the coroner only agreed to hold an inquest after the Serious Case Review (a mechanism whereby serious safeguarding concerns are reviewed) found failings in care.

Relatives also focussed on the lack of legal parity, what INQUEST has termed the 'inequality of arms', suggesting the imbalance in power between the state and the individual can only result in a coronial system that protects the state, its institutions and representatives:

You are against three or four institutions which are publicly funded, without our lawyers we wouldn't have had an inquest. […] That's outrageous.

Five sets of highly paid lawyers, publicly funded, unlimited pockets, funded by the state or insurance. We weren't entitled to public funding so we had to crowd fund, our lawyers were generous with their time.

With INQUEST's support, families are signposted to legal firms that specialise in human rights cases and inquests. This is crucial as families explained,

Everyone we knew said don't, no judicial review, you will never win against coroners. It's only because our [legal] firm is a long-standing human rights firm and said you must.

But even then, families face significant legal obstacles in seeking article 2 inquests,

Before the Judicial Review we tried to go to the ombudsman and they said no.

The importance of the right firm is also important:

We had a big firm. No small firm could have gone through the evidence. No small solicitors could deal with the level of paperwork involved. It was 20 boxes of unpaginated documents and some of it wasn't even related to our daughter, can you imagine how many hours the solicitors put in?

All those present were in agreement that expert legal representation was vital:

No chance we could have done it without them.

As was pointed out, if the state 'arms' itself, families must do the same:

If all the trusts turn up with all the legal teams, if they haven't done anything wrong then why do they have them? Maybe they should ban them and everyone represent themselves.

The families' experiences of the inquest proceedings

In a wide-ranging conversation, families spoke about their experiences once the inquest started, which for some was years after the death of their relative. They spoke about the inconsistencies they encountered as participants, the perception of double standards in their treatment, the protocols for asking questions and challenging inaccuracies, the protection afforded trusts and witnesses by some coroners and the

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> **WITHOUT SOMEONE WHO’S GOT EXPERIENCE OF BEING AT AN INQUEST BEFORE AND HOW YOU ADDRESS THE CORONER AND ALL THESE LITTLE THINGS, WE WOULDN’T HAVE GOT ANYWHERE**

sense that the process is simply not designed in a way that places relatives or their loved ones at the centre of proceedings. There were some examples of positive experiences, where families felt they were at the centre of proceedings, but these were in the minority.

Venues and facilities for families

The arrangements for attending the inquest are unpredictable. Issues such as venues, travel distance, seating arrangements and private family space within the court were raised as challenges. This unpredictability is played out whilst families are also dealing with a range of other considerations like time off work to attend, length of the inquest, child care and for some, dealing with other factors like the press and media.

The whole thing, it’s just so much, there’s a whole array of outside factors, my other children etc, the media and so on …

For some present there was also the stress of attending during the Covid-19 pandemic, which meant some sessions were in person and some online, although this was rarely explained prior to the start of the inquest. Families felt this was daunting and added to their anxiety and tension.

Families explained how arrangements for travel and venues impacted on their experience:

We had a seven-day inquest. We had a two-hour drive each way during rush hour. It was a hybrid hearing. We were worried about what to expect but we had a reasonable inquest, but there were no facilities for us. We had to use the same toilet as the jury and other witnesses. The jury had food and sandwiches delivered to them and had tea and coffee. We had no food and nowhere nearby to buy food. We had a jug of water in the family room and nothing else.

The notion of ‘them and us’ was embodied by some of the venues and facilities provided for families:

The venue was an abandoned school with no facilities, just a room and cold jug of water.

While another felt the venue was chosen for the convenience of the trust and its lawyers:

Not at all family-focused, [it was] right beside the hospital, so easy for them to get to but not us.

For families that experienced an inquest during the pandemic, there were issues with the proceedings taking place remotely, creating an impersonal process that was difficult to follow and participate in. Their preference would be for an in-person inquest if at all possible.

However, whether remotely or in person, there was agreement that inquests are not designed with the families' needs in mind:

At the inquest it did not feel like I was the most important person in the room, not at all.

Another family highlighted the importance of expert support:

You're up against people in positions of authority and respect and there's little you and without someone who's got experience of being at an inquest before and how you address the coroner and all these little things, we wouldn't have got anywhere.

There were some examples of behaviour that families felt really helped, and although simple, they proved significant. In one case this was recognising the importance of expert witnesses, which felt like an acknowledgement of their daughter's specific medical needs:

The new coroner put her at the centre of the inquest. He demanded we have two separate experts on autism.

One family member said she got what she wanted out of the inquest:

[For] the situation to be exposed […] the truth was aired as far as possible.

And for another relative it was a reassurance from the coroner that the proceedings would be conducted without favour and be utterly independent:

He really was impartial. He listened impartially to everyone.

Another was reassured:

We had a good coroner. He was asking questions all the time.

It was agreed that this should not even have to be said and that impartiality and inquisitiveness should be a minimum requirement of a thorough and effective inquest.

Another issue that families raised was the different approaches taken by coroners to pen portraits and photographs of those that had died. Families expressed the belief that these simple and personal touches helped everyone in the room focus on who the inquest was actually about. Some were granted an opportunity to describe their relative and it meant a lot to them:

The coroner did allow us to show a picture and read a pen portrait.

One family member witnessed the impact of personalising the proceedings:

We played a video montage of our brother which caused the other side to go out and cry.

Others had similar requests denied on the basis that:

[…] allowing pictures was upsetting to witnesses.

Families were also dismayed by behaviour that felt insensitive or disrespectful to both them and the memory of their loved ones. Some of this related to unfamiliarity with the processes:

The first day of the inquest the coroner said "this is a road traffic accident. It is not my job to find out why she died, just how she died".

The family involved were unaware of the narrow remit for the inquest and felt it missed an opportunity to look at all the circumstances surrounding their daughter's death. When they tried to raise this, the coroner became hostile and shouted at them.

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> **WHEN STAFF HAVE AN OPINION, IT'S VIEWED BY THE CORONER AS A FACT. WITH FAMILIES IT IS A “BELIEF”.**

For another relative, the inadequacy of preparatory information left them feeling they had missed an opportunity to say more:

We didn't know whether we were allowed to speak or not, if the coroner had said on day one, we would have said more from the witness box when we were giving our statements.

When families did engage with the inquest, they often faced a dismissive attitude to their observations, which they felt were relevant to examining quality of care:

It's like your view doesn't matter if you're not a lawyer.

This type of attitude undermined trust in the proceedings:

There is inequality of methods. If our version of events is not in the records then it is treated as ‘hearsay’ but staff can regularly refer to things which are not in the records.

This prompted another observation:

When staff have an opinion, it's viewed by the coroner as a fact. With families it is a “belief”.

Understandably this proved extremely frustrating, suggesting that families' versions of events simply doesn't carry the same weight or importance as those of the hospital staff or other ‘experts’.

Professional behaviour and respect for grieving families

If anything symbolises the families' dissatisfaction with the inquest proceedings most, it was the behaviour of some of the lawyers representing the trusts, hospitals and other state bodies. This dissatisfaction was framed by a sense of disrespect and insensitivity, the unprofessional behaviour pointing towards a laissez faire approach to uncovering truths and saving future lives.

There were a number of examples given:

The lawyers were laughing, having a good time.

The solicitor for the GP was falling asleep.

And she added:

The lawyers all basically went to Eton etc. and have probably never met anyone with mental [ill] health or learning disabilities.

Another family member was upset by a barrister, whose summing up came across as “very very cold” and said of their child's death:

[I]f it hadn't happened this day, it would have been on another day.

Another person was appalled that the “CEO [of the trust] don't even come to inquest” and argued it should be compulsory.

Families also felt “the legal language is isolating and excludes families” and the inquest needed to be conducted in a way that was inclusive to ensure family participation.

Prevention of Future Death reports and implementing change

Coroners are able to issue a Prevention of Future Deaths report (PFD) at the conclusion of an inquest. There were a range of concerns raised about PFDs, mostly centred on their lack of enforcement; failings in sharing findings more broadly; the discretionary nature of reports being written at all; and families’ anger that the recommendations contained in PFDs were repeatedly ignored, resulting in avoidable deaths.

Enforcement of recommendations was a key worry and one participant suggested PFDs were:

[A] waste of time. What’s the point? If a High Court or County Court judge makes a decision it’s enforced […] a coroner, all they can do is issue guidance, it’s up to the organisations to respond within 56 days to show what has been done.

They added: “there is no system of follow-up on this”.

Some families suggested there needed to be a rethink of the powers afforded to coroners:

They’ve told me from the beginning the coroner doesn’t have any power, they can only make recommendations, they don’t act on the recommendations.

In every other legal case, decisions are enforced but coroners decisions are just, “well, read the letter and file it then thank you very much”. There’s no culpability.

Families outlined the recommendations in their individual cases, and we heard a number involved failure to conduct observations, concerns around ligature points, staffing shortages and lack of specialist staff - all of which have appeared in PFDs in the past.

One relative explained:

The law should change, the coroner can’t make enough impact; they don’t have the power. In our case it happened three years in a row and the coroner should be able to say it has to stop. If they said that three years ago then my [relative] would still be here.

Another outlined why they fight for change:

We are fighting to change the system so you don’t find PFDs in 2029 that have the same issues identified. It is a failing of the system. You can’t request PFDs, it’s down to the coroner. The coroner will finish and decide on PFDs. They submit what they want to do, arguments are made, then eventually the coroner has the option to issue it. A lot of us are fighting for national oversight to ensure deaths will be prevented.

Other concerns were raised about the motivation of coroners around what should be included in the PFDs, not least when there was evidence of repeated failings within a trust:

The only PFD we got was in regard to anti-ligature clothing. They said it’s a huge business issue. It’s not about money it’s human life. It’s a huge problem with inquests that it’s so dependent on the coroner. Ours had a background in repping for private providers.

Several people mentioned their concerns about the failure to share PFDs with other hospitals, with trusts or as part of investigations where the findings may be relevant:

It's disgusting that a PFD issued in [redacted] goes to no other county. It isn't seen by frontline staff etc.

It was pointed out that failing to share PFDs impacted on actually preventing future deaths:

The institutional failure to take action was counteracted by families who committed to sharing the findings with staff, and continuing their fight for change:

If a PFD is made following my daughter's inquest, I am going to stand outside every hospital and hand this to staff.

Another added:

We are going to go and send the PFD made at [our] inquest to staff in all the local mental health hospitals.

Whereas one person believed:

I know we'll go through the inquest and there might be recommendations, but as a parent I would be insulted if people issued PFD notices that aren't followed through. I'd rather not have one if they can't. It's about placating families, it's like saying you've won tickets but you're never allowed to use them.

The impact of non-implementation was addressed by one family who were witness to unchanged treatment and safeguarding systems:

The trust have always said about plans, not implementation. Our other daughter is on the same ward, we would say her treatment is worse. She has access to a plastic bag on the ward.

In another case, involving the availability of choking hazards on the ward, the family described their despair that despite a coroner's recommendation, things stayed the same and all they were asking for was compliance on the part of the trust:

My coroner said remove bags in mental health settings, if they'd done it earlier my [relative] would not have died, but the MP came back and said they didn't need to. If they had done that it would have been a real change.

For some families, the content of the PFD had been a positive experience, and more so when it was allied to action on the part of the trust. Implementing recommendations was seen as crucial to the process:

Knowing that the hospital removed the doors. But that is tinged with "what about the rest of the country?"

There was some positivity around the inquest bringing up issues that could be used to hold trusts to account by raising broader awareness:

We are talking about mental health now more than we ever have before, these are our children and they can have fulfilled lives if we support them properly, that's our only hope, by talking and making a fuss we are raising awareness.

What needs to change?

Many of the families we heard from had developed clear thinking about what needed to change in the inquest process to make it better for families, more accountable and ultimately more effective in identifying ways in which future deaths could be prevented.

If one thing united the group it was the desire to ensure others were not placed in the same position as them in the years to come. Some of the families' suggestions focussed on the actual process – the practicalities of engaging with the system – and others had identified culture shifts that needed to happen in order for transparency and accountability to become embedded in the culture of providers.

Process changes

Some expressed a desire to introduce an appeals process that meant coroner's decisions or mistakes could be challenged by an independent coronial oversight body because they felt "you can't appeal a coroner's decision".

There should be a right of appeal when the coroner makes a mistake.

This should take the form of a standardised "national coronial service with a complaints system".

Families agreed that:

It frustrates me that we can have such different experiences with the coronial system.

With a request that:

The [coronial] process should be standardised.

Families also suggested there needs to an obligation that recommendations arising from a PFD report are implemented. The absence of such a framework for follow-up and enforcement resulted in a missed opportunity to enact real change:

All the coroners can do with a PFD is issue guidance to the organisations from what they heard. It's up to the organisations to respond with actions they feel will negate the issues the coroner identified. [The] coroner has no obligation to follow up or monitor, there's no current system to follow that up. The PFD system is a failed system as it doesn't prevent future deaths.

If this was to be coupled with mandatory analysis of PFDs, Safeguarding Investigations and Serious Incident Reviews, then repetition would quickly become apparent. It would be reasonable to adopt a "3-strikes"-type approach to move towards a position where a provider has to demonstrate "positive obligation" rather than the family "proving failings" with accountability for leaderships that repeatedly fail and/or fail to declare services/wards/staffing etc as "unsafe" and requiring additional measures.

A further change was a suggestion of penalties for those trusts that failed to provide accurate information regarding the quality of their care:

One of the things that can be prosecuted is that if the NHS provide inaccurate information to Parliament in their annual quality accounts. No one has ever been prosecuted.

Changes in culture

Families felt that there needed to be a significant culture shift if the investigation and inquest system was to provide tangible change. They identified concerns around candour, transparency and accountability.

As things stand at the moment, families feel let down by an adversarial process that created mistrust, and an over-reliance on legal might rather than acceptance of responsibility when things went wrong. In this scenario, families were denied apologies and truth on the basis that acknowledging such implies guilt. This was deemed unhealthy to effecting meaningful change to failing care systems:

We know what happened with [our relative]. The more they covered that up, that pushed us to find out more. It would've made a difference to us if there was acknowledgement from the start.

It was argued that without acknowledgement of failings, accountability is difficult or indeed impossible to achieve:

I'd like people to be held accountable for what they've done. If [my relative] was at home and he was ill and I'd refused to feed him or care for him, I would be brought to social services, probably charged with manslaughter. But in a hospital you think they're safe, and these people don't do their jobs – it should go right up to the top, they all need to be held to the account.

I want someone physically held to account. If I do a job badly there are repercussions, especially if someone dies.

Without accountability, families felt it was too difficult for the trusts to say sorry. This was a major insult to families, with apologies being either unforthcoming or delivered begrudgingly:

We got an apology on thinnest paper ever seen, one letter to five people. We forced them to send it on proper paper to five people.

They apologised to TV cameras outside the inquest. We thought they might follow up. They didn't.

Another woman added:

If they'd said sorry I wouldn't have sued them, it's as simple as that.

Without accountability, families argued that change is impossible because the repercussions for professional and systemic failings go unpunished. However, to make a real difference accountability needs to underpin the whole process, to enable all those involved to be open about admitting errors and asking key questions: what could we have done differently, what are we doing at the moment that could be improved and what do we need to change?

Families also highlighted the pain and anguish of having to fight for the truth when this could have been avoided if someone, anyone, had told them the truth at the beginning:

We need those meaningful answers of what they could've done differently early on, and that might save us as families years of our lives.

They felt the current system was described as inquisitorial when in fact it was adversarial, reliant on solicitors and barristers to defend the care providers from meaningful scrutiny. Some felt the solution was to either publicly fund families' lawyers or do away with legal representation altogether:

We need to remove solicitors from the process for everyone and we'd be getting a system of openness and encouraging people to ask what they could do differently. Civil litigation has to be applicable, but could that system prevent people from actually really critically looking at the answers?

We need a truly non-adversarial system where everyone is on equal footing.

I work for [the] NHS and we have regular reports on learning and what went wrong. You just need to replicate that in a system without lawyers for people to be open.

One participant referred to different legal jurisdictions and the impact there:

Australia and New Zealand have removed some litigation processes so you can't sue the doctors which apparently has supported them in changing.

One of the key desires expressed by families was a requirement for the process to be more honest. Families agreed there should be a duty of candour, as included in the 'Hillsborough Law', compelling witnesses and those giving evidence to tell the truth. It was suggested:

Why not take statements under oath as you'll have broken the law to say something else?

Another example was given which demonstrated the need for good legal representation when confronted by dishonest evidence:

When nurses lie on the stand, you can't even answer back, because of the order of the lawyer speaking. Legal teams need to guide us on where to go.

Families said the whole experience would have been better for their health and well-being if trust employees had just been honest from the start:

I would like people to tell the truth and look me in the eye. I am [the] only one in the room who needs that truth. I don't want accidental death; I know people it's devastated.

Others agreed:

Honesty is gratefully received. We had to revert to the media […] we would have disappeared into the background if we'd received the truth in the first place.

I thought that people would have genuinely tried to find out what happened. You just want to know the truth.

In the end, without the suggested changes in culture, families were left with a negative view of the process; one that nominally promises to ensure accountability and change, but feels very different for those that have been through it:

I've had the inquest, but it has not helped. I have had no justice. They've walked away having killed people.

When you talk to people who haven't been in the process they have no idea. The perceptions come from Hillsborough or Manchester, these huge, long ones. People think it happens fast but it takes years. And people don't realise how emotionally draining they are.

It impacts your grief. Ten years on we haven't scattered ashes, as we thought we could do that after the inquest. It has wounded us so much.

Until the investigation and inquest system is overhauled, families felt they were isolated, unsupported and unheard:

The law isn't for people like us. The law doesn't support us, the government doesn't, the CQC doesn't. There's a fault in the system, the system needs to be changed.

What families recommend

Families suggested the following for improving their experiences of investigation systems:

- More compassionate, empathetic and humane treatment of families grieving the death of a loved one.
- A proper appeals process to challenge coroners' findings.
- A national coronial service.
- Non-means-tested funding for all families involved in inquests where state bodies are also involved.
- Inquests to be conducted in simple and accessible language.
- Families to be given private facilities and reasonable venues for the inquest.
- Support for families before and during the inquest.
- Enforcement and oversight of PFDs and coronial recommendations.
- Ensure the duty of candour placed on trust staff and other organisations and agencies involved is properly enforced.
- An end to the culture of defensiveness.
- An open and honest approach from trusts.
- Apologies delivered at the outset.
- Greater oversight by the Care Quality Commission of the issues arising from investigations and inquests and the treatment of bereaved people.

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