

Report of the Independent Advisory Panel

on

Deaths in Custody

Family Listening Day September 2011

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1. Introduction

On Thursday 22nd September 2011, 11 families (comprising 19 family members and friends), who have direct experience of the investigation and inquest system following the death of a relative whilst in mental health detention, met members of the Independent Advisory Panel (IAP) on Deaths in Custody (and representatives of its secretariat)¹. The event was organised on behalf of the IAP by INQUEST following an independent tendering exercise. INQUEST provides a casework service directly to families bereaved in such circumstances and is thus uniquely placed to organise such an event.

The aim of the event was to share details of the post death experience, the investigative and inquest process, and the aftercare and support provided by Trusts and hospitals. Two facilitated group discussions elicited thoughts and opinions, and members of the IAP had an opportunity to listen first hand to the families' concerns, experiences and ideas for improving the system. Further evidence was sought using a questionnaire that was made available to all those families in attendance and has been included in this report. Several families provided independent information in the form of letters or reports for the attention of the IAP. It should be noted that the purpose of the event was not to compile statistical evidence but to provide a "personal" snap shot of the process for those who have experienced the death of a relative in such circumstances.

This report aims to bring together the key themes from the day with further evidence via questionnaire to outline specific family examples of both good and bad practice and to encapsulate the suggestions, made by families, for improving

¹ Lord Toby Harris, Chair of the IAP, panel members Simon Armson and Deborah Coles, Secretariat Laura McCaughan, and Deputy Secretariat Matthew Leng

the system. It should be pointed out that this report makes reference to Trusts, which can mean NHS, Mental Health and Foundation Trusts.

2. Families notification of the death

In some cases families were informed by the hospital, usually by phone and / or by a police visit. Families consistently described the sense of shock and trauma on being told the news, and the absence of any further information or immediate emotional support. They made the point that any practical thoughts are put on hold whilst in a state of shock, and as a result, much of what happened in the immediate aftermath was a blur. As one person said *"you don't know what's happening, you're in remote control"* another felt *"in a void"* while one mother explained that she was told about the death by a ward manager after telephoning the hospital and was then visited at home by a police officer but that *"I and my husband were in such a state of shock everything else he (the police officer) said went over our head"*.

However within these broad based descriptions some fairly dramatic personal stories emerged. One family were informed of their son's death by his consultant who was reported to have said *"there is a 99% chance your son is dead"* and to compound the insensitivity, the consultant told her he was driving at the time.

For a number of families information was only released as a direct consequence of their persistence and concern:

One parent described her concern for her daughter's well being: *"I just kept ringing the hospital. Apparently she was with another patient – a heroin addict – when she was let out. They told me that she had died. I was in shock. I told them not to just leave me like this. The hospital mentioned Victim Support, but they couldn't help."* Another family (partner and sister) described their concern for the well being of their partner / brother after a change to his care plan highlighted his vulnerability. The family spent the day with him before he went back to the hospital. They were due to collect him the following day to bring him

home. Due to problems with the roads, the family kept ringing the hospital to keep them informed of the delays in their arrival time, and to check on his well being with repeated requests to check he was ok. On arriving at the hospital at 2.30pm the family were informed their son had died at 11.00am. The family pointed out that they had made continual calls on route to the hospital to suggest checking their son. The hospital said they had been unable to contact the family during the time between death and their arrival at the hospital. *"When we got in (to the hospital), they put us in a room and told us he had died at 11.00am. Nobody had checked him"*.

Families also described failings in communication, with hospitals and trusts being charged with failing to either keep or use families contact numbers:

One man, who had travelled out of the area in which his wife was detained, was informed of her death by a member of his extended family. The hospital had made no attempt to contact him on his mobile phone. *"I was outside London at the time. I did give them my mobile phone number so I don't know why they didn't call me directly"*. His wife had died in the morning and he found out, via his in laws, on the Saturday night. Another explained how they were visited by a police officer three hours after the death of their son. When he challenged the hospital as to why no-one had rung them, he was told the hospital had tried several times that night to make contact but no-one was in. The man and his wife had been in all evening and received no phone call.

Another family described leaving their son at the hospital but feeling anxious about doing so. Their son had been in three hospitals in less than 24 hours and the family were concerned that he had become agitated. They were with their son throughout his admissions and transfer, and initially were going to sleep in the car park but were convinced to return home and get some rest. Later the same evening their son's friend rang to tell them there had been *"an incident"*.

The family at this point were unaware of their son's death following police restraint. The hospital had not been in touch apparently unable to find the number of the family in order to make direct contact. They were subsequently visited by *"the head of the Police Station who came to our door to assess who we were. He was surprised we were not a "drug addict" family. He was looking for stereotypes"*.

Other families were present at the hospital when their relatives' died. In one case a mother worked at the hospital in which her daughter was brought to A&E and, having been present for forty five minutes whilst staff attempted to resuscitate her daughter was informed by her manager of her daughter's death. *"My boss came back in and told me that (her daughter) had died. We were all traumatised. L had bi-polar and was only sectioned 4 days previously. They told me the psychiatrist's number to ring during the weekend. I worked in mental health in the past and knew there had been big failings."* In another case *"We knew what happened as my wife had been present when our daughter died"*. His daughter had gone outside for a cigarette; she was on the 4th floor and jumped from the walkway. Other families were faced with decisions regarding ending the use of life support machines. This was hugely traumatic for one family in particular, when members of the transplant team made ongoing reference to *"harvesting"* organs. The family knew what was meant but found the repeated use of the term inappropriate. *"That's what it felt like. My son was failed by the NHS so that his organs could be harvested. Horrendous."*

There would appear to be a variety of protocols at work when it comes to informing the family of someone who has died following a mental health detention. Families' experiences suggest a level of inconsistency and a lack of sensitivity.

3. What access did families have to advice and support?

The group discussions revealed a consensual agreement that advice and support was patchy in some cases and absent in others. Families pointed out that they were at their most vulnerable on hearing the news of a relative's death and were unable to take on board the information and advice they were given. The families were given no indication of what action needed to be taken, and felt those responsible for the care of their relatives prior to death, needed to guide them through the process by providing greater access to advice and support. In short, a clear guide to the next steps, and a clarification of what to expect.

There were individual cases where families had received support and advice, but not from the hospitals or trusts. One woman explained that following her son's death she had received tremendous support from *"carers, service users, families and support groups"* but made the point that at no point was she given guidance from any agency on what would happen next and it was only down to *"relentless questioning that motivated the Coroner's office to give me information, which led me to INQUEST"*. Those that had found out more about the subsequent process of investigation, the inquest etc only did so because of their own persistence and resolve.

Families felt they had been *"left in the dark"* regarding the process, future investigations, post mortems and inquest procedure. One man was warned by a police officer *"there is a chance they would not find out for months what really happened"*. Another woman explained there was no support, the police were ill informed, and she eventually found out about ICAS (Independent Complaints Advocacy Service) through a web site, but this was down to luck rather than design. She continued that the only immediate contact with the hospital after her son's death was to receive a black bin liner marked *"NHS household waste"* which contained her son's personal possessions. Several other families

mentioned ICAS in their testimony one woman explained *"We had ICAS helping us. They came to visit us and it was them who put us in touch with INQUEST"*. Another woman was confronted by the difficulty of having to prove herself as the next of kin after her son's death. The Trust was unable to verify her relationship with her son, and this resulted in a delay in seeing the body. Again, there was no advance warning or advice as to the protocol for such an event. Another person pointed out the dearth of independent support for families bereaved in such circumstances, *"Coroner gave us a card about counselling services to our barrister but we did not want to contact NHS for any help. The same NHS who caused our son to die?! This is a horrible club to be in. There is no one to help us out there"*.

The accidental discovery of sources of help and support via internet research was not uncommon. One woman explained *"I looked up the Carol Savage case on the internet and got in touch with some specialist solicitors. They then told me about INQUEST"*. Another family agreed; *"we got no help or advice, only what we stumbled across on the internet"*. They did receive *"a small leaflet about sudden deaths and the Coroner's intention of M (her son) having to undergo a post mortem. The hospital sent representatives to our house to try and answer some of our questions but they were not actually treating M. They were senior staff and we got absolutely no help or advice"* One other family present also recalled receiving a leaflet with information regarding INQUEST, possibly from the police, but from a total of 11 families represented, only two received any information regarding advice and support.

Other organisations mentioned by families included, MIND, Rethink and INQUEST all of whom were described in positive terms, and as valuable sources of information, legal advice, support and help. What was upsetting to the majority of families was the failure on the part of Trusts to point people in the

direction of organisations equipped to offer meaningful specialist support to families.

It was agreed that any information should be given in person not just in the form of a leaflet, and that every trust and hospital should have people whose job it is to provide independent advice on what to expect following a sudden death. Families were dismayed at the lack of consistency and haphazard approach to supporting and advising people facing an unbelievably traumatic experience. As one person said *"In their state of mind after the death- they needed someone to sit with them and explain the process; not just leave them to it"*. Another suggested *"They need to provide support for families- beyond just leaflets. Someone who can identify issues and advise them as to what steps they should take"*.

4. Families experience of the investigation

It is good practice for each Trust to have a policy explaining how it investigates the death of patients under their care, how long the process should take and the steps involved. Families should have the right to see a copy of this policy. In some cases this did happen, with families being visited by members of the Trust and in a couple of cases by representatives of the Mental Health Act Commission (now part of the Care Quality Commission CQC). In spite of these guidelines however, families seemed unaware of their right to participate in the investigation process. Even those families who were more involved felt the initial visits made by Trusts representatives felt like a *"fishing exercise to find out what we knew already"*.

Families reported a lack of information from the Trusts. One family reported that they *"were unaware of any investigation, everything was released in drips"*. Another claimed, *"They didn't disclose anything, it was a battle to the end"*. One family said *"it was not the trust policy to disclose statements; they didn't want the report to come out until after the inquest"*. Another said *"the shutters came down as soon as I started asking questions"*. In some cases there were no investigations at all, and one woman reported there was *"...no investigation into my son's death and the Mental Health Act Commission was not informed"*. If it had not been down to her persistence she said that little would have been done to shed light on the events leading up to the death. As she pointed out, *"I had to battle to get a Strategic Health Review"*. Families felt that it was unfair and unjust that the inconsistencies of the Trusts should leave them in limbo. One parent explained that it was like being *"in a void whilst waiting"*.

What was even more alarming for families was the misinformation provided to them. Families were told they could not see the reports following investigation, or indeed participate in the gathering of information. Best practice would suggest that Trusts should carry out investigations into the deaths of detained patients reasonably speedily, with a degree of independence and with the involvement of the family of the person who died. The Trust "should normally arrange to meet the family during the investigation in order to identify any concerns that the family has and to explain the investigation process".² This was not the experience for the majority of those present on the day. One man explained that *"When I met with the trust they told me that I will not be able to see the report but they will discuss the findings with me. I then found out that it was not only my right to see this but I also had a right to be involved in the investigation. They never ever consulted me"*.

Another family outlined their concern regarding the investigation process thus: *"I was unaware of what investigations would occur and what they would look at. When my son died the police were not called and the crime scene was not secured"*. Another mother outlined her experience in more detail, and it provides a sense of the frustration with the investigation process and its perceived flaws:

"First time I had opportunity to speak to anybody was the consultant. Nobody told me about the investigation. I told the consultant that I wanted a meeting with nurses and see what happened. Through PALS, I found out about 'Critical Incident Review'. Consultant and matron came for the meeting with no pen and paper. I was the only one who was taking notes. After that the matron told me that she would try to get answers for me. I asked how she would remember 20 questions which I asked as she was not taking notes. It took 3 years for them to give this evidence". The same woman commented later in the morning that the

² INQUEST Handbook, Section 5.5 Deaths of psychiatric patients

only written response from the Trust during the whole process was a *"2 sides' letter with no dates, no nothing. They told me that I wasn't entitled to the full report for years I have been demanding to see the Serious Untoward Incident Report, so I am hoping that I will get it now. They are not independent. They lie"*.

In the absence of consultation families felt that crucial information from the family's perspective that may assist the Trusts establish what had happened was overlooked. Families felt that they had knowledge and experiences that would benefit the Trusts and help avoid *"others having to go through the same thing as us in the future"*. One woman explained *"The report [into her son's death] did not mention that her son had asked for help but only been sent home with a leaflet. Also, the report did not refer to NICE guidelines"*. For families the details matter, and for all but a minority, the investigative process was distant, evasive and perceived to be a *"whitewash"* exercise or as a mechanism for protecting jobs and staff. One person had the opportunity to speak to someone conducting the investigation and they suggested to the family *"that they had spoken to staff and they usually took their word at face value"*. Another explained their dissatisfaction with the process, *"An Incident Review was eventually sent to the family in December, well outside the specified time limit. This incident review had numerous blatant omissions and manifestly failed to record or analyse events witnessed on the ward by my wife. The basic timeline was also deliberately confused"*. Another detailed the failure of the Trust to listen to what the family had to say *"We knew my brother better than they, and they ignored our concerns, didn't make notes of our phone calls and did not pass on messages. Basically the whole thing was a shambles, a tragedy waiting to happen"*.

It is relatively rare for the police to be involved as part of an investigation unless they were directly involved in the events leading up to the death, or if there is a need by the Trust to establish the involvement of a third party. However families

present did have some experiences of police investigations. The fact that these deaths occurred whilst in mental health detention seems to blur responsibility for action in the eyes of the families involved. One man expressed his frustration "*The police investigation took three years which is way too long*". Other families complained that the police failed to secure what may have been crime scenes.

Ultimately the way in which families regard the investigative process is shaped by a lack of information and their perceptions of the staff they deal with. There can be no avoidance of the anger, suspicion and mistrust expressed by families during the course of discussion. Families described the attitude of trusts as "*insensitive and obstructive*". Their experience of Trusts was that they were inconsistent with their approach to investigations, there was little or no information provided regarding what to expect, little communication during the process, and delays in making subsequent reports available to the very people who need them most. This will inevitably lead families to conclude that there are lies and whitewashed accounts of events, and the families' perception is that the Trusts are simply going through the motions in an effort to hide or manipulate the truth. One man was forthright in his criticism, claiming "*The Trust has been underhand, told lies and very un-cooperative*". What was needed for the families was openness, not, as one family recounted when they made efforts to ask questions during the investigation into the death of their son, to be told "*they couldn't answer our questions without legal representatives*". As one woman said regarding the investigation into the death of her son, "*There are several interested and influential parties involved and they are reluctant to release information in its true unpolished state*".

4.1 Example of Good Practice

There was one very positive example of a family being involved in the trust investigation from the outset and is an example of what is possible within the

current system. After their son's death there were two parallel investigations, one by the IPCC (Independent Police Complaints Commission) and one by the NHS Trust. They were contacted by the Trust and with the support of their solicitor informed of its terms of reference, were involved in the investigation, and sent the draft report and invited to comment on its content. They found this opportunity to play an active role a very constructive experience. This positive experience of a family given the opportunity to play an active role in the Trust investigation was the only such example in the group discussion.

5. Families experience of legal advice and obtaining funding

All but one of the families represented had managed to secure some advice, but the routes to finding legal representation were described as difficult and personally very intrusive. What became evident as the testimonies unfolded was that without some form of legal advice and representation, the investigative and inquest processes become an ordeal for families. What also became clear was that legal representation can come at a hugely prohibitive cost.

As with previous sections one of the key concerns was the difficulty in obtaining specialist legal advice and funding. The lack of adequate information and support at the outset (Section 3) meant that families were initially unaware of what was required or expected. In two cases, prior to the start of the inquest, families were told they did not need representation at all. One family explained that the *"coroner told us we did not need legal representation, in fact they told us we didn't even have to be present at the inquest. If your child dies you want to be there"*. Another stated that the *"Coroner's officer told us that we didn't really need a solicitor"*.

For other families not having knowledge of where to go to obtain specialist legal advice led them into potential financial crisis. One family outlined the financial burden for them, *"We are in 27 thousand pounds in debt. There should be more help there when the hospital admitted failure but we are still paying"*. One woman explained how hard it was to get legal advice on such matters in her home town, and that she was eventually quoted a cost of *"£17,000 for three days attendance at court"* and this from a law firm with no particular expertise of deaths in mental health detention. Another man explained that he *"was granted legal aid, but still needed to find the first £700 of costs. Not every person would even have that"*. The lack of financial assistance for families facing an inquest, or requiring legal representation for the investigative process, angered those

present. *"We could not get legal aid for a solicitor to represent us or our son's dependents at the inquest although the Trust was represented by a lawyer whose fees would have been met out of public funds".*

What is evident is that for those families who did manage to acquire legal help, the experience was transformed. Those lucky enough to stumble upon organisations like, MIND, Rethink and INQUEST were able to place their trust in those with experience, skills and specialist knowledge. The provision of pro bono legal advice is a lottery, and families suffer because of it. As a counterpoint to that, from testimony on the day, the sooner a solicitor is involved the more control and direction families have over the system. *"By Monday morning INQUEST got me a solicitor. He got an independent pathologist. I told them that I wanted to have my own post mortem. That initial help determined everything. You feel that you have weight behind you. It changes the way people look at you. The IPCC had 2-3 meetings with us. We had an opportunity to have an input. This has all happened because INQUEST got us a lawyer from the very beginning".* Families described how empowering it proved to have support and advice that allowed them to an opportunity to establish what happened. Patently for some, the outcome of the investigation or inquest still posed unanswered questions, but there was a sense that they were now participating in the judicial process rather than being passive bystanders to unfolding events. Families variously reported that;

"There is no chance that [issues we raised in the investigation] would have been looked at if we didn't have a solicitor".

"Representation made a difference. We feel very fortunate that were put in touch with INQUEST. We got the answers we were hoping for".

"I was allowing myself to be guided before. I would have not been able to do anything and the inquest would have been a white wash. I had a good solicitor and the INQUEST team and 'Mind' and it felt like I was part of a strong team now".

"As soon as we had a solicitor, things started moving again. We waited 4 years for an inquest. We did everything ourselves for two years".

"We had no support apart from the solicitor and the barrister".

The one family who did not have legal representation during the inquest described how their surviving son took on the responsibility of representing the family. The parents felt unable to speak during the inquest, and as they movingly explained *"Our son was our rock. He asked questions for us. All the information at the inquest was new to us. The Trust Manager was a new member of staff-not involved in the death of our son. The Trust had a solicitor to support them. We, as tax payers, are paying for the Trust to have the best legal advice. Our son was a nervous wreck by the end of the inquest and the pressure caused arguments between us as he was being relied on in the place of a solicitor".*

6. Families experience of the inquest

The lack of information, or inadequate information provided on a drip feed basis, also came to represent the pre inquest and inquest experience for families. Families felt they were left to fend for themselves, and described an atmosphere of *"them against us"*. One family explained *"The coroner's officer contacted us but seemed in a rush to get everything sorted immediately. When you are grieving, it is hard to be rushed, we felt hassled"*. Another echoed these views, *"the autopsy was very quick, the coroner pushed for a quick burial: trying to take over and organise everything"*. He said they *"felt we were on a conveyor belt"*. Conversely another family reported that the *"coroner seemed like an absent professor, everything took a long time"*.

Misleading information included families' being told they did not need to attend the inquest, *"the coroner's officer told us that we didn't really need a solicitor. a failure to inform families of pre-inquest hearings, minimal information on the protocol of the inquest process and in some cases a level of hostility*. One family summed this up; *"We had a Pre Inquest Review, very nasty Coroner. He didn't acknowledge us. (He was) Very rude and very nasty"*. As has been noted earlier in this report, families who did not have legal representation prior to the inquest beginning were placed at a distinct disadvantage. *"We were given no information. We were not told about anything. We had a pre inquest review which was before we got a solicitor and had no idea what to expect"*.

Some families felt that like the Trusts, some coroners did not pay them the respect, sensitivity and compassion due to a relative of someone who had died whilst in the care of the state, and this was a recurring theme of the discussion. Various people described being treated like a *"second or even third class citizen"*, with a lack of *"dignity"*. One said *"you're not looking for sympathy but you deserve it, you deserve at least an acknowledgement. You deserve common*

decency. Even a dog would get that". Some families reported the inquest to have been "*horrendous*" and one woman's summing up provided stark evidence of failings in the whole system when she described how "*apart from my son's death it (the inquest) is the most distressing experience I have endured*".

These comments are made in the context of families having to go through the dreadful experience of bereavement, with its incumbent uncertainty, grief, sadness, anger and loss. This failure on the part of authorities to acknowledge the grieving process also framed families' concerns at the lack of disclosure of information, some of it hugely personal, until the inquest took place. One family described their dismay at having to wait until the inquest to discover whether their son had left a suicide note or not, furthermore the same couple only found out at the inquest that there had been a near death incident (not involving their son) at the same institution before their son died but they were not given and cannot find any details of who was involved or when it occurred. Another made mention that "*he only found out, thanks to his legal representation, that there had been an incident report 3 years previously without his input*". Another woman was informed of a "'72 hour report' at the inquest- this was the first she knew about it. The inquest transcript did not include details of this report and it took years to get a redacted version". Families found it hard to cope with finding out that crucial information relating to their loved ones was held back, sometimes for years, and led one man to speculate that in his opinion, "*the family were the last to know, nothing is done for us*".

A number of families also felt let down by the amount of time it took for the inquest to take place. "*It doesn't matter how long ago the death happened, it is raw*". Some families waited years before the inquest happened and several present had still not had the chance to establish the circumstances surrounding their relative's death. The waiting is "*anguish*"; another spoke of being in "*limbo*" and putting "*your life on hold*". The families agreed that they were forced to

become experts and learn for themselves; *"it takes years and took over your life"*. *"There should be a limit to how long you can wait for the inquest. A lot of nurses couldn't remember what happened."* The longer the time it took for the inquest to take place, the greater the burden, as one woman said about waiting, *"you had to keep reliving your child's death"*.

In addition families were disappointed with the narrow remit provided by the inquest process, which in some cases was exacerbated by perceived failings on the part of the coroners to allow certain evidence, consider reports and witness statements, and to question in sufficient detail those tasked with caring for those who had died. Several families flagged this up during the course of the discussion. Evidence from families included complaints that the *"the inquest jury were guided as to what they could or could not make recommendations on"*, and that the *"Coroner gave very narrow directives to the jury. We walked out feeling awful"*. Another family described their frustration; *"Guidelines, codes of practice are there but nobody takes any notice of them, including the Coroner. Coroner refused to hear evidence from the witnesses. We then took him to court and then managed to convince him. But inquest process was useless because when trust is talking you can't get up and say it is a lie"*.

Families' perceptions again prove crucial to their views of the impartiality of the inquest system, and for some families it felt as though the process was configured to prevent them accessing truth and justice. *"It was a farce. Coroner had been in the pocket of the trust all along. We had to really fight to get the jury on our side. He said he treated every inquest as an article 2 inquest. My solicitor told me he had never come across a Coroner as bad as this. It was awful. You put so much energy into researching. On paper their policy is great. He hardly asked me any questions. His questions for the witnesses were rubbish. He was just giving evidence and witnesses were just nodding"*. Another family described how giving evidence at the inquest felt for them; *"I found going*

on the stand an awful experience. After the person who saw (their son) jump off the fence gave evidence, we found out that three of the members of the Jury worked for the NHS so it all had to be postponed. I felt like it was us against them. They forget that it is your loved one they are talking about. They were there supporting each other. We had no support". The lack of rights of families to call witnesses to give evidence, and the failure of coroners to consider all the evidence before them was also raised. One woman outlined her frustrations, "27 *people were interviewed and every single person contradicted each other. I wish the coroner had more power but they can't apportion blame on anybody".*

6.1 Practical Concerns

Further concern was expressed regarding two practical problems. Firstly the location of inquests, the inappropriate settings and subsequent lack of privacy afforded families, and secondly the cost of obtaining transcripts of the inquest itself. Families in the main were accepting of the venues, but in a couple of cases the practicalities of the venue did pose a problem. One family explained how their setting had an impact on proceedings; "*For our inquest we were in the civic centre but we couldn't hear anything. Worse thing however was that it was recorded but no one could transcribe it as you couldn't hear it. We were waiting for the jury to return the verdict but the Coroner said there was a council meeting at 5.00pm and that they had to return the verdict by then. The privacy aspect was ridiculous. Trust staff walked up and down so we couldn't talk".*

Another family were initially doubtful about their venue; "*Our inquest was in a football club but because we had a lot of friends with us it was a little easier. At first we thought 'football club?' but then I thought (their daughter) would have found it amusing".* The lack of privacy was a concern, and left one family feeling quite distressed; "*I found the inquest very distressing. There were no private rooms where we could talk to our legal team. When the nurses or doctors got upset after giving evidence, someone was there to support them, give them a*

cuddle or flowers. The flowers were left in the toilet which we as family members had to use”.

The cost of transcripts also came up in discussion and families were upset that they had to find between £1,000 and £1,500 to access the court transcripts. For some present the mere mention of the costs involved, in some cases brought up by Coroners, were upsetting. One family found the Coroner critical of their request for the results of blood tests carried out at the time of their daughter’s death. As one woman said, *“I did not want to hear about costs, it was nothing to do with me”.*

It is also important to note that the inquest was seen to serve families’ when the Coroner made Rule 43 recommendations. A number of families mentioned how positive an impact this had made on their experience of the process. During the day families’ consistently made reference to their wish that lessons be learned from the deaths of their relatives, and the coroners recognition of changes needed using Rule 43 provided some comfort and reassurance. One woman commented that *“they got to the bottom of things and made Rule 43 recommendations – about door hinges for example”.* Whilst another was relieved to note that *“we had a Rule 43 and care plans are being reviewed”.* The challenge for the Trusts and hospitals is that action was seen to be taken to prevent future deaths.

6.2 Examples of Good Practice

The groups also presented a number of cases which highlighted how well properly conducted inquests can work and how this serves the families’ needs. These positive examples share much in common, principally a Coroner who sympathised with the family, who was perceived to have done his / her utmost to discover what happened, and where the time lapse between the death and

the inquest conclusion was as brief as possible. Praise for Coroners and their approach included; *"we only waited for ten months and had a fantastic Coroner. He was very nice. He made it very easy when we were giving evidence, and the coroner's officer also kept us up to date"*. Another agreed that the role of the Coroner was crucial; *"the Coroner was a gem, she left no stone unturned and made sure the jurors could ask the witnesses questions. She was understanding towards my family, she even gave us a card with the number for counselling. She said it was a distressing case, and the family was not at fault. She praised me and my husband for the love and care (their son) received"*. Other families voiced their own gratitude, *"the Coroner was very thorough with his investigations, and fair"*, and *"If it weren't for the inquest and good Coroner we would have no questions answered"*. The empathetic nature of some coroners enabled families to place faith in the system, and ultimately seek some solace in seeing justice done, and have their key questions answered. *"The sympathy of the coroner and his staff helped us and treated us like we had had the horrific loss we had"*. As one man pointed out, it was crucial that the system works properly for the family as *"the inquest was the only place where they gathered the facts"*.

The behaviour of the coroner would appear to set the tone for the resulting proceedings. This, as was noted previously in the report of the Independent Advisory Panel on Deaths in Custody Family Listening Day March 2010³, seems to stem from there being two identified coroner archetypes as explained in a previous Home Office Research Study (241)⁴

³ Independent Advisory Panel on Deaths in Custody Family Listening Day March 2010

⁴ Home Office Research Study 241: Experiencing Inquests (Davis, Lindsey, Seabourne and Griffiths-Baker, 2002)

<http://webarchive.nationalarchives.gov.uk/20110220105210/rds.homeoffice.gov.uk/rds/pdfs2/hors241.pdf>

[The first is] *seen as punctilious and correct. These coroners did not appear unfeeling, but their attitude to the family was perhaps 'correct' rather than 'warm'. They concentrated upon satisfying the formal purposes of the inquest. The second archetype is that of the coroner who conveys the impression that the inquest is, first and foremost, for the family.*

7. Families experiences post inquest

For some the inquest came to represent the end of a journey to establish the truth about how a relative has died. But for many there remain unanswered questions, a lack of closure and a continued struggle to establish clarity of information surrounding the death and recognition from the Trusts that their actions or omissions were contributory. The following comments reflect this.

"Verdict was that the care had extensive failings. Rule 43 recommendations were made. Hospital still will not admit it. We still didn't have an apology. The only way the trust takes any notice is to ask for compensation. 7 years on and they still don't accept liability. It is going to happen again".

"The inquest verdict into our son's death was misadventure, were told later there were plenty of issues that could have resulted in a different outcome if we had been advised prior to the inquest".

"We were told that trying to take the issue any further (beyond the inquest) would only upset us further".

"They rely on exhausting you".

"My mother became so unwell I am sure this did not help. Something has got to be done to stop that happening to others".

"We need to speak for him. We need to do all that we can do to make them listen to what we say".

"There must be a fundamental cultural change – one of cooperation and collaboration rather than seeing you as the enemy".

"I'm not looking for compensation but for lessons to be learned, for something positive to come out of my wife's death".

"I heard nothing at all after the inquest from the trust".

"There is a lack of joined up thinking. There were too many bodies, pointing the blame at each other. All that is required is that the Trust 'considers' independent inquiries".

"The idea that the inquest was a final conclusion that drew a line under an incident was used to stop further inquiries or investigations".

"Someone to say sorry; an apology".

"No sorry yet, we haven't received any apologies".

"Trust should issue guidelines. I never heard of ICAS for example this is the first time (the discussions at the listening event) I am hearing about them".

8. Areas for improvement identified by families

The following suggestions must be considered in the light of a number of key factors. Firstly, they are as a direct consequence of the dialogue that took place between families, members of the IAP and the staff of INQUEST who were present. As such, they are framed in a way that directly reflects the suggestions of the families:

- Families should be informed as soon as possible after a death in mental health detention. All Trusts must have a rigorously adhered to protocol for informing families of a death.
- Information about the death should be delivered by properly-trained staff with sensitivity and compassion.
- Families should be given clear guidance on bereavement services and independent sources of advice and help as soon as possible after the death, both in person and in writing.
- All information relating to the investigation and inquest and sources of support should be re-iterated after the initial advice is given.
- Trusts make explicitly clear how the investigative process will operate and ensure the full co-operation of families. Families should receive an on-going flow of information, keeping them up to date at every juncture of the investigation.
- Realistic time scales should be established from the outset, laying out the possible delays to the investigation and subsequent inquest.

- Families should be given the opportunity to meet the coroner or coroner's officer, see the court and familiarise themselves with the environment prior to the start of the inquest.
- Open and transparent timescales for the inquest should be set shortly after the death by the coroner, with the opportunity to review, hear any reasons for delay and reset timescales.
- Advance disclosure of materials which have a direct bearing on the family e.g. the presence of suicide notes, draft investigative reports etc.
- The inquest setting should wherever possible, afford the family privacy and space.
- Funding for legal representation for families.
- All inquest transcripts should be made freely available to families.
- Funding for travel and subsistence should be made available so that family members can attend the full inquest.
- A post-inquest protocol needs to be established whereby families are kept informed of subsequent actions and changes to policies and procedures enacted by the Trusts as a result of the death and the investigation and inquest.
- Where any information needs to be conveyed or communication takes place, it should be done in a humane and compassionate way, thus respecting the families' grief.

I would also like to draw attention to an existing protocol that provides a nationally agreed template for the aftercare and support of families facing the death of a relative in mental health detention. In 2009 The National Patient Safety Agency (NPAS) and the National Reporting and Learning Resource (NRLS) published their guidelines "Being Open", a document that revised their previous guidance from 2004. It is a set of principles that healthcare staff should use when communicating with patients, their families and carers following a patient safety incident in which the patient was harmed. *"Being open supports a culture of openness, honesty and transparency, and includes apologising and explaining what happened"*.⁵

"Being Open", endorsed by the NHS, has been accepted by Trusts and hospitals throughout England, including some of those which the families represented have been dealing. This framework considers a suitable response from health care professionals in the event of a death:

*"When a patient safety incident has resulted in a patient's death, it is even more crucial that communication is sensitive, empathic and open. It is important to consider the emotional state of bereaved relatives or carers and to involve them in deciding when it is appropriate to discuss what has happened. The patient's family and carers will probably need information on the processes that will be followed to identify the cause(s) of death. They will also need emotional support. Establishing open channels of communication may also allow the family and/or carers to indicate if they need bereavement counseling or assistance at any stage"*⁶

⁵ ⁴"Saying Sorry When Things Go Wrong – Being Open", (NHS, NRLS, NPAS) 2009

⁶ "Saying Sorry When Things Go Wrong – Being Open", (NHS, NRLS, NPAS) 2009 pp 29

Not one family present made reference to these guidelines, no mention was made of any Trust or hospital implementing their “Being Open” policy. Perhaps this document should be made more widely available to families and their legal representatives to highlight what constitutes a minimum level of openness, support, empathy and involvement.

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