The Experience and Training needs of Key Workers for Child Death Within Berkshire

Survey Results and Summary 2021

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Background

Keyworkers for bereaved families have been put into the 2018 Statutory Guidance on the Child Death Process, having previously been an aspiration. The Guidance states 3.6.2 that “A “key worker” should be assigned to every bereaved family, to act as a single point of contact in relation to the child death review process.”

In 2018 the Pan-Berkshire CDOP reviewed 2018 guidance and concluded that there were a range of professionals who could take on this role (figure 1).

Figure 1: Likely Professionals to hold Keyworker role.

Context	Keyworker
Home Office Post Mortem or RTI	Family Liaison Officer
Neonatal and under 28 days	Bereavement Midwife
Already known to service	Children's Community Nurse
Child or sibling < 5 years	Health Visitor
Otherwise	Decide in JAR (Joint Agency Response)

Within the Berkshire area, there is therefore a range of professionals taking on this role, but with limited knowledge about what their training needs are or their experiences. This mirrors the national experience, where there is limited published material, despite the national imperative to provide this function.

We therefore sought the experiences of those people within Berkshire fulfilling those roles.

Methodology

In order to gather information, responses were sought from professionals who had been involved in working as a Keyworker where there had been a child death. Responses were sought from a variety of sources, with a Microsoft Forms link sent out to senior staff in the main NHS providers in the area, and via the link professionals represented at CDOP, to request that it is forwarded to relevant staffing groups. This questionnaire was available for 1 month for staff to complete.

Results

1.Current Working Role of Responders

A total of 29 responses were received from a wide range of professionals, with 31% (9/29) returned by Nursing Professionals, 31% (9/29) submitted by Health Visitors, and 24% (7/29) returned by Police professionals including Detective Constables in Child Abuse Investigation Unit (CAIU).

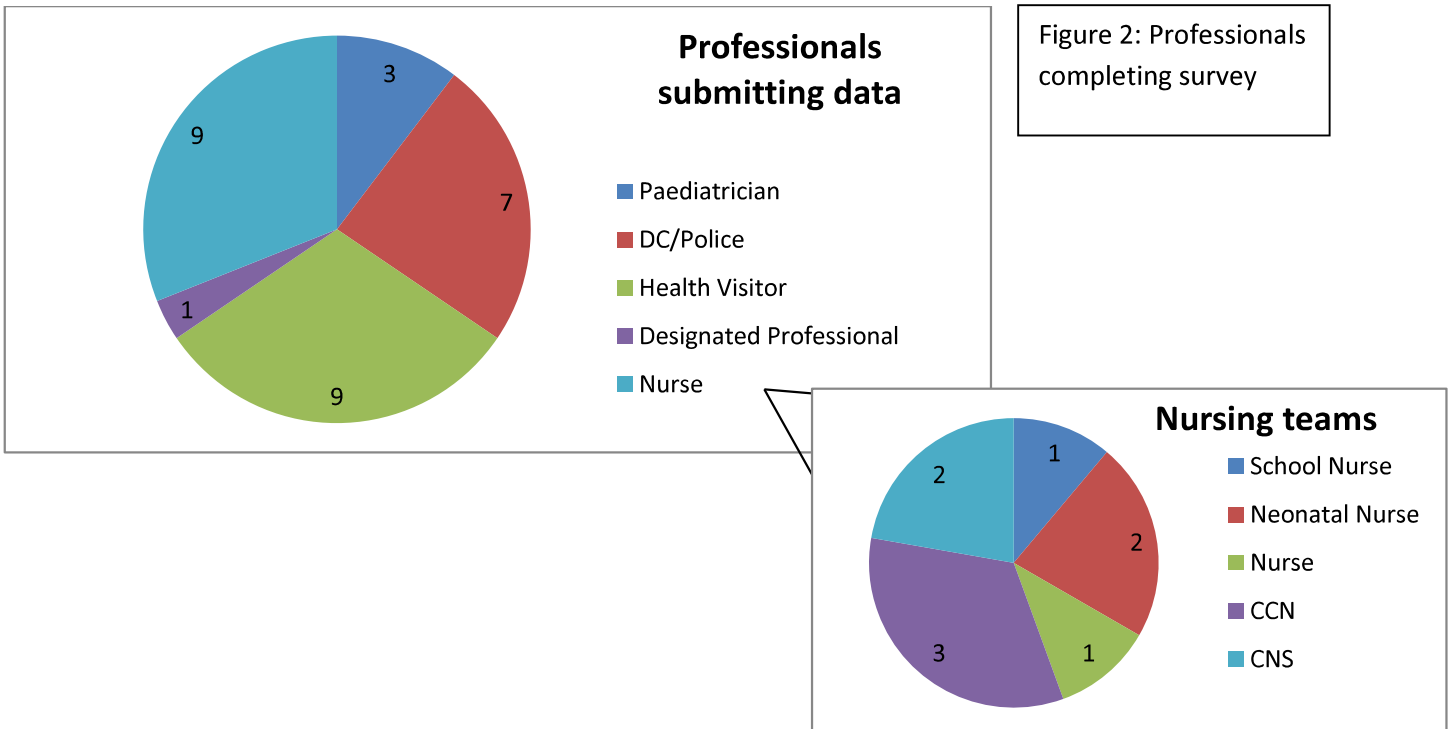


Figure 2: Professionals completing survey

2. Child Death Training

13/29 (44%) had never had any training about the Child Death Process

61% (8/13) of those who had never had training were from a Health Visiting background; with only one Health visitor responder having identified having had training in the Child Death process in the past as part of a generic training course.

For those who could identify previous training,

- 18% (3/16) confirmed training within generic training courses, for example counseling courses.
- 31% (5/16) confirmed attending specific Child Death study days and regional training days.
- 100% (7/7) of the police responders confirmed having had specific police-related CDOP training.
- 6% (1/16) had felt that attending a CDOP panel meeting had been part of their training.
- 56% (9/16) had mentioned the training received by being part of a team, for example membership of a network group, or sick nursing children's training.
- 6% (1/16) had attended very specialist course.

3. Key Worker Training

24/29 (82%) had never had any training about working as a Keyworker.

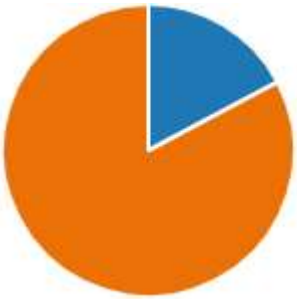


Figure 3: Have you had any training about being a Keyworker

Of the 5 who did identify prior training:

All reported having had some training during generic training.

- 80% (4/5) were nursing staff.
- 20% (1/5) was a member of CAIU.

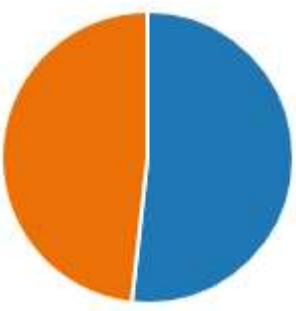
No members identified having had specific training courses about the Key worker role.

4. Prior Knowledge of the family

51% (15/29) of the responders had known the family and young person in advance of the death.

This was seen as a positive thing by the Keyworkers, and often meant that they felt that it was part of their role generally, but also that they were then able to "tailor my support according to their needs" and "trust was gained early".

Figure: 4 - Did you know the family before the Child/Young person died?



5. What were the positive things about the role?

All responders gave responses about the positive aspects. These were grouped thematically as follows, with some responders giving responses under several headings. Fuller individual responses are in appendix 1:

- **Continuity** –8 responders enjoyed having known the family prior, which gave both personal satisfaction but also felt it comforted the family and allowed them to respond to the family needs better.
- **Palliative care involvement** – 3 responders described having being involved in supporting the child and family through the child's death as having been a positive feature for them.
- **Being able to offer support for the family** – 12 responders talked positively about the support that they had offered to the family, including finding answers, relieving pressure, and being able to take calls from the family at times of need
- **Professional liaison/ Information sharing** – 3 responders talked about the broader elements of the role, for example supporting with information sharing, helping arrange death certificates and housing applications.
- **Personal Satisfaction** – 3 responders described their personal satisfaction, often using the word "privilege" in their response.
- **Personal Grief** – 1 responder talked about their personal grief and that being with the family helped them personally.
- **Team support** – 4 responders described the support from the child's team as having been a positive aspect for them.
- **CDOP process** – 1 responder mentioned being part of the CDOP investigation as a positive aspect

6. What were the difficult things about the role?

All responders gave responses about the more difficult aspects. These were grouped thematically as follows, with some responders giving responses under several headings. Fuller individual responses are in appendix 2:

- **MDT care** - there were a range of concerns from 7 responders, including managing expectations, difficulty with communication and information sharing. There was no common single theme in this section
- **Finding time to do the job** - 5 responders talked about the difficulties in finding the time to do the job well.
- **Supporting families** – 10 responders described the difficulties in supporting grieving families and the desire to make things better or be able to answer their questions.
- **Training issues** – 1 responder raised insufficient training as a barrier
- **Managing uncertainty** – 6 responders flagged up the difficulties they faced in knowing what to say, hoping they were supporting families enough and not always having the full details.
- **Knowing the process** – 2 responders described having to learn in the job how child death processes work.
- **Time delays** –Time delays on obtaining some information (1)
- **Balancing the need to investigate with being supportive** – this primarily related to the experience that police staff face when taking on this role, as they have to balance the need to investigate with the need for empathy and support. (2)
- **Pandemic** – 3 responders commented upon the extra burden placed on the role by COVID 19 pandemic.
- **Personal impact** – 3 responders talked about the personal impact

7. How satisfied do you feel with the support offered by your manager/Department?

On a scale of 1 to 10, where 10 is extremely satisfied, professionals were asked about their satisfaction. The average score was 7.72/10. Range 2-10

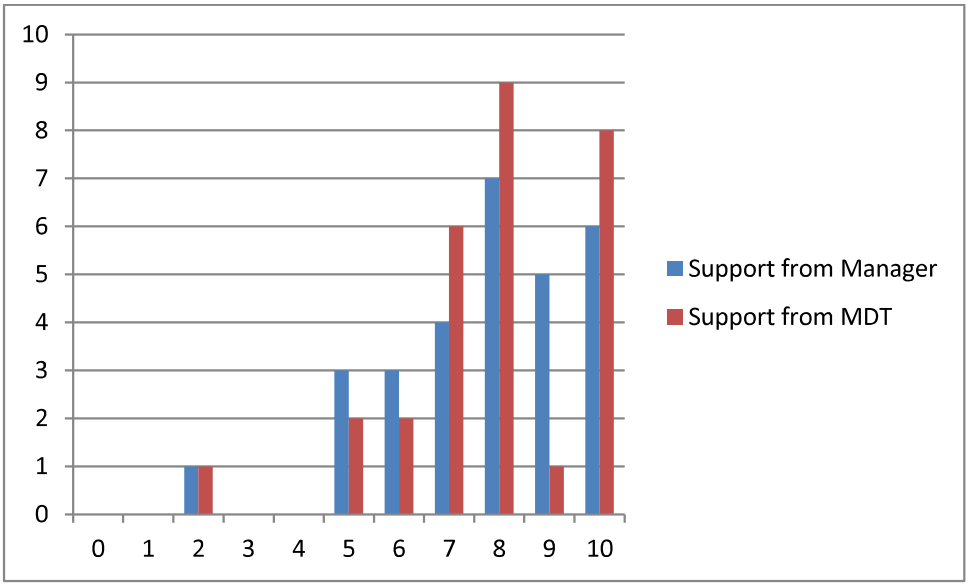


Figure 5 : Satisfaction scores

8. How satisfied do you feel with the support offered by the Multidisciplinary team?

On a scale of 1 to 10, where 10 is extremely satisfied, professionals were asked about their satisfaction. The average score was 7.83/10. Range 2-10.

9. Were you given enough time?

25/29 (86%) felt that they had had enough time. However of those that did feel they had enough time, 13/25 (52%) describe the need to either complete the work in their own time, or take back time in lieu.

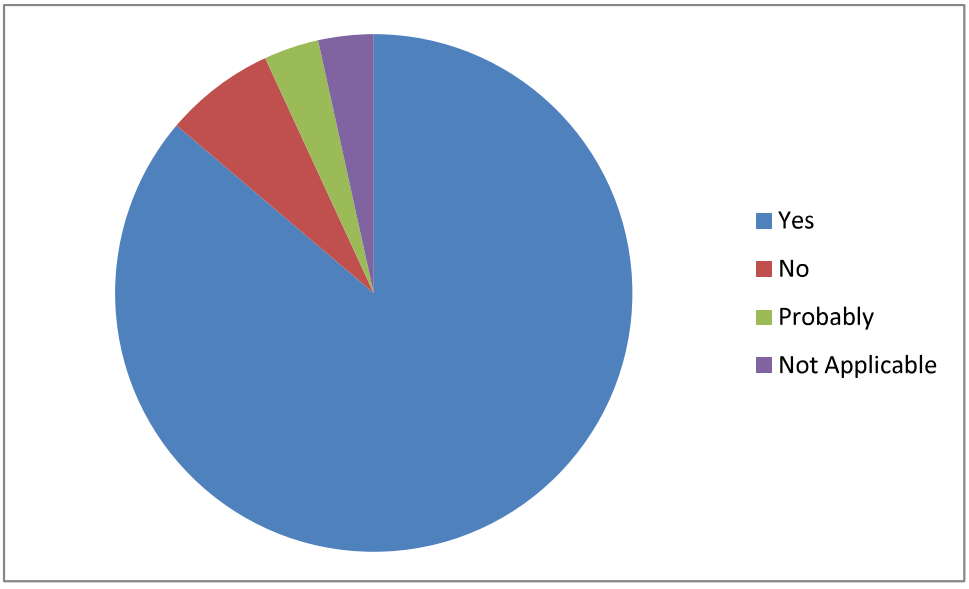


Figure 6: Were you given enough time to do the job?

Sample responses included:

- *"End of life takes president, so we often have to arrange other visits or request support from colleagues if these cannot be rearranged."*

- *"As a team we try to support each other as best we can"*
- *"I took the time needed, often meaning working extra hours"*
- *"I made the time by working over my contracted hours. "*
- *"It is impossible to do this within your allocated working hours."*

Full responses in Appendix 3

10. Would you do this role again?

27/29 responders would undertake the role again. At least thirteen commented about this being seen as part of the job of working with families. Of the two decliners, one commented that there was not enough time within their role.

Sample Responses:

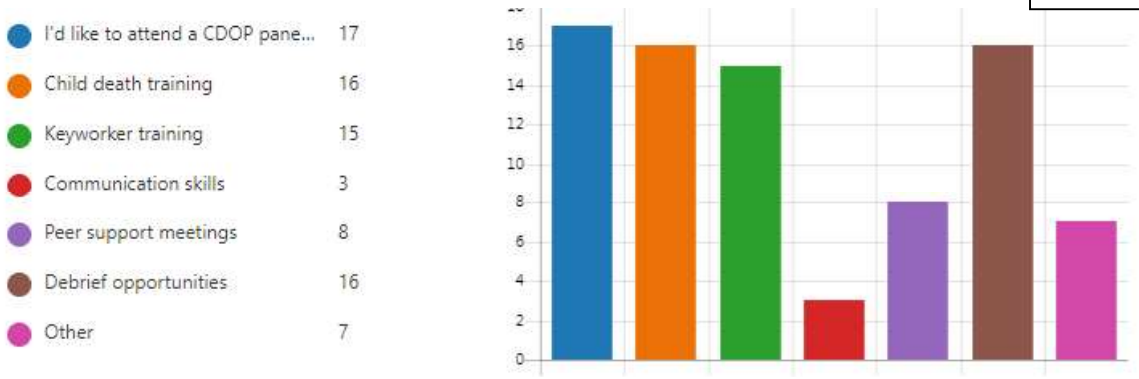
- *"Yes. I feel it is a vital part of the process of families. I think it is very important that the key worker is a person that wants to do the role, not just the person present at death or allocated to the family. The approach and attitude at this time can make the family's experience positive, or can have one sentence negatively affect the whole experience"*
- *"Yes, absolutely, it's very difficult and emotionally challenging but very rewarding to be able to support a family through such a tragedy. As health visitors, with some support, we hold the relevant skills to support families and we are also in a great position to liaise with other professionals. The added benefit is that we may already know the family and do not have direct links to the hospital where they may have links to the event."*
- *"Yes - 100%, my role is to support the families that are on my caseload both through life and end of life."*
- *"yes - I also feel there is possibly the role for a champion in each area of BHFT/Berkshire, someone who would know the procedures and be able to take on the role or support the health professional through the process rather than a manager who might not know the process any better than the individual. No one wants a child death especially unexpected but this is quite a specialised part of health visiting role and would (in my opinion) benefit from some peer support"*

Full responses in Appendix 4

11. What do you feel are your training needs?

Staff identified a number of training needs as per figure 7

Figure7: What do you feel are your training needs?



7 additional training requests "others" were as follows:

- General updates (1) (not otherwise specified)
- To verify death (3) – Advanced Nurse practitioner, Community Neonatal sister x2

- Dealing with emotional support for family (1)
- I would like training to become a TRiM practitioner so that I could better support practitioners (1)
- Attending a post mortem of a child (1) – Specialist investigator

Conclusions

This survey has had input from a range of professionals expected to be involved in the Keyworker aspect of Child Death Process. It provides some initial information about the experiences of the responders and their training needs in this area which will be of interest to Designated Professionals and the CDOP body, as well as to prospective Keyworkers and their colleagues.

Experiences of Keyworkers

Half of the responders (51%) had previously met the family and this was reflected on as a good aspect by staff when considering the positives of the role. For some, they had been involved in the palliative care the child received prior to death and again responders seem to have seen this as a positive aspect to the role.

All the responders had both positive and negative aspects identified.

For the most part, they felt supported by their managers and teams, and by the wider Multidisciplinary team, with 96% (28/29) giving an average or better score for satisfaction.

One outlier with respect to their support (scoring 2/10 for support from both groups) reported having felt the positive aspect of being a constant support for the family but had felt that the care was not joined up. They did, however, want to do the role again, which may suggest that the positive aspects of supporting the family outweigh some of the negative aspects faced.

The need for peer support and support from those with knowledge of the Keyworker role is raised on a few occasions in the text and present for 27% of the requests for training and is relevant for consideration to improve satisfaction scores and skill sets. Additionally debriefs are flagged as a training need in 55% of responders and there may be a cross over with the suggestion that a number of champions with extra skills are developed within the region.

Training Needs

There is a significant training gap in the area for professionals, with only 56% having had CDOP training and no responders having had formal Keyworker training. A range of training requests were made with only a few identifying communication skills as a training need for themselves.

Further questions

There remain a number of further questions that remain unanswered, including

- details about the amount of time that this role takes. 14/29 (48%) responders were happy to share contact details, and this could be an easy source of further information.
- Staff were not differentiated by locality, so variation across the region cannot be determined.
- Effect of Key workers upon the family experience of child death was not explored in this review.

Recommendations

CDOP Executive Panel, CDOP panel and Designated Professionals in Berkshire have met to confirm the recommendations made by the authors. We agreed the following actions.

1) CDOP Panel and Designated Professionals in Berkshire to review the training options for this group of professionals:
a. Liaise with external bodies eg Child Bereavement UK to see what courses are offered nationally – there appear to be limited options and none specific to keyworkers in Child Death (see appendix 5)
b. Develop a training course bespoke to Keyworkers in Child Death in the pan-Berkshire area. This should cover both the CDOP process, the Keyworker role and communication skills for bereaved families, based upon TRiM model.
2) Develop an information leaflet including FAQ for those new to the role, based upon the experiences reported here and for their managers.
3) Prioritise the training of Health Visitors
4) Identify dedicated Keyworker Champions within agencies to co-ordinate training, enable peer support and debrief, where required.
5) Facilitate attendance at JAR and CDR meetings as part of a training programme for key workers
6) CDOP Panel to agree to a training placement on panel to enable those involved in the pathway to understand the process better.
7) CDOP to consider develop a training video as part of the offer to enhance skills of potential key workers.
8) CDOP to review the Key worker offer in the response to the national guidance that is available on website.

Appendix

Appendix 1: 5. What were the positive things about the role?

Continuity	• Being the one constant professional in the family's life • Families were family with me and my role, so I could offer support and listening ear, having known them prior to their child dying • I had carried out the 6-8 week review on the younger sibling; mum remembered me from this. • Family having a familiar person to support at such a difficult time. • Knowing the family, I was able to tailor my support to their needs. • Knowing the child and family prior to the death gave me an understanding of their dynamics which enables me to advocate for them with compassion. • Relationship with family. I had met the family several times antenatally and was present at the birth. Trust was gained early. • As I had met the family on a number of occasions before, I had an existing relationship with them and their child.
Palliative care involvement	• Being able to support the child and family until the end (3)
Being able to offer support for the family	• Helping the family to get answers as to how their child passed away (7) • Sharing the PM report so that the parents could better understand why their baby ha died and that they could not have predicted it or changed the outcome. • Providing support to the family (8) • Relieving unwanted pressure from them at such a difficult time • I was the one person they could call when they were sad or angry or didn't know what to do. • Mother was very angry about her experience. Eventually agreed to meet at her home. Good relationship established.
Professional liaison/ Information sharing	• I supported with housing and liaising with many other professionals which meant they didn't have to. I supported them to access their GP and bereavement counseling, enabling them to get the right support when they needed it most. • Helping to coordinate information • Help given with obtaining death certificate, funeral arrangements.
Personal Satisfaction	• For this family, I think I was the best person to discuss the incident that led to their child's death; it felt like a privilege to support them at such a difficult time. • Being able to support the family if they needed you to. • A privilege and professionally satisfying to support a bereaved family through the worst of times.
Personal Grief	• Being able to grieve with the family, supported at funeral
Team support	• Good support from senior members of the team • Immediate debrief with the acute team • The professionalism of the medical staff. • Excellent support from consultant who came to family home to certify death.
CDOP process	• Being part of the investigation, which may ultimately lead to further safeguarding

Appendix 2: 6. What were the difficult things about the role?

MDT care	• How un-joined up the child's care was • Managing expectations of some professionals • I do not think the follow-up support for family is enough. • Lack of information when the child dies in the hospital • Getting colleagues to understand the role • Lack of communication between services. • GP refusing to verify death
Finding time to do the job	• Balancing my workload to give these families the time they need when the service is understaffed. • Managing end of life cases as well as the normal day to day caseload requirements. • Every family will require a different level of support, therefore you do need adequate time to be able to fulfill this role for the family. • Time taken to do this well, learning on the job and through reflection meant that earlier families didn't get the best service. • Being oncall for a prolonged period (making it difficult to be in touch)
Supporting families	• Being overwhelmed by the enormity of a child dying unexpectedly and how that ripples out and effects all family members • Not being able to make it "better" for them or have the answers to all their questions of why it happened. • Dealing with the parent's grief / emotions(3) • Talking to families. • Not wanting to over contact a family but also not wanting to avoid the situation. • I had underestimated the families subsequent anger/blame towards each other. This made it difficult to show that I was impartial and not taking sides, which the family tried to get me to do. • Wanting to say the right thing • Gaining trust to be able to discuss areas of concern.
Training issues	• Insufficient training
Managing uncertainty	• Not knowing if what I was doing or saying was the right thing. • Not knowing the family before and how best to support the mum • Hoping you are supporting the family/child enough. • Uncertain when to offer various types of support – immediate, weeks, months • Explaining delays/timescales for getting answers • Not always able to get the full facts to be able to answer questions families have.
Knowing the process	• Knowing the correct process re if the family chooses for the child to pass away at home • Not being familiar with the Child Death process meant I had to learn on my feet; as a nurse this is nothing new, however, I may have felt more confident with previous training.
Time delays	• Time delays on obtaining some information
Balancing the need to investigate	• The police role is to investigate. The very initial communication with the family is vital. Getting the balance of being empathetic and supportive and also being open minded as to why the child died and the possibility of the cause being suspicious.

with being supportive	• Difficult to answer some questions (Balancing police enquiries with supporting the family).
Pandemic	• Supporting a bereaved family is hard and doing this during a Pandemic is somewhat harder due to the reduce peer support. • It was during the first lockdown and very difficult with COVID restrictions • COVID 19 lockdown made accessing difficult
Personal impact	• Managing personal emotions • Lack of bereavement support for the keyworker. • This was an unexpected death and was very traumatic.

Appendix 3: Were you given enough time to do the job?

Were you given enough time to do the job? (Please answer yes or no and then describe your reasoning)
End of life takes president, so we often have to rearrange other visits or request support from colleagues if these cannot be rearranged. As a team we try and support each other as best as we can. If a family choose for their child to be at home for end of life, an on call support rota is drawn up with the local hospice. Any support is done as extra on top of our full time roll.
I made the time by working over my contracted hours.
I was allowed some time to support the family, but it was not enough time due to other work commitments.
I was allowed to go to the funeral.
It's difficult to know how long is needed to fulfil the role as the families needs change day-to-day and week by week. I was able to achieve this and the team would have supported me if I needed more time.
N/A
no
probably
yes
Yes
yes
yes
yes
yes - the child death was unexpected but had happened a few weeks previously out of the uk, I had to complete reports in my own time however this was recognised by my manager and TOIL/ overtime was paid. the role fell to me on safeguarding duty so potentially a less experienced HV might not have known what to do
Yes - I took the time needed, often meant working extra hours
Yes - support of line managers ensured these cases took priority
Yes as it is impossible to do this within your allocated working hours
Yes but the Police role is quite difficult as it is all quite fast moving and you want to ensure that all evidence is captured.
yes- child death dealt with very well in our department. Full support from line managers and colleagues.
Yes- Difficult to answer, Child death are a high priority so we get the time needed but each incident is different
Yes I had time to do the job and if I needed extra time than this was made available to me.

Yes I have allocated the time to ensure I have plenty of time at the visit.
yes- time put aside
yes, although on the day it can be difficult to juggle commitments because it was unexpected
Yes, although there were delays waiting to hear back from certain departments which delayed things
yes, usually.
Yes. Able to be flexible in timings and place of contact
Yes. Although there has been issues in A&E with the consultant trying to rush the process.
Yes. Working in the community gives more freedom to manage case load. Would have been a different experience if ward based. Had the flexibility to change working days and hours.

Appendix 4: Would you do this role again?

Would you do this role again? (Please answer yes or no and then describe your reasoning)
I have not undertaking this role as yet
no as at present with the pressure on the job there is not enough time to do the job properly
yes
Yes
yes
yes
yes
yes
Yes - 100%, my role is to support the families that are on my caseload both through life and end of life.
Yes - confident due to previous exposure to such cases
yes - I also feel there is possibly the role for a champion in each area of BHFT/Berkshire, someone who would know the procedures and be able to take on the role or support the health professional through the process rather than a manager who might not know the process any better than the individual. no one wants a child death especially unexpected but this is quite a specialised part of health visiting role and would (in my opinion) benefit from some peer support
Yes - it is part of my core role
yes - it is part of my job requirement
Yes - there is a need particularly for families where the child was not under 5 years or known to services e.g. CCN or where there was a HOPM
Yes- Although can be stressful the role is key to finding out why a child has died
Yes as I felt I gave a valuable service to the family and I received positive feedback from the family and my colleagues.
yes for families I know prior to the death.
yes- I work closely with families
yes I would but I would like more training to provide more confidence when doing this role.
Yes, absolutely, its very difficult and emotionally challenging but very rewarding to be able to support a family through such a tragedy. As health visitors, with some support, we hold the relevant skills to support families and we are also in a great position to liaise with other professionals. The added benefit is that we may already know the family and do not have direct links to the hospital where they may have links to the event.
yes, but I was not the key worker
Yes, especially if I know this family best
Yes, I know feel more confident

Yes, I will do it again even though it is emotionally challenging.
yes, I wouldn't have any choice if it is a family I was supporting previously
Yes, it is a sad part of my role.
Yes. Have been key worker for 6 families in the past 2 years
Yes. I feel it is a vital part of the process of families. I think it is very important that the key worker is a person that wants to do the role, not just the person present at death or allocated to the family. The approach and attitude at this time can make the family's experience positive, or can have one sentence negatively affect the whole experience
Yes. Part of job role

Appendix 5: National Training Options

A review of nationally advertised Training courses for Keyworkers Feb 2021:

Agency	Weblink	Options	KW	Grief	CDOP
Child Bereavement Trust UK		Webinars – When a child dies – supporting parents and Families	-	Y	-
		Information leaflet on supporting families	Part	-	-
Portsmouth Death Immersion Programme	https://www.port.ac.uk/study/courses/portsmouth-child-death-immersion-programme	Fully immersive one day course covering CDOP process – aimed at Police and Doctors	-	-	Y
Together for Short lives	-	-	-	-	-
Yorkshire education services	https://nyestraining.co.uk/Event/131082	Child Death Review: Advanced Training for Professionals. Paediatricians, Ambulance Workers, Midwifery, ED Workers, EDT Workers, Police, Education, Social Work Teams, Health Visiting, GPs and Named Nurses.	Y		Y