



Serious Case Review Family A

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Preface

The lead reviewers and serious case review panel thank all those who have contributed to this serious case review following the deaths of three young children tragically killed by their mother in April 2014. The mother admitted manslaughter by diminished responsibility.

The children's father met with the lead reviewers on three occasions both to contribute information and understanding of what happened from the family's perspective, and to provide feedback on the report. We want to express our gratitude to him in helping our learning in such personally difficult times.

Over 100 staff across all involved agencies were involved in providing information and feedback, both in individual and group sessions, to the authors of the individual agency reports as well as to the serious case review process. They were without exception extremely distressed at what had happened and wanting to help us learn how to improve services. This input and commitment has enabled the authors to understand more fully the complexity of the circumstances of this case for family and professionals alike.

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EXECUTIVE SUMMARY

Initiation of Serious Case Review

This review was initiated by Kingston Local Safeguarding Children Board as a result of the tragic deaths of three children P, Q and R who were smothered by their birth mother on the 22th April 2014. The mother was given a hospital order in November 2014 after admitting manslaughter by diminished responsibility of her daughter and sons.

The children

There were four children in the family and practitioners observed that they had good relationships with each other and with their parents. The eldest, N, was aged eight when her three younger siblings died. P was aged four years old and Q and R, twin brothers, were aged three years old.

The three youngest children had spinal muscular atrophy type 2 (SMA2). The condition affects voluntary muscles causing severe muscle weakness, which can result in problems moving, eating, breathing and swallowing. It is recognised as a life shortening condition.

All the children were attending mainstream school in 2014; the three youngest attended the same school, P starting in September 2013 and her brothers joining the nursery class during the Spring term of 2014. This was earlier than originally planned but it is understood that this was a result of the parents seeing how much P was enjoying being at school.

Practitioners described the three children with SMA Type 2 as intelligent, bright, lively children who enjoyed their life. P especially appreciated the increasing opportunities being offered as she got older, to mix with peers and teachers.

P presented initially as a shy child. She was animated when talking about her school work, what she was doing and her favourite colour, with a 'mischievous twinkle in her eye, even when ill in the hospital's paediatric intensive care unit'. She loved pink and fairies, happy to join in activities and knew what she wanted, vocalising this to others. Staff at the school recalled how much she enjoyed dancing (both in her wheelchair and when carried), her sunny personality, good sense of humour and strong will. She was a very intelligent child who enjoyed school, being with friends, playing and learning. She never complained or seemed sad and was described as 'a real inspiration', 'delightful and bright', 'bubbly and inquisitive', 'smiley and happy' and an 'able learner'. P was always well turned out, never showed any distress around her parents and appeared to have a positive relationship with her nanny.

Q and R had recently commenced at the nursery class in school so were not as well known by the staff, but were described as 'happy, chatty boys', able to vocalise what they wanted to do or see and especially enjoyed investigating the cars and trains in the nursery. Both were always well turned out and comfortable with their parents and nannies. Mother was very positive when introducing them at school, pointing out the children's different personalities.

N and P had a close relationship with each other, both talking about the other to their respective teachers favourably. N decorated her desk with pictures of her siblings. N described P as cheeky and P described her brothers as cheeky.

N cycled to P's school with Mother and Father before P started and the family would attend school events together; they presented in school environments as a happy close family.

Mother was always responsive to the children's needs at school, collecting her children immediately if any of them were unwell and communicating well with the staff about their health and their needs. P was observed to have a very affectionate relationship with her mother, was cuddled when being collected and when leaving her at school saying 'bye my angel' and exchanging 'baby high fives'.

Summary of Case

The period covered by this serious case review is the 42 months from the premature birth of the twin boys, R and Q, in July 2010 to the date they and their sister P died in April 2014.

During this period the life of the family, and particularly of the mother, changed dramatically with an adjustment from being a family of four, to a family of six, with three of the four children being diagnosed with SMA2. This diagnosis meant a huge emotional and practical adjustment for the parents and the children's complex health needs meant that the family had support from nannies and from a large number of health practitioners, both in the community and from the three hospitals involved, as well as the local social care team for children with disabilities.

The mother had responsibility for the domestic sphere, having given up work when she became a parent. Because of the children's disturbed sleep patterns, the mother was reported to never have a full night's sleep and often presented to professionals as tired and tearful. There were professional concerns about mother's ongoing low mood, but she told professionals, including her GP that she did not want or feel she needed any help for this.

The parents wanted their three disabled children to have a good quality life, and experience as little pain as possible. They did not want medical intervention for the children if this would cause their children pain. They characterised this as putting a priority on the quality of their children's lives as opposed to extending the length of their lives. The children's specialist and expert doctors though were of the view that medical intervention was needed for P in order to decrease her current discomfort as well as to be able to maximise her potential. It was possible that her brothers would also need such intervention eventually.

Alongside the concerns about the possibility of medical intervention, some allied health professionals involved with the children were of the view that the mother did not consistently accept and act on their advice about feeding, physiotherapy, speech and language therapy and the use of aids.

The level of concerns led to professionals discussing whether the child protection threshold had been met, but this was never agreed. Legal advice though was sought by two of the local authorities and by two of the hospitals, regarding the possibility of legal intervention.

The debates between parents and professionals over what was the best health care for the three children continued throughout the period under review. In the last months, there appeared to have been progress made. In particular the professional network was under the understanding by April 2014 that the father had agreed to P having a gastrostomy¹ and that he was giving serious consideration to the potential benefits of spinal surgery, albeit he was worried that this may cause his daughter a great deal of pain and might not lead to significant improvements in her life. It was not clear if the mother was in agreement with this view, as the parents had consistently made it clear from the summer of 2013, that all such discussions about medical intervention be undertaken with the father.

The father was away during April 2014, first on a trip to the USA and then taking the eldest child to see paternal family in South Africa. During this period maternal grandmother stayed with mother and P, whilst Q and R stayed with the family's main nanny. Mother asked for her sons to be returned home the same day as maternal grandmother left. That evening she smothered her three youngest children.

Relevance to wider context of safeguarding children with disabilities

The tragic death of these three children, has been an enormous shock to all those that knew them and their parents.

Whilst the tragic outcome here is extremely unusual, this case itself raises many of the common professional dilemmas faced by practitioners who are supporting a family where there are safeguarding concerns for children with complex health needs. At the heart of this is the tension about whether to focus primarily on providing support to the family so the parents are better able to care for their children or to also move into more assertive intervention using child protection processes. Allied to this are also the challenging ethical dilemmas around quality of life, palliation and parental views.

It is not unusual for parents of disabled children to feel grief and depression on hearing of a child's diagnosis and the loss of the type of life that they had imagined living and the achievements they wished for their children. It may though take some time to come to terms with the diagnosis and understand the quality of their child's life and appreciate her/his enjoyment of life.

It is usual for parents to feel physically exhausted through the demands of looking after their children, as well as through the constant demands of appointments with health practitioners if the children have complex needs.

SMA Support UK has advised the authors that 'whilst the emotional impact of a diagnosis is initially devastating and the caring role is hard work, the majority of families 'find a way to manage and do a wonderful job caring for' and 'encouraging the hopes and dreams of their children with SMA Type 2, who go on to live productive and fulfilling adult lives'. (See the Kingston Safeguarding Children Board website for further information from the SMA Support UK).

¹ Gastrostomy is the construction of an artificial opening from the stomach through the abdominal wall permitting intake of food or fluid.

Safeguarding concerns for disabled children can arise in a number of ways. One way, as in this case, arises from parents being unwilling or unable to follow medical and allied health professional advice and there are consequent potential impacts on the children's health and/or development. This can occur when children are receiving a good standard of care in other aspects of their lives.

In such circumstances the tensions for professionals is between supporting the parents to help them understand the need to follow health advice, balanced with a need to safeguard the children's welfare. Whilst professionals strive to be able to accomplish both, the balance between support for the parents and protection of the children can be difficult. In particular, in this case, was whether the care provided to the children might be deemed as neglectful of their medical or developmental needs. At times in such circumstances the focus may need to move to explicit child protection processes, but professionals can find this difficult in the face of parents who are overall providing the children with a good standard of care and attention.

Summary of Findings

The tragic killing of the three children who are the subjects of this review was in the view of the authors unexpected and could not have been predicted by the professionals who had been working with the family.

There is no certainty that any of the findings below would have made any difference to the tragic outcome in this case. At the time of the deaths, from a professional perspective there had been progress made in enabling the children to have the medical intervention they were diagnosed as needing. In fact, had best practice been followed, it is not known how the mother would have reacted to the open expression of child protection concerns at an earlier stage.

The findings are split into those relating to:

- Family and professional interactions
- Professional and organisational culture
- Safeguarding practice

Findings relating to the family and professional interactions

This case highlights the impact on parents of the diagnosis of disability of their child/ren and the importance of an early understanding of the family's attitudes towards health and disability, so as to provide the right support. This needs to take place within weeks of confirmation of diagnosis by an allocated health practitioner. As this diagnosis occurred out of the UK, it is not clear that this was ever offered to the family, or whether they would have been open to have such a discussion.

Practitioners had insufficient understanding of how the parents' background and experiences impacted on their views about disability, health and social services. In particular their background in South Africa of selecting services to use as opposed to being advised about what they should do for their children. There has been consideration whether the family's social status led to a different safeguarding response. There is no evidence that this occurred, but this may have contributed to the cautious approach in moving into child protection processes described below.

What made this family extremely unusual and challenging for professionals to work with was the difficulty some professionals experienced in delivering the advice and support that was considered necessary for the children's health and development. The reason for this was the lack of parental co-operation, and in particular the difficulties in developing a good working relationship with the mother. Her distress and perceived resentment towards some professional advice provided an obstacle which practitioners struggled to break through sufficiently.

Throughout the period under review there was professional concern about Mother's presentation, recognising possible depression due to her crying, her flatness, and her avoidance of eye contact. She was asked to see her GP repeatedly to discuss counselling, as well as being offered support from a psychologist at St George's Hospital. Her GP, following professional request, visited her at home to discuss this. Mother declined any offer of help, spoke of being stronger than before and was observed as patient and caring with her children. There was nothing in the mother's behaviour that suggested she would need to be detained in a hospital in the interests of her own health or safety, or with a view to the protection of others (criteria for a compulsory admission). There was also no evidence that the impact on the children of her observed low mood was causing a risk of significant harm.

Findings relating to professional and organisational culture

The fact of three children with complex health needs led to a very large number of services and practitioners visiting the family home as well as a high number of hospital appointments. Without exception practitioners went out of their way to provide services for the family and the family were provided with every available resource. The staff involved made considerable efforts to reduce the burden on the family by working outside of usual working hours, undertaking home visits instead of clinic appointments and whenever possible minimising the intrusion into family life through joint visits and sometimes covering colleagues roles. The complexity of the case led to direct involvement of some senior managers which had the unintended consequence of a loss of objective oversight at times.

The role of the lead professional is critical in such complex circumstances to co-ordinate the multi-agency services and act as a single point of contact. Consideration needs to be given how all the functions of a lead professional can be undertaken, when, as in this case, the role was held by a consultant paediatrician for most of the time. Whilst the consultant paediatrician is the lead with regard to health provision, the responsibility for acting as the single point of contact, liaison and co-ordination of the multi-agency planning and review of services may be better undertaken by other professionals.

Because health was seen to be in the lead there was a lack of formal child in need planning and review in Kingston, with a lead professional from children's social care. Instead there was a looser, less formal health focused forum used for planning co-ordinated interventions.

There were shortcomings in the management of the transfer of case responsibility between social workers. This led to a lack of full appreciation of the reason for the unusual communication arrangements with the parents, whereby the father acted as an intermediary in discussions about medical intervention. Any changes needed to be carefully and explicitly negotiated. Moreover, this was a complex case and should not have been allocated to a newly qualified member of staff, even if the team manager planned to retain a high level of involvement.

The policy of not making direct payments for support in the home contributed to the family not using many of the hours of care the children were assessed as needing. The current policy of funding via continuing care payments limits the families' abilities to undertake their own selection process and decide what type of support they want.

Findings relating to safeguarding practice

This was a case of children with complex health needs, parents who provided good and at times outstanding care, but where there were specific concerns of medical neglect which meant that there was suspicion that one or more of the children might be or might become at risk of significant harm.

In common with many neglect cases, there was a dilemma for professionals about the best way to promote the children's welfare. Was this through continuing to try to get the parents to understand that the medical interventions proposed would enhance the quality of their children's lives (the parent's priority), or should there be a more direct and potentially confrontational approach, using the child protection processes? The latter approach was never progressed because the main decision makers in the professional network considered that on balance the children's welfare would be best served by slowly making progress with the parents. The fear was a risk of putting too much pressure on the parents, which could result in family breakdown.

The search for consensus amongst medical practitioners acted as an obstacle to the initiation of child protection procedures, with social workers taking the lead from doctors and waiting for them to agree the level of risk. Such consensus of opinion was not achieved.

Whilst individual practitioners did consider at points that the child protection threshold was met, and communicated this view to colleagues including the social worker, such communications were not framed as specific requests for the initiation of child protection procedures on the basis of the suspicion of significant harm. Instead what took place was information sharing as opposed to specific requests for a child protection enquiry or a child protection conference.

Instead of using the child protection process, the use of legal intervention was debated and at times mentioned to parents. This included legal intervention within health in relation to specific medical interventions, as well as legal intervention by children's social care.

Not moving into child protection procedures, despite the concerns, gave mixed messages to the parents and other professionals. Whilst the parents were constantly aware of the veiled criticism of their views, this was not clarified formally. The father has expressed to the authors of this report that he wanted the opportunity to be able to resolve the fundamental differences between the parents' beliefs and the medical standpoint. Although the parents would have been shocked at the prospect of the child protection process being initiated, it would have been the first step in reaching the clarification they wanted and the professionals needed.

Recommendations

1. Merton, Wandsworth and Kingston LSCBs to assure themselves that there are reliable systems in place to ensure that whenever a child is diagnosed with a disability the parents are offered counselling and information support as a routine, and that professionals also explore with them their understanding of and views towards such disability.
2. Merton, Wandsworth, Kingston, Camden and Tri-borough LSCBs to consider how to improve assessment practice so that practitioners routinely explore parents *individual* cultural background and attitudes to the provision of services .
3. Wandsworth and Kingston LSCBs to consider what checks and balances are needed in the system to identify when a complex case is resulting in staff working outside their normal roles and responsibilities, and if then independent objective consultation needs to be available for staff.
4. Wandsworth and Kingston LSCB to agree with member agencies a consistent process for identifying the lead professional and the responsibility for the various functions of the lead professional.
5. Wandsworth and Kingston LSCB to agree with member agencies minimum expectations regarding the conduct of Team Around the Child (TAC) meetings, including when to use written agreements, when to request further assessments, consideration of all family members needs as well as identification of involved professionals and non-professionals to attend meetings, process to enable others to have their views adequately represented both at the TAC and directly to the lead professional. Critically there needs to be understanding of the circumstances when this form of multi-agency co-ordination should become part of the Child in Need planning, co-ordinated by a social worker, as opposed to a lead health professional.
6. Merton, Wandsworth and Kingston LSCBs to establish if the Designated professionals receive professional supervision, and if not what arrangements should be in place to ensure that this is available.
7. Kingston LSCB to assure itself that the existing transfer protocol within Achieving for Children is developed further to include transfer of cases between social workers within the same team.
8. Merton, Wandsworth and Kingston LSCBs to establish if the system for providing carers to families has sufficient flexibility to ensure that children receive the care they need. Such arrangements need to recognise that for some families:

- the ability to directly employ and manage their own staff will work better, along with provision for the local authority or agency to be involved in a vetting process to ensure they are competent to undertake the tasks required
 - such funding should be available for domiciliary help as well as health care tasks, so that parents are able choose if they are released from some house hold tasks to have more time to provide the health care needs themselves, as opposed to the other way round
9. Wandsworth and Kingston LSCBs to establish what occurs when there are instances that the full package of care is not taken up over a prolonged period; there should be senior management involvement to consider the impact on the safety of the children
 10. Kingston LSCB to consider is there are adequate resources available for practitioners to seek consultation on complex cases such as 'complex multi-agency panels' to offer advice on 'stuck' cases, as well as the consultation with named, designated and specialist staff.
 11. Kingston LSCB to establish the extent of use of specialist tools by practitioners to order thinking and keep sharp focus on the need to safeguard the welfare of the children e.g. chronologies, centile charts, risk assessment tools;- the use of multi-agency chronologies is particularly helpful to understand the history
 12. Wandsworth and Kingston LSCBs to establish if professionals are able to make specific child protection referrals when they have child protection concerns on open cases, so their view does not get lost as part of the usual information sharing process.
 13. Wandsworth and Kingston LSCBs to ensure the culture in their area is that where:
 - every professional understands their own individual responsibility to make a referral to children's social care if they suspect that a child is suffering or is likely to suffer significant harm
 - all practitioners, whatever their role, feel *able* to make such specific referrals and to escalate their concerns
 14. Kingston LSCB to establish if the practice in this case of wanting to go straight to legal proceedings without going through the child protection process is unusual, or representative of a misunderstanding of the child protection process in the children with disability service.

What will the LSCB do in response to this?

Kingston LSCB has prepared their own document which describes the actions that are planned to strengthen practice in response to the findings and recommendations of this serious case review.

1 INTRODUCTION

1.1 Initiation of Serious Case Review

- 1.1.1 This review was initiated by Kingston Local Safeguarding Children Board as a result of the tragic deaths of three children P, Q and R who were smothered by their birth mother on the 22nd April 2014. The mother was given a hospital order in November 2014 after admitting manslaughter by diminished responsibility of her daughter and sons.
- 1.1.2 All three children had spinal muscular atrophy type 2 (SMA2). The condition affects voluntary muscles causing **severe muscle weakness, which can result in problems moving, eating, breathing and swallowing**. Though this is a serious inherited neuromuscular condition that may shorten life expectancy, improvements in care standards mean that the majority of people can live long, fulfilling and productive lives.

1.2 Agencies and local authorities involved

- 1.2.1 Due to the complex needs of the three children with SMA Type 2, there were many different health agencies involved in the family, along with the three local authorities in which they lived during the period under review: Merton, Wandsworth and Kingston.
- 1.2.2 The following is a list of the agencies involved with the family including the dates of their involvement, the services they offered. Where abbreviations have been identified these will be used throughout the report to denote which organisation the authors are referring to. :
- Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) October 2010 – April 2014 provided Neuromuscular Service support and advice in regards to management of the children's condition including speech and language and physiotherapy evaluation
 - St George's University Hospitals NHS Foundation Trust July 2010 – April 2014 provided a mix of secondary, community and specialist services including staff from St Georges Hospital (SGH) and from community services division: Consultant Paediatrician Hospital Psychologist, Physiotherapist, Paediatric Intensive Care staff, Health Visiting, Children's Community Nursing Staff
 - Royal Brompton & Harefield NHS Foundation Trust (RBH), Late 2011 – April 2014 provided specialist respiratory care and advice at Royal Brompton hospital.
 - Kingston Hospital, November 2012 – April 2014 provided A&E services and dietetics.
 - Kingston Hospital, Community Paediatrics, November 2012 – April 2014 provided community paediatrics
 - NHS England provided GP Services
 - Your Health Care, September 2012 – April 2014 provided Speech and Language Therapy
 - Focused Health Care, September 2012 – April 2014: A commissioned service providing Health Needs Assessment and Health Care Assistants to deliver care packages on behalf of Kingston CCG

- Merton children's social care, November 2010 – August 2011
- Wandsworth children's social care, August 2011 – December 2012
- Kingston children's social care (including health provision through integrated teams), May 2012 – April 2014
- Kingston school
- Private school, November 2010 – present date
- Spinal Muscular Atrophy Support UK, November 2010 – January 2011

1.2.3 All the health organisations listed above provide extra safeguarding support through Named and Designated Professionals for Safeguarding Children.

Process

1.2.4 This has been a systems review, focusing on the strengths and weaknesses in the multi-agency system in supporting families and safeguarding children with complex health needs.

1.2.5 The review was managed by a review panel consisting of senior managers of the involved agencies, working with two independent lead reviewers. In recognition of the complex health and safeguarding issues for the children, the Safeguarding Board chair, Deborah Lightfoot, appointed two experienced lead reviewers, one from a health background (Nicki Walker-Hall) and one from a social work background (Edi Carmi) and also engaged an independent and experienced Designated Doctor Child Protection.

1.2.6 The representation of the panel was agreed at the beginning of the process to include representation of the main agencies involved, or of those that commission their services. The NHS England (The Commissioner for services at GOSH and RBH) representative left her substantive post at the end of 2014 and NHS England did not send further representation to panel meetings.

1.2.7 The process used included:

- Chronologies from all involved agencies
- Individual management reviews [IMRs] for all health agencies, in line with the serious case review [SCR] requirements of NHS England: this review was being used as a pilot for NHS England participation in systems' approach serious case reviews
- IMRs from children's social care areas in Merton, Wandsworth and Kingston
- Meetings with the authors for the agencies that were not asked to provide management reviews: police, Spinal Muscular Atrophy Support UK, schools attended by the children in the family
- Individual and various group practitioner and management sessions to maximise learning from those involved with the family at the time, both in the IMR stage and in the 'overview' phase of the review: this staff participation enabled an understanding at the time behind actions and decisions (and lack of actions).
- Three meetings with father
- The lead reviewers were given access to documents that formed part of the criminal investigation and legal process, including police statements and psychiatric reports

Family and friends participation

- 1.2.8 The father was fully involved with the review once the criminal processes had been completed.
- 1.2.9 The author's access to police witness statements of maternal grandmother and family friends, has provided invaluable insights into the perspectives of family and friends.

Limitations

- 1.2.10 The mother did not participate in the serious case review process. Father explained that she was not sufficiently well to do so, that this could interrupt her recovery and that they had agreed he would be able to represent her perspective. It is understood that this is what she wants, but as she has not herself responded, we do not know if she would provide a different perspective. We have therefore not been able to explore with her directly how the professional network might have been better able to help the family, whilst focusing on the children's welfare.
- 1.2.11 A further limitation was the lack of consent for access to mother's health records, although this was compensated for by agreement for the lead reviewers to see the expert psychiatric reports provided for her sentencing.
- 1.2.12 The other accounts we have of the mother's thoughts and feelings are those she communicated at the time to staff, her husband's explanations to the lead reviewers as part of his contribution to the review and through lead reviewers' access to police witness statements and other evidence collected as part of the criminal investigation.
- 1.2.13 The family's main nanny (nanny 1), who was involved in caring for the children over several years, did not respond to the offer of interviews with the lead reviewers. At the time she still worked for the family. This is a limitation to the review as she was involved in caring for all the children over a long period and sometimes had the boys stay with her at her home. However the authors had access to her police witness statement.

1.3 Structure of the report

- 1.3.1 The report is structured as follows:
- **Chapter 2** provides a summary of the overall context, a summary of what happened, details of family members and a description of what was known about the children in the family, in particular the three children who died and an explanation of Spinal Muscular Atrophy Type 2
 - **Chapter 3** describes what happened from the perspective of those involved at the time, including both professionals and family, explains the rationale for actions and decisions and appraises the practice
 - **Chapter 4** considers the facts of the children's health needs
 - **Chapter 5** provides the findings and recommendations
 - A glossary of terms used in the report and the membership of the review panel are provided at the rear of the report

2 CONTEXT

2.1 The Family

- 2.1.1 The parents are white South Africans who moved to the UK as adults. Their children were born after the couple moved to London; the children held British nationality and were resident here.
- 2.1.2 Table 1 shows the family composition living in the household in Kingston. Table 2 provides wider family and significant people who were involved with the children during the period under review.

TABLE 1

Term used in report	Relationships	Age in April 2014
N	Eldest child	8
P	2nd eldest child	4
R	One of the twin siblings	3
Q	One of the twin siblings	3
Mother	Mother of all the children	
Father	Father of all the children	

TABLE 2

Term used in report	Relationships	Comments
MGM	Maternal grandmother - mother's mother	UK
Paternal grandparents	Father's parents	South Africa, but paternal grandfather died in October 2013
Nanny 1	Directly employed by the family and involved in all aspects of the care of all the children Had worked with the family for many years and had a close relationship with all family members, and sometimes had care of the boys in her own home to give Mother a break	
Nanny 2	Originally privately employed nanny but employment transferred to the Health Care Agency where she became a health care assistant: this enabled her costs to be met by the continuing care grant. She received agency training and supervision. Within the family, she remained known as a 'nanny' not a healthcare assistant and will be called this in the report.	

The children

- 2.1.3 There were four children in the family and practitioners observed that they had good relationships with each other and with their parents. The eldest, N, was aged eight when her three younger siblings died. P was aged four years old and Q and R, twin brothers, were aged three years old.
- 2.1.4 The three youngest children each had spinal muscular atrophy type 2 (SMA2). The condition affects voluntary muscles causing severe muscle weakness, which can result in problems moving, eating, breathing and swallowing (see section 2.3).
- 2.1.5 All the children were attending mainstream school in 2014; the three youngest attended the same school, P starting in September 2013 and her brothers joining the nursery class during the Spring term of 2014. This was earlier than originally planned but it is understood that this was a result of the parents seeing how much P was enjoying being at school.
- 2.1.6 Practitioners described the three children with SMA Type 2 as intelligent, bright, lively children who enjoyed their life. P especially appreciated the increasing opportunities being offered as she got older, to mix with peers and teachers.
- 2.1.7 P presented initially as a shy child. She was animated when talking about her school work, what she was doing and her favourite colour, with a 'mischievous twinkle in her eye, even when ill in the hospital's paediatric intensive care unit'. She loved pink and fairies, happy to join in activities and knew what she wanted, vocalising this to others. Staff at the school recalled how much she enjoyed dancing (both in her wheelchair and when carried), her sunny personality, good sense of humour and strong will. She was a very intelligent child who enjoyed school, being with friends, playing and learning. She never complained or seemed sad and was described as 'a real inspiration', 'delightful and bright', 'bubbly and inquisitive', 'smiley and happy' and an 'able learner'. P was always well turned out, never showed any distress around her parents and appeared to have a positive relationship with her nanny.
- 2.1.8 Q and R had recently commenced at the nursery class in school so were not as well known by the staff, but were 'happy, chatty boys', able to vocalise what they wanted to do or see and especially enjoyed investigating the cars and trains in the nursery. Both were always well turned out and comfortable with their parents and nannies. Mother was very positive when introducing them at school, pointing out the children's different personalities.
- 2.1.9 N and P had a close relationship with each other, both talking about the other to their respective teachers favourably. N decorated her desk with pictures of her siblings. N described Pas cheeky and P described her brothers as cheeky.
- 2.1.10 N cycled to P's school with Mother and Father before P started and the family would attend school events together; they presented in school environments as a happy close family.

- 2.1.11 Mother was always responsive to the children's needs at school, collecting her children immediately if any of them were unwell and communicating well with the staff about their health and their needs. P was observed to have a very affectionate relationship with her mother, was cuddled when being collected and when leaving her at school saying 'bye my angel' and exchanging 'baby high fives'.

2.2 Summary of what happened

Context

- 2.2.1 Both parents originate from South Africa, met as university students and moved to London before the birth of their children. Father's employment can involve long hours as well as international travel. Mother gave up her successful career in design when she became a mother, but it is understood that this background is evident in the attractive way the family home has been adapted for the needs of the children. The focus on the home not looking institutional was a major factor for the family, which on occasion led to disagreement with those practitioners who were advocating particular aids such as supportive seating systems for eating, vital to ensure the children didn't aspirate, and adaptations which were perceived by the family to be more in keeping with a hospital setting, than in a home.
- 2.2.2 All four children were born when the family were permanently resident in London, living first in Merton, then Wandsworth and finally Kingston. They moved from Merton to be able to have a suitable home to meet the need of the three children with disabilities, living in temporary rented accommodation in Wandsworth whilst the building work was being undertaken on their home in Kingston.
- 2.2.3 Paternal grandmother lives in South Africa as did her husband who died in 2013. Maternal grandmother lives in the UK and has provided support, usually during periods of hospitalisation, to the family. Maternal grandfather is deceased.
- 2.2.4 The family had two nannies to assist them in caring for the children. Latterly they settled into a routine where Nanny 1 supported the twins and Nanny 2 supported P particularly in school. Nanny 1 was very close to the family giving additional support by sometimes having the twins stay with her at her own home.

Background prior to period under review

- 2.2.5 The parents had two elder daughters prior to the period under review. N born in 2006 and P in 2009 and there had been no professional concerns about their care. The parents and a health visitor identified concerns relating to P's physical development in the month prior to the twins birth' and had been awaiting specialist assessment in the UK.

Period under review

- 2.2.6 The period covered by this serious case review is the 42 months from the premature birth of the twin boys, R and Q, in July 2010 to the date they and their sister P died in April 2014.
- 2.2.7 During this period the life of the family, and particularly of the mother, changed dramatically with an adjustment from being a family of four, to a family of six, with three of the four children being diagnosed with SMA2. This diagnosis meant a huge emotional and practical adjustment for the parents, with the children's complex health needs meaning that the family had support from nannies and from a large number of health and disabled children's team practitioners, both in the community and from the three hospitals involved.
- 2.2.8 The mother had responsibility for the domestic sphere, having given up work when the eldest child was born. Because of the children's disturbed sleep patterns, their mother reportedly rarely had a full night's sleep and presented to professionals as tired and often tearful. The family did initially try to use help at night, but ceased to do so as they preferred to retain their privacy.
- 2.2.9 There were concerns about mother's ongoing low mood, but she did not want or feel she needed any help for this (see 5.4 for further discussion). She was asked to see her GP repeatedly to discuss counselling. Her GP eventually visited her at home when the mother declined any offer of help, spoke of being stronger than before and was observed as patient and caring with her children. There was nothing in the mother's behaviour that suggested she would need to be detained in a hospital in the interests of her own health or safety, or with a view to the protection of others (criteria for a compulsory admission). There was also no evidence that the impact on the children of her observed low mood was causing a risk of significant harm.
- 2.2.10 In this case the child protection risks to the children were predominantly around medical neglect and this was understood as being linked to both parents' views, as opposed to mother's mental health.
- 2.2.11 The parents wanted their three disabled children to have a good quality life, and experience as little pain as possible. They did not want medical intervention for the children if this would cause their children pain. They characterised this as putting a priority on the quality of their children's lives as opposed to extending the length of their lives. The children's doctors though, were of the view that medical intervention was needed for P in order to decrease her current discomfort as well as to be able to maximise her potential. It was possible that her brothers would also need such intervention eventually.
- 2.2.12 Alongside the concerns about the possibility of medical intervention, some allied health professionals involved with the children were of the view that the mother did not consistently accept and act on their advice about feeding, physiotherapy, speech and language therapy and the use of aids.

- 2.2.13 The level of concerns led to professionals discussing the possibility of whether the child protection threshold had been met, but this was never agreed. Legal advice though was sought by two of the local authorities and by two of the hospitals regarding the possibility of legal intervention.
- 2.2.14 The discussions between parents and professionals over what was an acceptable standard of care for the three children, continued throughout the period under review. In the last months, there appeared to have been progress made. In particular the professional network was under the understanding by April 2014 that the father had agreed to P having a gastrostomy and that he was giving serious consideration to the potential benefits of spinal surgery, albeit he was worried that this may cause his daughter a great deal of pain and might not lead to significant improvements in her life. It was not clear if the mother was in full agreement with this view, as the parents had made it clear that all such discussions about medical intervention be undertaken with the father and the email correspondence came from the father.
- 2.2.15 The father was away during April 2014, first on a trip to the USA and then taking the eldest child to see paternal family in South Africa. During this period maternal grandmother stayed with mother and P, whilst Q and R stayed with the family's main nanny. Mother asked for her sons to be returned home the same day as maternal grandmother left. That evening she smothered her three youngest children.

2.3 Spinal Muscular Atrophy Type 2

Nature of condition

- 2.3.1 SMA is a complex condition and every person with Spinal Muscular Atrophy (SMA) is different.
- 2.3.2 SMA is a rare (approximately 1 in every 6,000 – 10,000 babies are born worldwide with the condition) genetically inherited neuro muscular disease causing muscle weakness and loss of movement. There are 4 main types, classified according to the age of onset and severity of symptoms; these Types are not rigid categories and there is a wide spectrum of severity within each.
- Type 1 SMA the most severe type. Symptoms appear in babies less than six months old, and they never develop the ability to sit unsupported. Severe respiratory problems mean children rarely survive beyond two years of age.
 - In Type 2 SMA symptoms are less severe than type I. Symptoms usually appear in babies aged 7 to 18 months. Children with Type II can sit unsupported and in some cases are able to crawl or weight bear with support but never walk unaided. Symptoms may get worse over time.
 - In Type 3 SMA symptoms generally appear after 18 months of age. Children with Type 3 range from those able to take a few steps to those who can ambulate throughout their home and community. A child may require a wheelchair to navigate their environment. Life expectancy is normal and most people can live long productive lives.

■ In Type 4 SMA Type symptoms appear in adulthood and it is not life-threatening

- 2.3.3 Infants with Type 2 SMA are usually able to sit, but not stand or walk unaided. They may also have breathing problems, weakness in their arms and legs and some children find that their tongue or shoulder muscles twitch and they may have a slight tremor in their hands. In some cases, deformities of the hands, feet, chest, and joints develop due to lack of use.
- 2.3.4 As they grow, most children with Type 2 SMA develop scoliosis. This is an abnormal curvature of the spine which occurs when the muscles supporting the bones of the spine become weaker; there are standard steps that can be taken, medically, to slow its progression.
- 2.3.5 A child with Type 2 SMA has weak respiratory muscles which can make it difficult for them to cough effectively. This can make them more vulnerable to respiratory infections.
- 2.3.6 Type 2 SMA can weaken children's chewing and swallowing muscles which presents a risk that they may inhale liquids or foods into their lungs which can cause chest infections. In addition mealtimes may be very slow and effortful for the child.
- 2.3.7 Children with Type 2 SMA do not have mental disability and in the absence of other diagnoses are known to reach average or above average intellect, are articulate with prospects of completing a full education to and past university level.

Diagnosis

- 2.3.8 The inheritance pattern of SMA is autosomal recessive. This means that for the condition to arise both parents must be carriers. This is an asymptomatic status. Two carrier parents will have a 25% chance of having an unaffected child, 50% chance of having a carrier child and 25% chance of having an affected child. There is a 1 in 4 chance with each pregnancy that the child will have SMA.
- 2.3.9 Diagnosis during pregnancy can be made by chorionic villus sampling or Preimplantation Genetic Diagnosis in 'at risk'² pregnancies.
- 2.3.10 After birth children showing clinical signs can be diagnosed with the condition by taking a blood sample for DNA testing.

Prognosis

- 2.3.11 Although Type 2 SMA may shorten life expectancy, improvements in care standards mean that the majority of people can live long, fulfilling and productive lives. The majority of children are now expected to survive into adulthood.³

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² Parents who have had a previous child diagnosed with SMA

³ NHS Choices. <http://www.nhs.uk/Conditions/Spinal-muscular-atrophy/Pages/Symptoms.aspx>

Care

- 2.3.12 There are internationally agreed Standards of Care for SMA; these standards have been used to inform practice by all health organisations involved in the delivery of the children's care. It is expected that respiratory infections are managed through acute hospital admission and involve a multi-disciplinary team and at least one specialist hospital for monitoring and assessments. It is not unusual for more than one specialist hospital to be involved as parents are able to have some choice in how their child's care is delivered. It is recognised that aids will be required in order to support good care management e.g. spinal jackets, whizzy bugs and wheel chairs.
- 2.3.13 Each child should receive care from a multidisciplinary healthcare team, including specialists in neuromuscular conditions, respiratory medicine, orthopaedics, physiotherapy, occupational therapy, speech and language therapy, dietetics, and a hospital or community consultant paediatrician. It is usual for one of the team to be the lead professional whose job it is to help co-ordinate services for the family.
- 2.3.14 Children with SMA Type 2 should be seen by their medical team regularly to measure any change in their health and to offer advice and interventions at the right time. The aim is to enable the child to remain healthy and enjoy a good quality of life. At every appointment parents should be given time to ask questions and then jointly decide what support is best for the child.

3 NARRATIVE AND PRACTICE APPRAISAL

3.1 Introduction

- 3.1.1 The period under review covers a 42 month time from the premature birth of the twin boys, R and Q, in July 2010 to the date they and their sister P died in April 2014.
- 3.1.2 This chapter explains what happened, with a 'comment' box providing an appraisal of practice for each time period.

3.2 Birth of boys and first diagnosis of SMA: July 2010 - September 2010

- 3.2.1 The boys were born unexpectedly in Portugal during a family holiday, resulting in the siblings N and P being looked after by grandparents in South Africa, whilst both parents stayed in Portugal where their sons were in the special care baby unit.
- 3.2.2 Whilst in South Africa the grandparents, following the parents' instructions, arranged for P to be seen by a paediatrician and she was diagnosed as suffering from Spinal Muscular Atrophy Type 2 (SMA2). The parents understood at this point from the information provided via the grandparents that P was unlikely to reach adulthood.
- 3.2.3 The mother returned to the UK to look after her daughters, whilst the father stayed with the twins and brought them back to the UK aged around three months, when they were transferred to Kingston Hospital.
- 3.2.4 P was seen at St George's Hospital (SGH) in September 2010, aged 15 months old, and referred to the neuromuscular service at Great Ormond Street Hospital (GOSH) for support and advice.

Comment:

It is of note that from the outset, the parents were frustrated with what they perceived as undue delays in gaining an assessment of P in the UK health system and took the opportunity to obtain the desired assessment privately in South Africa. Significantly, the initial understanding of the parents was that P was unlikely to reach adulthood. This perception had an effect on their view of the future for the family, despite being told subsequently that this was not the case.

Also significant from this point was the pattern of Mother finding hospitals difficult, due to her difficulty being present when she perceived her children were having to undergo physical discomfort for a necessary medical treatment or intervention. Father explained to the authors this was the reason he remained in Portugal with his sons and his wife returned to London to look after the girls.

3.3 Family in Merton until August 2011

- 3.3.1 The family continued to live in Merton until August 2011 when they moved to Wandsworth.
- 3.3.2 In October, P was seen at Great Ormond Street Hospital (GOSH) and a plan was made for care to be provided; this included speech and language and physiotherapy evaluation at GOSH. St George's Hospital (SGH) provided local support and GOSH made a referral to Royal Brompton Hospital (RBH) for formal respiratory evaluation and advice. This latter referral met the family's needs of closer geographical access. A referral was also made to Merton children's social care for early involvement with the family.
- 3.3.3 Both boys were diagnosed with SMA Type 2 in the UK during October/ November 2010. There is little evidence of anyone being able to engage mother in a discussion over her feelings at this time; it is not unusual for parents in these circumstances to feel shock and experience feelings of loss at the consequent changes such diagnosis brings to their lives.
- 3.3.4 The pattern of father working long hours and mother being the primary carer, with the help of privately funded nannies (day and some nights) was set from this point. Also from an early period it became clear to some that mother was overwhelmed with the large number of appointments (sometimes on the same day) as well as the frequent sleepless nights involved with caring for the three younger children. The health visitor noted she sounded stressed at this time.
- 3.3.5 Support was being provided by a large number of services including:
- Community health services for the family including GP, health visitor and community nurse
 - SGH, where the lead Paediatrician was based and who co-ordinated the children's care locally, including physiotherapists and the Children's Continuing Care team and the Occupational Therapy service
 - GOSH neuromuscular clinic from October 2010, dieticians, physiotherapy, and speech and language therapists
 - RBH for specialist respiratory care
 - Merton Children & Families services: Children with Disabilities social worker, the Early Support team [including Portage] and the Occupational Therapy service
- 3.3.6 Mother also made telephone contact with SMA Support UK, and was visited by their outreach service. She spoke of struggling and feeling alone, but did not want further home visits as there were 'too many people in the house' and they 'want to be together as a family without involving new people and new situations'.

- 3.3.7 The focus of professional intervention at this time was with P; the twins' health and development were not yet identified as of particular concern although Mother had commented that the boys were 'stiff'. N had commenced at private school, where mother spoke of her guilt at feeling unable to give her eldest sufficient attention due to the needs of her siblings.
- 3.3.8 By the end of 2010 and early 2011, the mother reported that P cried at the sight of some professionals and was perceived by the mother to be fearful of the physiotherapist's treatment; this perception led to Mother discontinuing some of the treatments that her daughter was said to dislike. Mother was struggling to use some of the specialist equipment (such as the saturation monitor) or disliked doing so on the basis of disturbing siblings and father (saline nebuliser at night) or declined to do so on the basis that P disliked the aid (e.g. the reclined position in a snug seat).
- 3.3.9 Professionals in different settings began to identify that mother was possibly suffering from depression and lacked energy for some tasks. She was advised to seek counselling help via her GP on several occasions.
- 3.3.10 Concerns about P's weight began in 2011. Her weight had dropped from 75th centile at birth to the 0.4 centile, with feeding being very slow despite great efforts by Mother to provide food her daughter liked. The reasons identified for her feeding difficulties were frequent coughs and colds, as well as appetite suppression from constipation. In February 2011, mother reported talking on line with a mother of a child who required a gastrostomy; Mother was tearful, saying that they would not want this for their child.
- 3.3.11 By May 2011 the consultant paediatrician at SGH (and 'lead professional'⁴ for the children) reported in email communications that most professionals were raising significant concerns that mother's mental health was having an impact on P's health, and that the situation was deteriorating. However, the emails also stated that this was not yet a child protection matter. The plan was to speak with the GP to arrange a psychiatric nurse and the need to offer respite care with a hospice.
- 3.3.12 A hospice was offered for respite care purposes in May 2011, but ultimately, the parents declined this service as they did not feel the hospice was right for their children.
- 3.3.13 There was discussion between health practitioners about the need for an urgent professionals' or a multi-agency meeting at various times. This was to discuss concerns as well as to consider how to pare down the team around the family due to family concerns about the numbers of professionals involved; this took some time to happen. Such meetings were held in March and again in May 2011.

⁴ See 5.7 for discussion of the meaning of the term lead professional

- 3.3.14 Critically, by July 2011 mother was expressing the family's view that medically invasive treatment was cruel, and that the children should be designated Do Not Resuscitate (DNR) if need for on-going treatment arose. Mother also spoke about the possibility of returning to South Africa where she believed she would be allowed the choice of palliative care without medical intervention. It was explained that the lead professional would need to speak with the Ethics Consultant at SGH for advice and that as children's health professionals they had to be advocates of the children first.
- 3.3.15 By the time of the family's move to Wandsworth in August 2011, Mother's mood appeared to be lower, despite the boys having stayed with their nanny for a month to give her a break. The community children's nurse, during a joint home visit with the physiotherapist, found mother tearful, expressing her feelings of being trapped. Mother identified financial problems with the direct payments of 20 hours not yet materialising and a likely further delay after the house move.

Comment:

*Starting from this early period professionals were identifying mother's need for support and balancing this with the concerns that her perceived lack of co-operation was impacting on P's development. This worry became more critical following mother's opposition to medically invasive treatment and request that her children should be designated DNR. Alongside this was the recognition that P's weight was of concern and mother was opposed to the medical intervention that may be needed to address this. **This is discussed further in the review's findings in chapter 5.***

*A feature of the disagreements between mother and professionals was mother's rejection (at least initially) of certain recommended aids for her children in favour of ones that may be less supportive, but more visually attractive. Partly this arose due to mother's occupation as a designer and partly due to the family's desire to maximise the normality of the children's life and avoid anything that looked 'institutional'. **This is discussed further in the review's findings in chapter 5.***

Also pertinent is father's explanation that service delivery in South Africa is significantly different. Families pay for each service so are able to choose which ones they wish to use.

3.4 Wandsworth: August 2011 - October 2012

Overview

- 3.4.1 The family lived in Wandsworth from August 2011 to October 2012. During these 14 months they rented their accommodation whilst their new home in Kingston was being adapted to make it suitable for the children's needs.
- 3.4.2 The move to Wandsworth meant a change in part of the professional network supporting the family, including children's social care and some community health services. However, the same hospitals remained involved with the children and the same GP.

- 3.4.3 The majority of social work involvement in this period was focused around chairing the regular team around the child (TAC) meetings, ensuring the financial care and support packages were in place and then latterly with the transfer of the case to Kingston, that transitional plans were in place. The parents were provided with information on local services in Wandsworth including the Portage service but they felt the current arrangements with the nannies were enough especially as they were shortly to move to Kingston.
- 3.4.4 Within the professional network there was a move to identify the negotiable and non-negotiable aspects of the children's health care, with a professionals' meeting in August 2011 defining non-negotiable as treatment for chest infections, nutrition and spine management, and a draft respiratory plan to be discussed with both parents and a contract drawn up. There was consideration about whether the parents' attitude about treatment might require SGH to seek a treatment order through the courts or whether it constituted a safeguarding issue, but without any conclusion as to whether the thresholds for child protection had been met.

August to December 2011: period of assessment

- 3.4.5 Initial discussions in September and October between Wandsworth children's social care (service manager, team manager and social worker), the designated doctor in Wandsworth and the consultant paediatrician at St George's Hospital centred on concerns over parents' perception of 'unnecessary' medical intervention and resuscitation of their disabled children. Also mentioned was Mother's comment to the paediatrician earlier in the year that she wished her children were dead.
- 3.4.6 The medical professionals were concerned about the legal position and potential risks to the children, and on the advice of the designated doctor initially suggested to children's social care that a strategy meeting be held. The social worker and his managers appropriately advised that if concerns were about parenting capacity, as opposed to medical intervention, then Wandsworth children's social care would undertake further assessments and call a professional/strategy meeting to see if thresholds for a s.47 child protection enquiry⁵ were reached. However it was agreed (at the request of the consultant paediatrician) that she would first talk to the parents to alert them to the concerns and possible actions, prior to children's social care initiation of a strategy meeting.

⁵ s.47 enquiry refers to section 47 Children Act 1989 This states the local authority's duty to investigate when they 'have reasonable cause to suspect that a child who lives, or is found, in their area is suffering, or is likely to suffer, significant harm, the authority shall make, or cause to be made, such enquiries as they consider necessary to enable them to decide whether they should take any action to safeguard or promote the child's welfare'. Also referred to as a child protection enquiry or investigation.

- 3.4.7 It is understood that the consultant paediatrician experienced some difficulty in arranging the appointment to see the parents during 2011, so this 'bottom line'⁶ was not communicated to the parents at this point and the strategy meeting did not occur.
- 3.4.8 In September a social worker from the Wandsworth disabled children's team was allocated. The transfer information from Merton had not identified child protection concerns.
- 3.4.9 At the social workers first meeting with the family that month (joint visit with the Lead Professional, the community nurse), the mother advised the social worker not to speak with P directly as she could become distressed with strangers. He did though observe all three children, who were immaculately turned out in fashionable clothes.
- 3.4.10 The social worker, an experienced member of the disabled children team, undertook an assessment, involving financial information and had discussions with key health professionals, as the parents did not wish to repeat the assessment undertaken previously with Merton. Father was clear that 'they wanted services not assessments'. The social worker requested further information from the Merton Social Worker and was told that Mother was very attentive to the children's need and engaged well with early years and portage.
- 3.4.11 The social worker contacted involved professionals and gained positive information regarding P's progress in nursery school, as well as her good relationship with her mother. The Wandsworth social worker's initial assessment report concluded in November that the children were physically well cared for by their parents and presented as secure in their home.
- 3.4.12 Wandsworth Complex Needs Panel met in October and agreed a package of continuing healthcare for the three children. At the time Wandsworth had no policy to make financial payments directly to the family for healthcare services. Father strongly objected to this, wanting direct payments so that he could financially support arrangements the family already had in place. There was no mechanism for this at the time but in December an agreement was reached to support a pilot funding arrangement to enable the family to employ their trusted known care staff.
- 3.4.13 Meanwhile, in contrast to the positive social assessment, concerns were first raised at GOSH in November about P not wearing her Knee Ankle Foot Orthoses (KAFO) and about her now significant spinal curvature when sitting. P's weight was below 0.4 centile and her indoor wheelchair was not being used so she had no independent means of mobility.
- 3.4.14 The twins were seen by the physiotherapist in this period and noted to have delayed play skills.

⁶ The term 'bottom line' was used over the review period by some health practitioners to denote the minimum expectations that would be expected at any time of the parents in relation to agreement for medical intervention

January - October 2012: lack of consistent professional view

- 3.4.15 Agency records indicate that views on the extent to which the parents were co-operative and followed medical advice fluctuated, over time and between agencies.
- 3.4.16 Concerns about parents' refusing medical intervention declined in January 2012 when P was admitted to SGH for the first time with a chest infection and Father agreed to treatment including ventilation.
- 3.4.17 Mother was perceived to be less co-operative and the Named Safeguarding Nurse became involved due to concerns about Mother's mental health. Mother turned down the offer to meet with the psychologist at the hospital, so instead the psychologist was used as a resource for professionals on how to work with Mother.
- 3.4.18 By this period P's low weight was of concern to medical staff, albeit it was not being identified as being caused by neglect, as low weight can be a feature in SMA. There continued to be issues around missed or re-arranged appointments, especially in relation to GOSH and the SGH paediatrician.
- 3.4.19 There are references in the social work file of medical staff plans to meet to discuss the parents' views around medical non-intervention in the early part of 2012. The consultant paediatrician at SGH was still noted as wanting to agree 'the medical bottom line' and speak to the parents in relation to this. The record also shows the social worker was asked *not* to share concerns with parents before this occurred. This process included obtaining information from the neuromuscular disability team at GOSH in the consideration of medical neglect and in enabling defining the non-negotiable parts of the children's health care.
- 3.4.20 In February the family were discussed by SGH clinical ethics committee, which noted the difference in the parents' attitudes, with Father being more amenable, but clear that their home should not be a mini hospital. There was an understanding of Mother's distress and her need for autonomy in a situation where she had little power. It was also noted that there was a difference in what Mother said and her subsequent more amenable actions. There was no discussion whether the issues raised belonged in the child protection process.
- 3.4.21 From this point professionals were asked by the parents to go through Father to discuss medical interventions for the children. Regular early morning 'team around the child' (TAC) meetings were instituted, attended by both parents, the designated doctor, health professionals and chaired by the social worker. These meetings aimed to provide more co-ordination of practitioner contact so as to minimise appointments for the family.

- 3.4.22 Professional communications in this period demonstrated differing and fluctuating perceptions of the quality of the care provided to the children between health practitioners and agencies. Mother was not keeping some appointments and declining others, for example she declined home visits by the SGH consultant paediatrician, cancelled 6 meetings at GOSH for P (who was seen on just three occasions) and Q and R were not seen for eight months following their initial referral. However the notes of the March TAC meeting has reference to the family generally keeping appointments and attending the GP appropriately. Whilst Mother was perceived as often not wanting additional assistance, at times, for example in May, she requested and accepted help from the community children's nurse, when P was unwell and Father was away.
- 3.4.23 In June a physiotherapist flagged concerns regarding the development of the boys, who spent much time alone with the nanny. The SGH Consultant Paediatrician in Neurodisability saw R for the first time in over a year and found him to be developmentally delayed in all areas. Despite regular TAC meetings and regular involvement with allied health professionals R's development had not been regularly assessed. Q was also seen and was considered to be making progress.
- 3.4.24 By September, the Wandsworth social worker was aware of the difference of opinion between the parents and GOSH over the suggestion of gastrostomy feeding for P, because of her poor feeding.

Transition planning

- 3.4.25 There was evidence of a great deal of thought and preparation by professionals in planning for the family's move to Kingston, with communications between the two designated doctors in April, and contact made with the Kingston children's community nursing team as well as between social work teams.
- 3.4.26 By May, the Kingston occupational therapist was involved because of the major adaptations needed to the family's new home, including the lift, new door, ramp and hard standing areas. She helped obtain the Disabilities Facilities Grant, liaised with family and providers and undertook assessments for lifting and handling adaptations and equipment for the children, some of which were rejected because Mother did not want the home to look like an institution.
- 3.4.27 There was by this point liaison between each borough's complex needs panel and children's social care teams, with a Kingston social worker allocated the case in September and a confirmation in October that Kingston would maintain the joined up care package provided by Wandsworth. In fact, the family had not been using all the hours allowed due to difficulty finding an appropriate carer and were only using approximately a third of the hours they were assessed as being eligible for.
- 3.4.28 The family moved to Kingston at the end of October and case responsibility within children's social care transferred to Kingston, along with changes in the GP, Lead Professional and the community Paediatric Team.

Comment

What becomes apparent in Wandsworth is the patterns amongst professionals to try to 'go the extra mile' to support the family, and sometimes work outside of their normal professional role and usual ways of working. Examples included:

- *Regular TAC meetings held at the home before working hours - at 8.30am to facilitate Father's attendance*
- *The designated doctor's direct involvement with the family, attendance at regular TAC meetings locally and attending some hospital meetings and appointments with the parents*
- *Attempts to co-ordinate and minimise home visits and appointments*
- *Acceptance by the social worker that he would build on the assessment in Merton, as requested, to save the parents repeating the same information*
- *Acceptance by the social worker that direct work with the children might upset them (as Mother claimed), and to limit his contacts largely to seeing the children when attending the home for TAC meetings*
- *The complex needs panel agreeing a different way to fund care to enable the parents to continue to use their nannies*

At the time, the professionals felt that this approach was working well and that progress had been made on working in partnership with the parents, especially with the father taking the lead role in relation to sensitive negotiations, and the involvement of the designated doctor, who was seen to have the parents' trust and an understanding of disability through his own personal experience. This is further discussed in the findings.

It is of note that the initial intention to define and explain the 'bottom line' to the parents after the family moved did not occur, in part because Mother missed or re-arranged appointments, but subsequently due to parents' accepting medical intervention when P was in hospital and working relationships were perceived as having improved. Similarly the initial plan to hold a strategy meeting following this did not occur, presumably because health concerns had diminished and health did not come back to social care about having told the parents of the concerns.

However, the underlying areas of concern remained in terms of the different views about medical intervention for the children. Also in this period there were concerns about appointments missed or postponed, especially with the various hospitals, worries around P's weight; and worries regarding R's development which went without full assessment for many months.

The social worker and manager are though clear that the concerns were not of the level for the initiation of child protection processes. The authors would support that judgment from the January, although, it would have been appropriate to have held a strategy meeting when health made the request in October 2012, rather than wait indefinitely for the consultant paediatrician to meet with the family.

3.5 Kingston: November 2012 - April 2014

Period of assessment: November 2012 - March 2013

- 3.5.1 The family moved at the end of October 2012, and by early November the parents had attended a multi-disciplinary meeting at the Integrated Disabled Children Service (IDCS), a multi-disciplinary service in Kingston providing both health and social care services at one location. This acted as a transfer meeting between the boroughs. The offer of the designated doctor from Wandsworth to remain temporarily involved to assist the transition was accepted. All the children's weights were noted to be low and the parents were clear that a gastrostomy would not be considered at this point.
- 3.5.2 The Kingston social worker, an experienced practitioner, undertook an initial assessment. The assessment highlighted that the parents were grieving; mother presented as depressed but refusing assessment or treatment; the three youngest children were entirely dependent on their carers for basic care and access to stimulating activities; and the need to monitor the children's 'weight and eating by the health team'.
- 3.5.3 Soon after this [end of November to mid December], both R and P were admitted to the Paediatric Intensive Care Unit (PICU) at SGH with bronchitis and a chest infection respectively. During this admission concerns were raised including that P's weight had dropped below the 0.4 centile; worries of under stimulation on the basis of Mother declining therapeutic play for the children and the parents observed to be speaking on their phones and not interacting with the children. However, this was within the context of a parent resident all the time with their child at the hospital. GOSH was reporting that Mother had refused gastrostomy feeding, and whilst Father was considered to better understand the children's needs, he was not usually present at appointments.
- 3.5.4 Whilst these concerns were prevalent amongst health professionals, this view was not universal; the designated doctor (Wandsworth) reported observing a warm and loving home, and some hospital doctors were more sympathetic to the parents' wishes.
- 3.5.5 The Kingston community paediatrician was concerned about how to increase the nutritional intake of the children following discharge from PICU (where P had gained weight whilst being naso-gastrically fed). There were additional concerns regarding the lack of use of aids (e.g. KAFO's and wheelchairs), despite Q and R demonstrating improvement with their use. The IDCS commenced an assessment of the children's needs with an agreed plan for fortnightly multi-disciplinary meeting and review of the children's weights. This would involve liaison between all involved services: community nursing and paediatricians, the Kingston multi-disciplinary team and the tertiary hospitals involved (GOSH and RBH), dietician, speech and language therapists, physiotherapy and occupational therapy (the latter to provide supportive seating and spinal brace).

- 3.5.6 There were intermittent attempts throughout the period under review to establish mother's mental health needs, with the Named Nurse asking the GP to see Mother. The GP undertook a home visit in January. Mother acknowledged stress of the number of medical appointments, but mentioned her happy family, that she was stronger than ever and did not want medication or a support group as this did not comfort her. The GP observed her as patient and caring and her children as happy and appropriate.
- 3.5.7 A Brearley risk assessment⁷ undertaken in January 2013 by the Kingston social worker and Designated Nurse for Child Protection (as part of the Designated Nurse's supervision of the IDCS) concluded, according to social work records, that the case would be managed outside child protection. The assessment was sent to the named nurse from YHC, who concluded the risks were high. There is no evidence this discrepancy in conclusion was ever challenged or discussed with the designated nurse.
- 3.5.8 The concerns continued over the weeks for all the practitioners involved, particularly around the children's growth, albeit this varied, with P and Q gaining weight initially and R losing, but then increasing. Practitioners appropriately consulted their managers/designated agency leads at the end of January, with the decision to monitor and review concerns in three months' time. At the middle of February it was also agreed that the health assessments would be updated on all three children.
- 3.5.9 Mother continued to decline services that professionals considered in the best interests of the children in terms of their stimulation e.g. nursery for the boys [rejected after parental visit] and initial rejection of postural seating.

Comment:

There was good transition planning for Kingston's handover, and positive recognition of the requirement to undertake social care assessments of all three children and not just focus on P's needs. As the children had got older, their physical difficulties were becoming more apparent.

The joint assessment by the designated nurse and social worker was good practice. However, the subsequent discrepancy in terms of level of risk assessed is worrying, with those involved deciding the child protection threshold was not met, yet the named nurse at YHC concluding there was high risk on basis of what was recorded. This difference was not known, not acknowledged and never discussed, but led to a difference in viewpoint between the Named Nurse and the social worker.

The concerns about feeding difficulties increased for all three children, but for P the need for a gastrostomy became critically important in the opinion of some health practitioners, especially within GOSH.

As in Wandsworth, practitioners worked over and above usual roles and work arrangements, undertaking visits at home instead of the clinic. The Wandsworth designated doctor remained involved, attending professionals' meetings and trying to act as an intermediary, with some level of success. The lead professional (a community paediatrician) undertook joint home visits with the social worker.

⁷ Brearley, P. (1982) Risk and Social Work. Routledge, Kegan Paul.

On the brink of legal intervention: February - July 2013

- 3.5.10 During February 2013 there were professional meetings and communications that referred to both neglect and emotional abuse with regard to P. The neglect was in relation to the refusal to consider medical interventions and the scoliosis in all three children. The emotional neglect was in reference to Mother's response at GOSH that she wouldn't be around to see P's future attendance at university. It was queried whether this was a threat to commit suicide. Father indicated to the authors of this report that was mother expressing her frustrations and distress.
- 3.5.11 Mother and P attended an appointment at GOSH, when it was stated that a gastrostomy and surgical management of P's scoliosis was needed, but Mother was 'adamant' that the parents wanted no further medical interventions for her.
- 3.5.12 The first reference in Kingston of possible legal action by children's social care was made to the parents by a team manager (not the social worker's manager), who visited the home in February following the appointment at GOSH, when the social worker was unavailable.
- 3.5.13 Later that month following Mother's refusal to bring the children in for sleep studies the Consultant in Paediatric Respiratory Medicine (RBH) emailed the Wandsworth designated doctor about the difficulties in arranging the sleep studies for the children, as this had to take place in the hospital, and mother's refusal to bring the children to the sleep lab because things were 'too difficult'. The Consultant from RBH expressed a professional opinion that in the context of what had been discussed at a previous meeting at SGH, P had suffered physical harm from neglect although s/he would defer to the SGH consultant paediatrician on whether early and more intensive treatment would have prevented the scoliosis. The RBH Consultant also identified that Q and R were at risk of suffering harm from neglect, albeit it this view was acknowledged to be on the basis of the respiratory prognosis alone. The email setting out these concerns was sent directly to designated doctor at SGH and copied to the GOSH consultant, who forwarded the email to the Kingston Paediatric community consultant to coordinate the management of the safeguarding concerns.
- 3.5.14 The email from the GOSH Consultant Paediatrician to the Kingston Community Paediatrician at this point refers to the need for 'robust legal discussions', previous mention of the 'possibility of future legal intervention to parents in the event of P continuing to fail to thrive' and that 'this latest refusal to engage with respiratory assessment expedites our concerns'.
- 3.5.15 The Named Nurse at SGH was copied into this correspondence and responded that she would ask the social worker for a legal planning meeting. The Wandsworth designated doctor on receipt of this email queried the need for this decision being taken without a meeting of all the professional stakeholders.

- 3.5.16 The plan formulated at a subsequent Kingston professionals' meeting in early March, was to write to the family with the explicit concerns and expectations. The letter was sent by the lead professional, the community paediatrician. At a meeting at the home later in the month parents were given information booklets on SMA management and care to support the key areas of the care management plan: nutrition, postural management and respiratory functioning.
- 3.5.17 It was acknowledged that there had been some progress in so far as Mother was accepting help from the dietician and the speech and language therapist, and also providing nutritional supplements to the children.
- 3.5.18 In April the children underwent sleep studies at RBH. On the second occasion, Mother left the ward with her daughter prior to formal discharge and after concerns which resulted in the Matron Paediatrics instructing a 'top to toe' examination before discharge. Staff told one of the lead reviewers and the IMR author that the concerns were around Mother's extreme mood swings, not letting nurses near P, even when her oxygen levels were low and needed checking. She was rude and dismissive to staff and also shouted and cried in front of her daughter, saying that her 'life is hell'.
- 3.5.19 RBH staff contacted the social worker because of these concerns and that Mother taking P home before she had been checked. The social worker explained what was happening in the community and requested the information be faxed to her. The discharge letter to the GP was copied to the social worker, but did not articulate the detail of the concerns. When Mother was telephoned later, she explained that P was unwell, had vomited in the sleep unit and she just wanted to get her home. The social worker wrote to RBH following her joint visit with the community paediatrician (and lead professional), explaining about the reasons why Mother was especially tired on the day of the sleep study and concerned about P being poorly. The letter assures the hospital staff of the children's safety and that no additional support was needed.
- 3.5.20 During May P was admitted into PICU at SGH with a cough and concerns were raised due to Mother intermittently removing her mask and objecting to oral feeds. When P was in hospital again in June, there were incidents that raised concerns around Mother's non-compliance and interference with medical equipment (providing oxygen).
- 3.5.21 In early July there were further concerns again about Mother interfering with equipment, turning the alarm off when P was in PICU and the matter was reported to the social worker. Consideration was given to the involvement of the police but according to the social care records, SGH did not think that would be helpful. Children's social care held a 'pre legal planning meeting' where these new concerns (together with existing ones) were discussed and the solicitor wrote to SGH for further information. It was intended to hold a legal planning meeting the next week.

- 3.5.22 The Named Nurse from YHC recorded that she asked for the police to be informed of the concerns and that the social worker referred to a plan for the initiation of care proceedings unless the family agreed to naso-gastric feeding on discharge. A discharge meeting at the hospital on the Monday confirmed the plan as legal intervention.
- 3.5.23 When the father was told of the concerns, he provided information that defused the situation e.g. neither parent was ever told that they must not silence alarms nor did they remove the respiratory equipment. Mother admitted to turning off the alarm - but both parents had been unaware that this was prohibited and it was later confirmed by the PICU consultant to be normal practice for families whose children were frequently in PICU.
- 3.5.24 The hospital subsequently withdrew its statement of concern on the basis that the parents, having been consulted about the concerns, agreed to co-operate with the treatment plan. The changed view from SGH was that Mother's behaviour was not perceived as endangering her daughter's health.
- 3.5.25 On the basis of a written agreement being drawn up to address all the concerns, signed by the parents and the local authority, the planned legal intervention was dropped. The agreement included for:
- Mother to engage with social worker about her behaviour towards medical staff in presence of children
 - Parents to cooperate with overnight ventilation programme for P
 - Parents to engage in talks about alternative feeding options for children
 - Parents to attend and cooperate with meetings and agreed medical appointments for all children
 - During future hospital admissions, parents to refrain from interfering with any medical equipment
- 3.5.26 The parents' perception at this stage was that the air was cleared between themselves and professionals and that it was acknowledged that there was no foundation for the concerns at SGH. The written agreement was perceived to provide the basis for future progress to be made and Father felt this to be a breakthrough. The social worker also felt this, but other members of the professional network had less understanding of the origins of the concerns and why they were no longer considered to be relevant.

Comments

Professional concerns escalated in this six month period, partly with the children getting older, their needs for medical intervention became more apparent.

*The concerns during this period, in the view of the authors, reached the threshold for child protection intervention, but this did not happen, despite references to legal intervention. This is **further discussed in the findings, see 5.15).***

There was progress in agreeing a written plan with the parents and this reduced the perceived need for legal intervention at that point, by those directly involved. However, the need for a child protection enquiry should have been considered, to establish the basis of the various allegations made and then retracted. The lack of this meant that there remained professional confusion

around whether or not there was any truth in the original allegations. As a result some professionals were left with continued and heightened concerns without the means to gain additional perspective and no opportunity to challenge this change in thinking.

Without an adequate investigation into the concerns and an understanding of how they arose and why they were then found to be wrong such suspicions continued within the network.

Slow progress perceived by professionals: September 2013 - January 2014

- 3.5.27 P started school in September and she quickly settled, enjoying the company of her classmates. She was described as a lively and inquisitive learner. Mother had a good relationship with school staff, speaking more easily with them than with health practitioners and agreed for the twins to join their sister at the school after the Easter holidays in 2014. It was felt that Mother was beginning to understand the positive experiences life could offer her children out of the family home.
- 3.5.28 The community paediatrician (and lead professional) had consulted Kingston's designated doctor about the children's weight and the social worker understood that the view was that without a period of sustained loss there were no grounds for using child protection procedures, and that whilst a gastrostomy was desirable it was not essential.
- 3.5.29 The Kingston children's social care management review refers to parents at this time as co-operating with the care plan, with P overall gaining weight during this period, and the father requesting aids for the twins. There were more concerns relating to the boys' weight in this period, and they were referred to a dietician.
- 3.5.30 The parents (according to father) believed that they were complying fully with the plan and progress was being made.

3.6 The need for medical intervention becomes critical: February - April 2014

- 3.6.1 In the last eleven weeks of the three children's lives, professional concern initially increased, as a result of a clearer message from GOSH that the progression of P's spinal curvature, despite parents reporting she wore a brace for much of the time, meant that surgery would be unavoidable. Moreover, for her to be strong enough to undergo such surgery she would first require a gastrostomy so as to increase her nutritional intake.
- 3.6.2 At the same time there had been a change in the management of the social work disability service, following the arrival of a new interim team manager. This led to a change in approach, and a stronger focus on safeguarding. This was in line with the Improvement Plan across all of social care in Kingston (following Ofsted's judgement that the previous practice was inadequate) and reflected a change in culture. The case was transferred to a new social worker charged to undertake new assessments of each child, involving direct communication with the children themselves.

- 3.6.3 The new social worker visited the mother and children for the first time with her manager in early March. Neither had previously met the parents. They explained that the social worker would be undertaking a core assessment⁸. Father was not present, but recalled that he and Mother did not understand what this meant and perceived there was an intent to go down the legal route again.
- 3.6.4 A couple of weeks later a multi-agency meeting was held at the ICDC, attended by other agencies, including GOSH and SGH. The meeting notes indicate that there remained a disparity of views amongst the group. After the meeting the Named Nurse for Safeguarding (Your Healthcare) met with the social worker and team manager and agreed that children's social care would convene a child protection strategy meeting⁹.
- 3.6.5 The meeting was never convened due to a change in circumstances. At the beginning of April Father emailed the community paediatrician, asking her to arrange for a gastrostomy for P, after his return from a holiday at the end of the month. In his email he explained he was going away and that in his absence the situation was sensitive.
- 3.6.6 Also by this point the father had met the team at GOSH to discuss spinal surgery and agreed another appointment for further discussion.
- 3.6.7 The perception within the professional network was more positive with a shift perceived in the increased communication with the father. He has explained to the authors that this change of attitude was his own realisation that P's distress when she suffered with a cold, might be diminished through the use of a gastrostomy during periods of ill health. Also he was seriously evaluating the benefits and potential associated risks of spinal surgery, albeit had not yet made a decision.
- 3.6.8 Mother had by this point been pleased by P's positive response to being at school and had started the boys at school before the Easter holidays, earlier than originally planned.
- 3.6.9 During April, whilst Father was away, professionals continued to visit and found Mother able to engage better. The social worker began her assessment with direct work with P and noted that the children appeared to enjoy their interaction with her.

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⁸ A core assessment is an in-depth assessment that aims to inform the enquiry process and establish whether action is required to safeguard and promote the welfare of the child or children

⁹ Child protection strategy meeting is a meeting to share information, agree the need for criminal investigation; decide whether section 47 inquiries should be instigated; plan and agree what action may be needed to ensure the protection of the child

3.6.10 In contrast to the positive impression held by professionals, police evidence shows that mother experienced some professional interactions as distressing in her husband's absence, especially in relation to mention of Father's decision to accept the gastrostomy. She saw this as the beginning of ever increasing demands for surgery and that from this point onwards the family would never be left in peace. She was also not happy about direct work being undertaken with her children, albeit she allowed it to happen. This was a change from previous working arrangements in Wandsworth and Kingston, where social workers accepted a social work role without direct communication with the children.

Comment

The specialists within GOSH articulated that P needed surgery and that this could not be delayed. The clear communication of this judgment to the new social worker was undertaken by a social worker, who had joined the GOSH team in the autumn of 2013. His understanding of child protection processes and effective communication with the social worker, contributed to the understanding within social care that the bottom line had been reached: unless the parents agreed to the gastrostomy and the spinal surgery, the child protection threshold was likely to have been met.

The change in approach in children's social care may have been justified however the lack of sensitivity about how this was implemented in this case led to insufficient consideration of the feelings of the family (or the staff involved). As a consequence the family were not given the chance to say goodbye to a social worker with whom they had developed a reasonable working relationship and were wary of what this change meant for the family.

*Critically, there was a lack of adequate transfer between workers, so that some of the sensitivities of agreements with the family over communication were not sufficiently well understood leading to the negotiation of changes (such as direct work with the children) being more problematic for the mother than understood by the team manager. **This is further discussed in finding 5.10.***

Planning of the social care assessment was not cognisant of previous working practices and whilst the new ways of working with the family, involving more direct communication with both Mother and her children is good practice, the timing of this coincided with Father being away in April 2014. Given father's role in acting as an intermediary between professionals and his wife in relation to medical intervention and difficult discussions, his absence at this point was significant.

4 THE FACTS OF THE CHILDREN'S HEALTH

4.1 Introduction

- 4.1.1 The children's health is a significant factor within this review. N was the only child within the family who did not have significant health issues and for this reason alone she will not be discussed within this section.
- 4.1.2 P, R and Q all had significant health issues as a result of their diagnoses (see **section 2.3**). In addition R and Q had the added element of prematurity adding to their complex picture. The nature of their condition meant there were differences in their clinical presentations. Children with SMA Type 2 who are at the stronger end of the spectrum can be supported in standing and with some assisted walking. P, in particular was assessed to be at the better end of the spectrum because she had above average limb function and head control and also better than average quadriceps power.
- 4.1.3 Mother and Father's experiences of disability were nil, nor had either of them had significant health care issues meaning their experiences of hospitals was limited. Their first experiences of acute hospital admissions was at the time of the twins' births which father describes as extremely stressful and reports Mother struggled to both deal and cope with it. In that situation they often felt powerless as the doctors took decisions in emergency situations, which they would learn about later; this added to their sense of powerlessness. These past experiences and their impact were not sufficiently understood by the health professionals working with the family.

Good practice point:

All staff when taking initial histories must explore a family's previous experiences of health.

- 4.1.4 All the health professionals involved with the family viewed their role as to both support the family and assist the children to reach their potential. In particular there was an articulated aim to get the children to a point where they could make their own decisions regarding their treatment and care. The specialist hospitals were striving to provide internationally agreed standards of care for SMA.
- 4.1.5 One of the complexities for both professionals and the family during the period under review was the lack of clarity for all about the children's individual health needs and the extent to which there was consistency in the medical opinion available to family and professionals alike. This chapter explores the actual data that was available and the extent to which it was communicated to the family and professional network.

4.2 The children's weight gain

- 4.2.1 P, R and Q all struggled to gain weight to a greater or lesser extent and health professionals both in primary care and secondary care were cognisant of this. Slow weight gain is not uncommon in children with SMA Type 2, who largely fall into two distinct groups; overweight or underweight. The cause of their slow weight gain and monitoring to ensure they were gaining sufficient weight is a routine part of their care. There is an expectation that children will at best maintain and otherwise lose weight during acute periods of illness.
- 4.2.2 Concerns from health professionals largely centred round P who had significant difficulties in maintaining/gaining weight and who, at times of illness, was prone to weight loss. Weight is monitored by plotting it on growth charts.¹⁰ At birth P was on the 75th centile for weight and height but at point of diagnosis P had dropped to the 9th centile for both height and weight. Despite dietetic advice and supplements she failed to grow over the following year and dropped to the 2nd centile.
- 4.2.3 Statements suggest Mother felt criticised by the dietician who was said to be spending significant energies cooking good foods and trying to tempt P. In May 2011 the multi-agency plan was for P to be reviewed regarding her weight every 2-3 weeks in the community but there is no evidence this happened. A further referral to the dietician and the suggestion of supplements initially brought a resistant response from Mother, however following initial refusal Mother did start to give supplements. The downward trajectory in P's weight continued and although health staff voiced concern there is no evidence that the family or the multi-agency team were told what would be a reasonable or acceptable weight gain, although Mother was shown the GOSH weight chart in detailed discussions regarding the role of supplements and gastrostomy.
- 4.2.4 In January 2013 a clear plan for regular weighing and monitoring of all three children's weights commenced; the Kingston Consultant Community Paediatrician (and Lead Professional) articulated the children's expected weight gain of 50-100 gms/week to the family in February 2013. At this Point Q's weight had dropped to under the 0.4 centile; however the Lead Professional indicated they are more concerned about P's weight. It is understandable that there was increased urgency for P to gain weight in order for her to be strong enough for surgery however Q's poor weight gain was mirroring P's and required the same level of attention.
- 4.2.5 Mother, after much resistance, over the previous years, suggested an observation of mealtimes to show she provided good meals and supplements; this was taken up by staff and an assessment completed by the SALT worker.

¹⁰ RCPCH growth chart - These charts indicate a child's size compared with children of the same age and sex. The centile lines show the range of heights and weights for age and the number of children in the population expected to fall below a particular line

- 4.2.6 The children were weighed as per the plan and initially grew largely in line with this. When P's growth faltered the lead professional sought supervision from the Kingston designated doctor who, without being provided with the context of the case, and knowledge that weight gain was a precursor to surgery judged that weight gain overall for that period was satisfactory. The effect of this supervision was that the level of concern by the lead professional decreased, the supervisor's opinion was communicated to the social worker, the plan faltered and the amount of weight the children were gaining reduced.

Good practice points:

- *Lead professionals to articulate to parents an expected weight gain per week whenever there are concerns so as to ensure parents understand what is expected*
- *When professionals request supervision and provide information to their supervisor the whole context of the case needs to be explained.*

4.3 Respiratory function

- 4.3.1 Children with SMA Type 2 often have a degree of problem with their respiratory function due to weakness in the muscles that assist respiratory function, poor cough and swallow reflexes, therefore monitoring of their respiratory function is an important part of their care. Preventative treatment is essential and the children have frequent input from the community physiotherapists.
- 4.3.2 Concerns that P was generally very weak arose within weeks of her diagnosis and a respiratory appointment was pursued. P was reported to be waking at night coughing and struggling to clear secretions and was not eating as much as usual. Early discussions took place regarding the use of BiPAP cough assist¹¹ and suction¹² as helpful possibilities but they were refused. Over the next year P had a couple of colds; antibiotics and saline nebulizers¹³ were suggested. Mother was adamant they did not wish to consider non-invasive respiratory support. Mother also questioned use of antibiotics as they (parents) did not wish to prolong P's life unnecessarily. Mother expressed she was very concerned having seen deterioration in P in the last year and was concerned should her siblings follow the same path. On one occasion Mother indicated to the Physiotherapist she thought P was getting weaker and more floppy.

¹¹ BiPAP, or bi-level positive airway pressure - a type of non-invasive ventilation that helps keep the upper airways of the lungs open by providing a flow of air delivered through a face mask. The air is pressurized by a machine, which delivers it to the face mask through long, plastic hosing.

¹² Suction - removal of material through the use of negative pressure (sucking).

¹³ Nebulizer - a device for dispensing liquid in a fine spray

- 4.3.3 In January 2012 P had her first chest infection requiring hospitalisation and was an inpatient for 3-4 weeks at SGH. P was commenced on CPAP¹⁴ (continuous positive airway pressure) before being switched to BIPAP (non-invasive ventilation). P responded well to treatment but it was believed she would need suction at home; Mother initially refused this but then allowed P's Nanny (Nanny 1) and father to be taught how to do this; a contingency plan was put in place for support from the community nurse if either were not present.
- 4.3.4 In November the same year P was again admitted with chest infection on PICU (SGH) requiring Oxygen, suction and antibiotics. At the same time R was admitted to PICU with a chest infection, given intravenous antibiotics, and paracetamol, oxygen and CPAP.
- 4.3.5 The following May 2013 P had a further prolonged admission to SGH with respiratory illness requiring CPAP, oxygen and nutritional support; she was reviewed at RBH for a few days and then returned to PICU after a brief discharge.
- 4.3.6 Q had no acute hospital admissions. All other admissions to hospital were as part of on-going monitoring of respiratory function and centred around sleep studies where the children's abilities to breath effectively without respiratory support whilst asleep were monitored.
- 4.3.7 During all admissions and most outpatient consultations there were concerns about Mother's behaviours. Staff were concerned both for Mother's mental wellbeing and that Mother was either preventing essential treatments, interfering with equipment and/or assessments, whilst resisting changes in care.
- 4.3.8 Advice was sought within SGH from the legal team and medical ethics committee about whether it was morally defensible to allow a child to pass away from natural causes rather than being dependent on artificial respiratory support for the rest of her life. Because mother and father then allowed emergency care the concerns diminished and the committee concluded no action was required at that time.
- 4.3.9 The parents' response to the concerns raised was to strongly indicate their opinion that external legal advice should be sought through the courts with potential appointment of a QC by the father. When the medical ethics' committee concluded no further action was warranted this paralysed the safeguarding process.

4.4 Swallowing function and feeding.

- 4.4.1 Children with SMA Type 2 often have difficulties in swallowing and feeding due to weakness in the muscles that assist swallowing. At times of illness or as their muscles get weaker this can be more problematic. It is recommended that parents choose textures which give maximum calories for minimum effort.

¹⁴ CPAP or continuous positive airway pressure - a treatment that uses mild air pressure to keep the airways open. CPAP typically is used by people who have breathing problems.

- 4.4.2 P, R and Q all had a degree of difficulty with swallowing and feeding. As early as January 2011 Mother reported that P was having difficulty swallowing food and indicated she would find it useful if there were SMA related diets she could use. The specialist paediatric dietician referred P to the community dietician and requested the GP prescribe a nutritional supplement. P attended the Neurophysiology ward the same month for peripheral investigations and a Multi-Disciplinary Team review. There was no evidence of difficulties in swallowing at that time but it was thought she might have reflux.
- 4.4.3 Throughout the children's lives, there were concerns around the length of time taken for the children to feed and, at times, storage of food in their cheeks. Advice was offered frequently to mother about nutrition and feeding; mother maintained food diaries and the children's weight gain was reviewed, however advice to give supplements that P did not like or had previously been tried was not followed. Mother did not always want to meet health professionals so the team often talked and advised Nanny 1.
- 4.4.4 A year later (January 2012) P was reviewed again by the Respiratory Care team at SHG when her appetite was fairly good; she was observed feeding and swallowing. Mother/parents declined contact with SALT on a number of occasions and thus no SALT assessments were carried out prior to the family's move to Kingston.
- 4.4.5 In March 2014 Mother indicated to the Neuromuscular team that she wished to give P foods she liked, e.g. French bread; there were concerns that some textures would take a good deal of P's effort and Mother was advised they should not be relied on to boost calorie intake.
- 4.4.6 There is a fluctuating picture for the twins; in June 2012 there were concerns and they were referred to the Speech and Language Team for assessment of language, chewing and swallowing, portage and for a Respiratory Paediatric assessment. In July 2013 Q and R's eating, swallowing and speech were much improved; they were finishing meals in 45 mins, demonstrated less food storing and were chatty making good responses. Following a period of illness in March 2014 R was found to have a slow but effective chew and a weak cough whilst Q, also recovering from chest infection, was poorly positioned for eating, did not chew any of the lumps and was storing these and swallowing purees. He began to cough but his cough was too weak to be productive. Mother was advised whilst unwell to only offer single textured pureed food.

4.5 Spine

- 4.5.1 In SMA Type 2 the muscles supporting the spinal column as with other neuromuscular conditions weaken. This means that most children will develop a sideways curvature of their spine (scoliosis). The medical team monitor each child regularly so that any increase in curvature is noticed early. The degree of curvature and a child's age are factors used to decide on management. Initially this may be with a spinal brace or jacket but surgery to correct scoliosis is recommended if the curvature has progressed beyond a certain point, as it may contribute to breathing difficulties, and prevent comfortable sitting.
- 4.5.2 It is not unusual for children with SMA Type 2 to require adaptations and equipment that will help with their everyday activities such as writing, playing, washing, dressing, cooking and eating; these are usually required both at home and at school and will assist each child to lead as fulfilling a life as their friends.
- 4.5.3 Whilst the family and carers knew the children needed to wear support jackets and use specialist seating, the children's perceived discomfort influenced how rigidly they were used in the home. At times this seemed more accepted by some professionals and criticised by others. Mother was not always available to community workers to discuss issues of compliance. Each discipline needed to devise a more formalised plan which would have given clarity to all, and allow for meaningful discussions with both parents and carers if the plan was not being followed or working.
- 4.5.4 P was most affected in terms of her spine and as early as 2011 the Neuromuscular disability team at GOSH indicated P's spinal scoliosis, showed significant deterioration since her last review. Mother indicated she did not want posturally supportive seating at home. There were no significant concerns with regards to R and Q's spines until January 2013 when both boys displayed signs of increasing contractures and developing scoliosis.
- 4.5.5 GOSH and RBH believed the deterioration in the condition of P's scoliosis was exacerbated by the delay in using specialist equipment provided for her posture and mobility in the home. In February 2013 there was discussion at GOSH around surgical management of P's scoliosis. It is noted that Mother was adamant that both she and Father did not want any further medical interventions for P. In February 2014 the Consultant Paediatric Neurologist focused on P's spinal scoliosis progression indicating it was inevitable that surgical intervention would be required during the coming year, in order for her to not develop complications as a result of severe spinal curvature.

- 4.5.6 Mother was clear that no intervention should be performed for P. This caused professionals at GOSH concern and distress; they felt mother was making this decision without acknowledging the advice that P would suffer more if she did not have surgery, eventually becoming unable to sit and in great pain and without father having the opportunity of an informed discussion. Mother agreed Father's opinion could be sought. Later that month Father was seen to discuss these recommendations. Mother was not present. It was explained to Father that a non-interventionist approach would result in more suffering, and optimal care would improve the quality of P's life.
- 4.5.7 Father reiterated his and his wife's view that they would prefer a palliative approach to the care of the children, optimising quality as opposed to longevity. However, Father was interested to explore the advantages and disadvantages of such an operation further and requested and was given research evidence on the benefits of spinal surgery. Before the children died he requested a further appointment to discuss this.
- 4.5.8 By 2013 professionals were clear the physical deterioration that all three children experienced was not in keeping with what would be expected for children with SMA, as management aimed to minimize the physical complications as far as possible. This was thought to be the result of inadequate management at home. The concerns were shared within the wider health professional network and with children's social care however these were either not well heard or responded to until latterly when there was a conversation between GOSH social worker and the allocated social worker.

4.6 What change was there over time?

- 4.6.1 When working with a diagnosis of SMA Type 2 there is an expectation there will be a fluctuating picture as with other neuromuscular conditions. Normal childhood illness such as coughs and colds take very careful management to prevent hospital admissions. There is evidence of periods of good planning and management of the children's conditions however there were times when there were no formal plans and draft plans took an excessive amount of time to be finalised and put in place. An example being respiratory care where a plan took 10 months, from it being initiated, to being finalised disrupted by unsuccessful appointments. There is evidence that plans and monitoring of those plans brought about positive outcomes for the children.

Good practice point:

Professionals to devise and provide plans of care for all conditions where a medical intervention is required which can be monitored both in-house and in TAC meetings

- 4.6.2 There was a deteriorating picture with regards to all the children's posture and scoliosis. Whilst some deterioration might be expected there was suggestion this may have been exacerbated due to care issues (see section 4.5).
- 4.6.3 The parents were aware that acute episodes of ill health had an impact on the children's life expectancy and consequently all illness produced significant anxiety. At times when the children had back to back illnesses the parents believed the change in their clinical presentation demonstrated an increasingly severe form of the condition.

- 4.6.4 Whilst professionals perceived Mother as obstructive and father and mother agree she struggled to accept emergency care and the medical intervention provided at the hospital, she was the person who brought the children to the attention of professionals when acutely unwell.
- 4.6.5 Father and Mother had similar views but responded to professionals in different ways. Mother's first response on hearing about new treatments and interventions was always negative though she moved in her thinking over time. Father would request more information and ask for time to consider the suggestion. Professionals found father's response easier to manage. Mother struggled and discontinued some treatments if the children didn't like them, however there were occasions when she chased up delays in getting equipment such as a wheelchair and spinal jacket.
- 4.6.6 In general Mother was unhappy about having so much equipment at home. Mother refused seating that was offered on the grounds it was "too clinical and unattractive," This impacted on the timescales to get equipment. Mother became upset that the "corporate we" were telling her what management her children should have.
- 4.6.7 Professionals tried to balance the children's health needs and their legal rights to medical treatment with the family situation and wanted the children to be cared for in their family. Health professionals despite considerable effort could not always understand the parents' views.
- 4.6.8 Some professional strategies worked better with the mother. She responded better to being given choices as opposed to being told one way was the best. When she perceived she was being judged or had a less than positive experience with a service she would withdraw and be less accepting if that service was required again. This was particularly notable with the dietician and SALT. We learned from statements that Mother spent considerable time cooking good quality foods for the children in an attempt to get them to eat; the fact that she perceived professionals did not recognise her efforts may have been distressing.
- 4.6.9 In 2014 there was significant change in P's scoliosis and further discussions were had, initially with Mother and then Father about the need for gastrostomy to assist weight gain in order for spinal surgery in the future. In an email at the start of April 2014, father indicates he and mother agreed to gastrostomy and requested the lead professional make arrangements for surgery at SGH, "without involving all the medical teams" as this would need to be "handled very delicately" for P and mother as it had been an "extremely difficult decision for us as a family". This news was taken as evidence by professionals that father was looking seriously at having P's spinal operation.

4.6.10 We now know this was a source of distress to Mother who was less convinced that this was desirable for P. Father indicated the rationale for agreeing the gastrostomy was a period of illness in the weeks before P's death which led to lost appetite and weakness. Father believed the gastrostomy could be made use of during times of illness but did not necessarily view this as a precursor to spinal surgery. From police evidence it appears that Mother became very distressed in April 2014, when, during Father's holiday abroad, she perceived the agreement to the gastrostomy as being just the start of constant medical intervention.

4.7 Mixed messages from health

- 4.7.1 All health staff wanted the children to reach their optimum potential. However, at times, they held differing and sometimes conflicting views on the right way to manage and progress the case. This was evident in terms of physiotherapy with the community staff taking a more flexible approach than GOSH. Roles and personal experience, as is expected played a part in thinking, but at times acted as a barrier. It was essential for this family to have clear and consistent messages. In this case there were natural and unavoidable complexities due to the significant number of highly qualified, well respected personnel required to care for the children's complex health needs. It was imperative that the allocated Lead Professional was of sufficient experience and influence to coordinate plans so all the consultants could work together effectively.
- 4.7.2 There were mixed messages from health professionals with regards to whether they should be pushing for interventions. This was notable when P was in PICU (SGH) with a comment that the Consultants were broadly sympathetic to decreasing intervention – 'let nature take its course'. These consultants whilst hugely experienced in acute care acknowledged there were others involved with more in-depth knowledge of SMA Type 2 and the children's potential long term prognosis. This led to the use of the medical ethics committee to promote discussion, education and consensus.
- 4.7.3 There is evidence professionals were considering the risk of future harm and the impact on the children of not having such regular treatments; however, there wasn't always consensus on this. This was particularly evident in the first half of 2013 (see 3.5.10-3.5.24) when concerns were raised by a number of professionals, shared internally between health professionals and sometimes shared with children's social care (see 5.13 for further discussion).
- 4.7.4 Lack of consensus amongst health professionals served to make social workers ineffective at times. There was a need for both areas of consensus and of disagreements to be explicit and for those to be shared with social workers and parents. Social workers indicated they were looking to their health colleagues for clear evidence of what was expected of the parents as a minimum ('bottom line'). The inability to provide explicit expectations meant that neither health professionals nor social workers were clear about the risk to the children (see 5.14 and 5.15 for discussion).

- 4.7.5 Although advice was sought, there were very few occasions when supervision was sought from Named Safeguarding professionals by involved practitioners, but when it was, the advice was not necessarily followed due to the lack of consensus. An example of this was in July 2013, when as a result of advice given, a child protection referral from SGH was communicated to the social worker, but was then withdrawn as other doctors provided a different perspective.

Good practice points:

A collaborative leadership approach was required where Acute Hospital Consultants were cognisant of the treating physicians' plans and opinions and discussed between professionals to reduce confusion for parents, as well as for colleagues in other agencies.

The named professionals should be used in the context of the disputed views about whether or not the children were at risk of significant harm: where there are such different opinions supervision should be sought and clear documented discussion of the decisions made.

Whilst consensus is desirable, lack of consensus should act as an additional factor to influence professionals to refer their concerns to Children's Social Care not a deterrent.

4.8 Acute health intervention v holistic understanding of children's needs

- 4.8.1 Acute health intervention is swift and timelimited in nature, it creates an abnormal situation for both child and family which has huge impact both on the individual hospitalised and the family juggling responsibilities to the sick child and their other caring responsibilities. Acute health interventon interrupts and differs from long term health care therefore any intervention in acute settings must feed into an over-arching hollistic plan.
- 4.8.2 There was a clear difference in practitioners' experience of Mother depending on the setting she was in. Staff working directly in the home often had a more positive view of Mother and while they spoke of her avoiding them/ or the intervention they were performing, they experienced less of the very tearful, withdrawn and on occasions blocking behaviours seen in the Hospital. In times of stress Mother would make statements about the children which professionals found difficult/unacceptable. Mother did express she felt powerless in the decision making process around the children and felt she wanted the children to die naturally.

4.9 Were all health practitioners and agencies required?

- 4.9.1 In order to deliver optimal care to children with complex multi faceted conditions there will always need to be a number of specialisms involved. There was no one directly involved in the care of the children who did not have a defined role and expertise to offer. Significant energy was put into reducing the number of professionals involved without losing that expertise and this was something the Wandsworth designated doctor in particular tried to achieve after at one point calculating that there were in the region of 60 different practitioners involved with the children. This mode of practice was continued following the family's move to Kingston.
- 4.9.2 Despite efforts by professionals to co-ordinate visits, so as to reduce the overall number of visits, the family still felt that they were inundated with visits and appointments with professionals. The authors have explored whether there was missed potential to reduce the numbers of staff involved, but because of the different specialisms involved, this appears to have been an insurmountable problem.

5 FINDINGS & RECOMMENDATIONS

Introduction

The tragic killing of the three children who are the subjects of this review was unexpected and not predictable by the professionals who had been working with the family.

There is no certainty that any of the findings below would have made any difference to the tragic outcome in this case. At the time of the deaths, from a professional perspective there had been progress made in enabling the children to have the medical intervention they were diagnosed as needing. In fact, had best practice been followed as explained below, it is not known how the mother would have reacted to the open expression of child protection concerns at an earlier stage.

This chapter provides the findings from this serious case review along with any associated recommendations.

Kingston LSCB has written a separate document, describing the actions that are planned to strengthen practice in response to the findings and recommendations of this serious case review.

The findings are split into those relating to:

- Family and professional interactions
- Professional and organisational culture
- Safeguarding practice

FINDINGS RELATING TO THE FAMILY AND PROFESSIONAL INTERACTIONS

5.1 The impact of diagnosis on parents

- 5.1.1 It is a hard task for professionals to give and parents to receive the news about a child's disability¹⁵. It is usual for parents of disabled children to feel grief, depression, or shame on hearing of a child's diagnosis and depending on the severity of the disability and the magnitude of the demand for coping, a few parents may even contemplate death for the child or themselves. These thoughts represent an all-encompassing need to achieve inner peace.
- 5.1.2 Research findings show that the manner in which a diagnosis is explained to parents can have a profound and prolonged effect on the parent's attitudes toward their child and professionals. In this case the parents received the diagnosis for P through a third party so all the essential discussions which are the norm did not happen. They understood SMA Type 2 to be incurable and that there was reduced life expectancy, but learnt little else of the condition.

¹⁵ Bartolo, P.A. (2002), Communicating a diagnosis of developmental disability to parents: multi-professional negotiation frameworks. *Child: Care, Health and Development*, 28: 65–71. doi: 10.1046/j.1365-2214.2002.00243.x

- 5.1.3 When the boys were also diagnosed Father describes that they were 'shell shocked'. Recent research has indicated that parents of children with special needs may even experience feelings and symptoms of traumatic stress, particularly at the time of their child's diagnosis.
- 5.1.4 Father indicated he had wanted a big family, he describes the couple as being at their happiest during the twins' pregnancy. Mother was able to mix with friends and they would come and visit; they had a good life. The contrast in their lives between pre diagnosis and post diagnosis was stark. Their lives changed immeasurably. For parents of children with special needs, feelings of stress are often compounded by a profound sense of grief that results from this loss of initial hopes, dreams and expectations.
- 5.1.5 Mother in particular found the changed circumstances difficult; she was reported to be sleep deprived as the overnight nanny could not comfort the children. It was difficult to have a family life.
- 5.1.6 In general parents want practical, flexible help and may express the desire for a 'breather' from the physical and emotional demands of caring for their child. At the same time, parents often express a wish that relationships between themselves and their disabled child could be more 'ordinary' and they did not always have to perform caring, nursing and other roles (SCIE¹⁶). That is what this couple wanted.
- 5.1.7 This case highlights the importance of early understanding the family's attitudes towards health and disability; this needs to take place within weeks of confirmation of diagnosis by an allocated health practitioner. As this diagnosis occurred out of the UK, it is not clear that this was offered to the family. It may not have been possible to deliver such a service as the parental attitude was less than open to a discussion of their inner feelings with professionals.

Recommendation 1

Merton, Wandsworth and Kingston LSCBs to assure themselves that there are reliable systems in place to ensure that whenever a child is diagnosed with a disability the parents are offered counselling and information support as a routine, and that professionals also explore with them their understanding of and views towards such disability.

¹⁶ SCIE (2008) Having a break: good practice in short breaks for families with children who have complex health needs and disabilities

5.2 The impact of culture, identity, class and previous experience on the family and professionals

- 5.2.1 The impact of the couples' class, background and culture was significant. The father explained to the authors that they were used to a society where people are able to select the services they purchase, including any health provision; hence the experience of being told what they needed to do for their children was a new and unwelcome experience for the parents. They had also never had any experience of involvement of social workers. Without fully comprehending the parents' background, professionals could not always contextualise some of the couple's comments, thoughts and wishes.
- 5.2.2 Also significant was the couple's affluent, middle class status which together with their assertiveness posed challenge to professionals, some of whom would not be used to this level of questioning. This was particularly the case in dealings with the father who as a lawyer and a company director was experienced as powerful. There has been consideration whether the family's social status led to a different safeguarding response. There is no evidence that this occurred, but may have contributed to the cautious approach in moving into child protection processes (see 5.15).
- 5.2.3 Neither parent had experience of disabilities, life shortening conditions nor disability services in the UK. Their only experience of acute hospital care other than the births of their daughters, had been in Portugal. The father explained to the authors that his wife had found the experience of seeing her children in distress so difficult that she returned to the UK to care for their daughters, whilst he remained with the boys in Portugal.
- 5.2.4 The management reviews and staff interviews suggest there was little discussion with the family of their background, with practitioners being uncertain where in South Africa the family originated, or whether they came from an English or Afrikaner heritage. In general it seems that practitioners did not explore the origins of the couple's attitudes to health and disability. However, from what the practitioners report, such personal conversations were difficult territory.

Recommendation 2

Merton, Wandsworth, Kingston, Camden and Tri-borough LSCBs to consider how to improve assessment practice so that practitioners routinely explore parents *individual* cultural background and attitudes to the provision of services

5.3 The impact of the family on professionals

- 5.3.1 The fact of three children with SMA Type2 is rare, albeit not unknown. The fact of three children with complex health needs is likely to contribute towards family stress. In these circumstances professionals are accustomed to being able to offer emotional support and access to services, which are perceived as helpful by the family.

- 5.3.2 What made this family extremely unusual and challenging for professionals to work with was the difficulty some experienced in delivering the support health professionals judged was necessary for the children's health and development. The reason for this was the lack of parental co-operation, and in particular the mother. Her distress and perceived hostility provided an obstacle which practitioners struggled to break through sufficiently, to achieve a good working relationship. Professionals were aware of Mother's low mood and her feelings of despair (which she expressed in front of P). However Mother never spoke openly about her own history, and the view of the staff who contributed to this review was that it was not possible to engage her in discussing her feelings or her history. She was perceived to regard professional contact with at best a sense of resignation and at times possible resentment.
- 5.3.3 What is not clear is whether any practitioner attempted to give the Mother space to speak about her despair, or if her manner effectively inhibited staff. They tended to do all that was possible to encourage Mother's co-operation, including seeking advice from a psychologist at SGH in how best to approach the Mother.
- 5.3.4 Understanding the parents' perspectives was though very difficult, due to the private nature of this family and in particular Mother's complex emotions which inhibited the possibility of exploration of feelings. In fact, by the time the family moved to Wandsworth in 2011, they were clear with the social worker that they did not wish to discuss feelings, just wanted services provided. This stance did not change over time.
- 5.3.5 Because of this difficulty in building a relationship with the parents, professionals tended to compare the 'usual' reactions/attitudes of parents to the reactions of this couple, without sufficient knowledge of why their reactions were so different to other parents of disabled children who the practitioners had encountered. Insufficient account was taken of their cultural background and of the way the parents learned of P's diagnosis, the impact of the preterm birth of the twins and then the devastating news that the twins also had the condition. There was though recognition by some that Mother could have been suffering from post-traumatic stress.
- 5.3.6 Professionals modified their working practices in order to accommodate the family. It has been questioned whether the professionals would have done the same for a less articulate or affluent couple, but there is no evidence that this would not happen for all families.

5.4 Mother's mental health

- 5.4.1 The Judge's sentencing remarks at the conclusion of the criminal proceedings referred to 'clear and convincing' evidence of diminished responsibility and a 'major depressive episode' which 'substantially impaired your ability to form a rational judgement at the time, and is the explanation for your carrying out the killings'.

- 5.4.2 In this context, the inevitable question is if anyone, professional, friend or family member, had or should have noticed the extent of Mother's mental illness before she killed her children? The evidence is that such a depressive episode was not apparent to professionals, friends or family.
- 5.4.3 Throughout the period under review there was professional concern about Mother's presentation, recognising possible depression due to her crying, her flatness, her avoidance of eye contact. She was asked to see her GP repeatedly to discuss counselling and her GP, following professional request, visited her at home to discuss this. Mother declined any offer of help, spoke of being stronger than before and was observed as patient and caring with her children. There was nothing in the mother's behaviour that suggested she would need to be detained in a hospital in the interests of her own health or safety, or with a view to the protection of others (criteria for a compulsory admission).
- 5.4.4 An adult who has capacity can refuse an intervention such as a mental health assessment. This refusal could trigger child protection procedures, as mental health problems including depression are recognised as risk factors for children and linked to safeguarding major incidents¹⁷. However, for this to happen there would need to be evidence that mother's mental health was a risk of significant harm to the children. In this case the child protection risks to the children were predominantly around medical neglect and this was understood as being linked to both parents' views, as opposed to mother's mental health. Whether her outbursts at hospitals around her 'life being not worth living' or the reported comment about not being around to see her children live to adulthood constituted a child protection threshold on the basis of her state of mind is unlikely. However, the issues of neglect in themselves did do so at times as is discussed in finding 5.15.
- 5.4.5 The father's view was that his wife's low mood and distress were only evident when she was with professionals. It is of note that school staff did not notice evidence of mother being mentally ill, and observed her in regular daily contact as a 'kind, loving and involved parent' who was 'always pleased to see her children'.
- 5.4.6 In July 2013, when the local authority were briefly on the brink of legal intervention there had been discussion by the Wandsworth designated doctor with the father of possible family therapy with the SGH psychologist. This was not subsequently pursued and no doubt the family would have resisted this. However, had the children become subject to child protection plans (as they should have done at this point - see finding 5.15), it would have been possible to include therapy within the plan and would have been more likely to have occurred.

¹⁷ Brandon, M., Bailey, S., Belderson, P., Gardner, R., Sidebotham, P., Dodsworth, J., Warren, C. and Black, J. (2009) Understanding Serious Case Reviews and their Impact: A biennial analysis of serious case reviews 2005–07. London: Department for Children

5.5 Family dynamics

- 5.5.1 The couple have a traditional marriage with Father providing and Mother taking care of the children and home. The parents value their privacy and have found it difficult to be forced into having so much contact with professionals imposed on them by virtue of their children's needs. Father indicated this has been particularly difficult for Mother, partly because she has to bear the brunt of this, but also because from the outset in Portugal she experienced difficulty seeing her children in pain or distress; the couple agreed at that point for the father to be the one to deal with the staff at the hospital. Mother returned home to look after her daughters whilst Father remained with their sons at the hospital.
- 5.5.2 Mother appears to have been wary, of much of the necessary therapies for her children, including physiotherapy and speech and language therapy. Partly this was due to her feelings about the number of strangers the children were exposed to, but also to her observations that such therapies involved some element of pain or distress for her children, at least initially.
- 5.5.3 From an early stage the parents jointly requested that discussions about medical interventions should be undertaken with Father directly, and not with the mother. She would deal with the routine health appointments and they would both be present for the regular six weekly 'team around the child' meetings. This request came from the family, and any attempt to speak to the mother about the medical intervention received the clear message that this was for discussion with her husband, as had been agreed. She also complained if Father was copied into communications with her on routine matters, as this was her area of responsibility.
- 5.5.4 This put professionals in a difficult position. They are often appropriately criticised within serious case reviews for ignoring the male carer, but in this instance they were being asked to exclude the main carer for the children from the critical discussions about the children's health care. This was an extremely uncomfortable position for staff, but following the crisis in July 2013 they did go along with the family's choice and this seemed to result in some measure of progress.
- 5.5.5 What is not though known is what impact this strategy may have had on the mother despite her stated wish not to be involved. When she was engaged in such discussions, such as at Great Ormond Street Hospital in February 2014, she showed no indication of having changed her position about the gastrostomy, and it is not known what she knew of her husband's subsequent agreement to this operation. Police evidence suggests that this was very distressing news for her when discussed with her, in her husband's absence.

PROFESSIONAL AND ORGANISATIONAL CULTURE

5.6 Commitment by professionals and the complexity of the case led to working outside professional boundaries

- 5.6.1 The commitment of the professionals involved with this family has been commendable in many respects. In recognition of the family's situation arrangements were made to reduce the burden on the family, even though it was at some inconvenience and additional work for those involved.
- 5.6.2 Without exception practitioners went out of their way to provide services for the family and the family were provided with every available resource, albeit the financial assistance for help within the home was problematic in Merton and in Kingston (for differing reasons). (See Finding 5.10)
- 5.6.3 The level of complexity of this case cannot be over stated. Professional input with this family was enormous. There were nine health organisations, three different local authority children's social care departments, two schools and briefly the charity SMA Support UK. At times there were over sixty professionals involved with the family.
- 5.6.4 This large number of practitioners was difficult for the family to cope with, and also impacted on a manageable team around the child. Attempts were made from the time the family moved to Wandsworth to streamline the numbers involved, so some professionals worked outside their role undertaking work of others, such as the community paediatric nurse who monitored growth instead of the health visitor. Joint visits were made whenever possible to minimise intrusion into the home (e.g. physiotherapy and the community nurse visiting together).
- 5.6.5 The efforts to make professional interaction with the children acceptable for the mother were enormous, and unique in the experience of those involved. People were visiting outside of their work hours, meetings were held early in the morning so that the father could attend before he went to work. Home visits were made by those who usually offer clinic appointments, for example Kingston community paediatricians, the Wandsworth designated doctor and the Kingston speech and language therapist. This therapist, in her attempts to negotiate access to the children, would agree to be available at the office and wait for a telephone call to say it was convenient to visit immediately. This meant she was unable on those days to arrange other appointments.
- 5.6.6 This sheer complexity for professionals meant that more senior managers and advisors were consulted, and on occasion became involved with direct family contact. This had the unintended consequence of resulting in a lack of objective oversight of the progress being made. What was gained though was some progress in the mother's acceptance of professional involvement with the children.

Recommendation 3

Wandsworth and Kingston LSCBs to consider what checks and balances are needed in the system to identify when a complex case is resulting in staff working outside their normal roles and responsibilities, and if then independent objective consultation needs to be available for staff.

5.7 Lead Professional role

- 5.7.1 Whenever there are large numbers of professionals working together there will be difficulties in promoting a united response, and the responsibility for the co-ordination of this largely falls to the 'lead professional'. In this case this role was variously undertaken by the consultant paediatrician at SGH, the named nurse at SGH, the community paediatrician in Kingston, with the GP in Kingston also sharing the role for a short period.
- 5.7.2 There was some confusion within the network about the existence of or identity of the lead professional (also referred to as 'key professional') and also about the functions of the role. Some understood the lead professional to not exist, some thought it was the community paediatrician, some, the social worker and some identified the role as the responsibility of the Wandsworth designated doctor (even after the family moved to Kingston).
- 5.7.3 This confusion about the identity of the lead professional is tied to the different understandings of the meaning of the role. In this case (and perhaps more widely within health) the term is used to refer to the professional in charge of the patients health treatment, usually a medical consultant. However, within the wider multi-agency environment, the term has a specific meaning. The lead professional role¹⁸ as defined in government guidance as 'a set of functions to be carried out as part of the delivery of effective integrated support'. These functions are to:
- 'Act as a single point of contact for the child, young person or family'
 - 'Co-ordinate the delivery of the actions agreed by the practitioners involved in the multi-agency TAC to ensure that children, young people and families receive an effective integrated service which is regularly reviewed: these actions will be based on the outcome of the common assessment and recorded in the CAF delivery plan'
 - 'Reduce overlap and inconsistency in the services received by children, young people and their families '

¹⁸ The Team around the child (TAC) and the lead professional, Children's Workforce Development Council

- 5.7.4 The role of the lead professional is critical in such complex circumstances, but consideration needs to be given how **all** the functions of a lead professional can be undertaken, when, as in this case, the role was generally held by medical practitioners, who are less used to undertaking the variety of functions associated with this role including acting as the single point of contact, responsible for liaison and co-ordination of the TAC, sharing the written agreement with the family and ensuring the plan is monitored and reviewed.

Recommendation 4

Wandsworth and Kingston LSCB to agree with member agencies a consistent process for identifying the lead professional and the responsibility for the various functions of the lead professional.

5.8 Team around the child (TAC)

- 5.8.1 The TAC met regularly and tried to formulate plans and implement them, albeit not always with the use of a written plan. This contributed to lack of clarity at times within the professional network about the content and rationale for the plans.
- 5.8.2 This was more complicated because of the large number of professionals involved, which meant that not all were invited or able to attend the TAC meetings. There was some feeling that decisions were taken by the TAC at times without sufficient understanding of the views of those not present, particularly ancillary health practitioners. This was also linked to the view of some of these practitioners, that decisions were being made by those with highest status and power, as opposed to being evidence based. In addition no Nanny was involved in TAC meetings and these meetings didn't consider whether other assessments might be indicated; of note there was no assessment of N as a young carer nor any carer's assessments.
- 5.8.3 In Wandsworth the term 'team around the child' is used to describe Child in Need meetings and was used in relation to the children in this family. In Kingston no formal Child in Need planning and reviews were undertaken by children's social care; instead the regular meetings followed a looser, less formal health focused forum.

Recommendation 5

Wandsworth and Kingston LSCB to agree with member agencies minimum expectations regarding the conduct of TAC meetings, including when to use written agreements, when to request further assessments, consideration of all family members needs as well as identification of involved professionals and non-professionals to attend meetings, process to enable others to have their views adequately represented both at the TAC and directly to the lead professional.

Critically there needs to be understanding of the circumstances when this form of multi-agency co-ordination should become part of the Child in Need planning, co-ordinated by a social worker, as opposed to a lead health professional.

5.9 Management and supervision

- 5.9.1 This was a complex case and its management within the multi-agency context involved a highly collaborative approach commenced in Wandsworth and continued in Kingston.
- 5.9.2 In Kingston monitoring of services was carried out via a structure of fortnightly multi-disciplinary meetings (MDT), monthly team around the child (TAC) meetings and weekly integrated team around the child meetings (ITAC). This multi-agency arrangement was an extremely positive and co-ordinated response by practitioners and managers.
- 5.9.3 Practitioners all involved their managers and in many cases senior managers in their own agency in the decision making and risk assessment discussions. Moreover some of the team managers, named and designated professionals attended the multi-agency meetings. Hence decisions about the level of risk for the children and agency response were owned by those at senior levels.
- 5.9.4 There is evidence supervision was sought at times in health with some supportive and active involvement by one of the designated professionals who, alongside the social worker, completed the only formal assessment of risk throughout this case.
- 5.9.5 There was a need for greater involvement of named professionals within some organisations. This was problematic due to vacant posts and sickness at times, but led to designated professionals taking on the named professionals' role. The named role is an operational role and allows for some direct work however the designate role is more strategic and helpful in complex cases affording an additional layer of objective scrutiny. The designated role therefore needs to have effective professional (as opposed to managerial) supervision, so that the risks of role confusion can be identified.

Recommendation 6

Merton, Wandsworth and Kingston LSCBs to establish if the Designated professionals receive professional supervision, and if not what arrangements should be in place to ensure that this is available.

5.10 Changing case holding social workers

- 5.10.1 There are times when professionals need to change for a variety of reasons. In this case a management decision was made to remove one social worker and replace with another who at the same time was instructed to take a more authoritative approach in line with a changed culture following the Ofsted inspection of 2012.
- 5.10.2 Change can be difficult for families and the way this is managed can either add to or ease the difficulty. In this case the abrupt departure of a professional the family knew and with whom they had developed a reasonable working relationship was not managed well. The family were unable to say goodbye to the first social worker with whom they had managed to develop the beginnings of a trusting relationship,

- 5.10.3 Moreover, there was a lack of constructive handover between social workers as a result of the way the change was managed. This had implications for the new social worker, who whilst undertaking the tasks associated with good social work practice, had less understanding of the complexities of the family. In particular the reasons behind the unusual agreement to channel all communications about medical intervention to the father, and routine treatment to the mother.
- 5.10.4 Whilst this arrangement seems to be wrong in principle, behind this was an understanding of the need for the father to act as an intermediary. The couple (according to the father) had self awareness that Mother's manner with professionals was such that she tended to immediately reject outright any suggestion of medical intervention. Any change in such well established arrangements would have needed careful negotiation.
- 5.10.5 Similarly the change, however desirable, of working directly with the children, needed sensitive handling and negotiation with both parents, which would have been much easier for the new social worker to achieve if she had full understanding of the background to this.
- 5.10.6 In this case the new social worker, did everything that would normally be expected in her role. However, the lack of management understanding of the need for a careful hand-over and negotiation of any changes, meant that during April, with her husband away, the mother was engaged in conversations about medical intervention, and the children were directly engaged in professional communication. Moreover, the decision to allocate a case of such complexity to a newly qualified social worker is problematic, even if the team manager provided considerable support as occurred in this case.

Recommendation 7

Kingston LSCB to assure itself that the existing transfer protocol within Achieving for Children is developed further to include transfer of cases between social workers within the same team.

5.11 Continuing Care Payments as opposed to Direct Payments

- 5.11.1 In this case great effort was made to try and support the family through funding carers. Exceptional arrangements were agreed in both Wandsworth and Kingston with the aim of recruiting suitable carers for the family's needs, albeit with the carers being trained, managed and supervised by the agency defined by each local authority.
- 5.11.2 Whilst part time nanny 2 switched from employment by the family to employment, training and management by the agency, full time nanny 1 did not do so as this would have led to a drop in her earnings. A further complication would have been that the tasks would be defined by the agency as appropriate as opposed to tasks agreed between family and nanny directly. So the parents would have been unable to request nanny 1 undertake domestic work to free mother to do the direct caring.

- 5.11.3 Whilst the agency made great efforts to be able to employ further carers, none were found that were acceptable to the family. The family also did not put forward any other carers to be employed by the agency, an exceptional arrangement that had been offered. The commissioners did not have a policy of making direct payments and thus only continuing care payments were on offer.
- 5.11.4 At the heart of this issue is the conflict between the responsibility of the local authority (delegated to a specified agency) to ensure that the care provided by public money is spent on adequately trained and supervised staff, and the desire of the family to select and train their own staff to their requirements. The family might want help (e.g. domestic assistance), but that would be outside of the remit of a 'health care assistant' employed to support the health needs of the children in line with 'continuing care' provision. Ironically, the family continued to use their full time directly employed nanny to undertake many of the healthcare tasks, as opposed to the trained agency healthcare assistant.
- 5.11.5 The family never used their full care allowance, in part because they chose not to have night time carers and in part because they wished to retain full control and management of staff employed in their home with their children. This stalemate between family and commissioners meant that the children and family did not receive the amount of support they had been formally assessed as requiring.

Recommendation 8

Merton, Wandsworth and Kingston LSCBs to establish if the system for providing carers to families has sufficient flexibility to ensure that children receive the care they need. Such arrangements need to recognise that for some families:

- the ability to directly employ and manage their own staff will work better, along with provision for the local authority or agency to be involved in a vetting process to ensure they are competent to undertake the tasks required
- such funding should be available for domiciliary help as well as health care tasks, so that parents are able to choose if they are released from some house hold tasks to have more time to provide the health care needs themselves, as opposed to the other way round

Recommendation 9

Wandsworth and Kingston LSCBs to establish what occurs when there are instances that the full package of care is not taken up over a prolonged period; there should be senior management involvement to consider the impact on the safety of the children

Findings relating to safeguarding practice

5.12 Tensions between supporting the family as a whole or safeguarding the children

5.12.1 The crux of the challenge for professionals was how to best ensure the children received the medical intervention and physical aids they needed to improve their quality of life and help them to achieve their potential? Should this be through slow persuasion and explanation, or through the more confrontational stance involved in the child protection route? The latter was relevant due to concerns about both neglect and emotional abuse:

- the children were not receiving sufficient professional input from dieticians, speech and language therapists and physiotherapists: such input was viewed as being essential to maximise the children's development through regular assessment of need and training of carers to be able to meet identified needs
- the children did not always have the optimal aids for their needs: the recommended aids were sometimes not initially accepted because of their appearance (e.g. not in keeping with the decor) or because they were not perceived to enhance the quality of the child's life
- the parents' wishes for their children not to be resuscitated and also to have minimal medical intervention (palliative care)
- Mother appearing flat and emotionally unresponsive at times, and being heard to make inappropriate comments in front of P in relation to doubts of her reaching adulthood, or of not being there herself to see it

5.12.2 Neglect is a form of abuse that practitioners find challenging to address. A recent paper by Brandon et al notes the fact that:

*'...numerous Serious Case Reviews show, professionals, may individually have concerns about a neglected child, but too frequently these concerns do not trigger effective action.'*¹⁹

5.12.3 Professionals struggle with the issue of intention with regard to neglect, especially in a family that is perceived to be 'loving' or 'caring'. Gardner (2008) refers to '*concern about blame where the parent is not intentionally abusive*'.²⁰

- 5.12.4 This was a family undergoing enormous stress and strain, caring for three children with complex needs as well as their non-disabled daughter. Other than the specific concerns cited above the children were observed to live in extremely comfortable surroundings with a high standard of care for their everyday needs. This was sensed to be achieved through a huge amount of effort by both parents, but in particular it was recognised that the mother carried an enormous burden and worked very hard in her care of the children.
- 5.12.5 Despite often considering the possibility of a more open and possibly confrontational approach with the family, this was ultimately never progressed because the main decision makers in the professional network considered that the children's welfare would be best served by slowly making progress with the parents. The fear was articulated by one professional as a risk of putting too much pressure on the parents, which could result in family breakdown.
- 5.12.6 The concerns about mother's mental health (see finding 5.4) was also important here, as her vulnerabilities were identified, but not assessed by a psychiatrist. The belief by some was that gradual encouragement and support (as opposed to increasing the pressure on her) would improve her mental wellbeing. The social workers, the community paediatricians and the designated doctors all believed that this approach was leading to slow and gradual acceptance of advice. There was some evidence that after July 2013 this was indeed the case.
- 5.12.7 Another factor at play with this family may have been their comparative wealth and power, and lack of automatic respect of professional advice, including that given by experts. This attitude is unusual and practitioners were wary. Whilst this feeling was not specifically acknowledged, the authors' detected practitioners were apprehensive that the parents would resort to official complaints and legal processes. This may have meant that they were unduly cautious about how to articulate safeguarding concerns to the parents.

Recommendation 10

Kingston LSCB to consider if there are adequate resources available for practitioners to seek consultation on complex cases such as 'complex multi-agency panels' to offer advice on 'stuck' cases, as well as the consultation with named, designated and specialist staff.

Recommendation 11

Kingston LSCB to establish the extent of use of specialist tools by practitioners to order thinking and keep sharp focus on the need to safeguard the welfare of the children e.g. chronologies, centile charts, risk assessment tools;- the use of multi-agency chronologies is particularly helpful to understand the history

5.13 Quality of life as opposed to longevity?

- 5.13.1 The parents' aims for their children were laudable in terms of wanting them to have a good quality of life, and that this should be as pain free as possible. Linked to this was the view that any painful treatments and interventions should be avoided as decreasing the quality of the children's lives, even if this meant that their children did not live as long. This attitude was behind the mother's reluctance to use any aids that might initially cause some discomfort to the children or agree to any medical interventions that might, in her view, involve pain or distress.
- 5.13.2 The perspectives of the medical practitioners with expertise in SMA also focused on the quality of the children's lives, and the recommended therapies and medical interventions for the children were all aimed to improve the quality of the children's lives, albeit some may have involved some short term discomfort. However, the view was that the children's overall health would decline without such intervention.
- 5.13.3 Whilst the parents believed they had a fundamentally different viewpoint to the professionals concerned, this was not the case. Despite many attempts it was not possible for this misunderstanding to be overcome, although, through discussions with the father some progress had been made with the agreement to a gastrostomy in March 2014 with him giving serious consideration of the benefits and risks of P having spinal surgery. The mother had also made progress in understanding how much her daughter enjoyed her life and in particular attending school. Through this understanding the mother had brought forward the date the boys were to commence at the school. It was hoped that she was beginning to appreciate that her children would be able to lead full and fulfilled lives.

5.14 Role of consensus in decision making as opposed to individual responsibility?

- 5.14.1 In this case, the search for consensus amongst professionals acted as a major obstacle in initiating child protection procedures. The social workers were relying on a consensus of medical opinion, which was never obtained. One of the designated doctors in this case commented that this is not unusual for social workers to rely on medical consensus in the face of such complex health issues.
- 5.14.2 However the error here was around the focus on evidence for legal proceedings (as described in the next section), when there needs to be confidence in the evidence, and a consensus of expert opinion will play its part in such decision making.
- 5.14.3 At this point the issue was whether or not the threshold for child protection procedures was to be initiated, and the practitioners' individual responsibility in relation to this, to communicate concerns about significant harm to social care and if they did not feel heard to escalate the matter.

- 5.14.4 Whilst many discussions were held between health practitioners and social workers about concerns and consideration of whether or not the child protection threshold had been met, the communications were seen as having dealt with the matter. It was left as a social work decision on whether or not this constituted child protection.
- 5.14.5 The named nurse at YHC in Kingston commendably was the one individual who did advocate on several occasions for the use of child protection procedures, in response to concerns from ancillary health staff in the agency and what she heard at multi-agency meetings. Despite her efforts child protection procedures were not initiated.
- 5.14.6 There was no evidence of escalation of concerns by any of the practitioners who felt at points that child protection processes should have been initiated. The reason for the lack of such action is not totally clear, but was partly due to the view that consensus was needed and that the social worker was in best place to make the judgment.

Recommendation 12

Wandsworth and Kingston LSCBs to establish if professionals are able to make specific child protection referrals when they have child protection concerns on open cases, so their view does not get lost as part of the usual information sharing process.

Recommendation 13

Wandsworth and Kingston LSCBs to ensure the culture in their area is that where:

- every professional understands their own individual responsibility to make a referral to children's social care if they suspect that a child is suffering or is likely to suffer significant harm
- all practitioners, whatever their role, feel *able* to make such specific referrals and to escalate their concerns

5.15 Focus on legal intervention instead of the wider child protection process

- 5.15.1 The concerns around the welfare of the three youngest children in this family included the suspicion that they were being neglected and at times emotionally abused.
- 5.15.2 The Children Act 1989 provides the legal basis for action by the local authority in section 47 (s.47): This states the local authority's duty to investigate when they *'have reasonable cause to suspect that a child who lives, or is found, in their area is suffering, or is likely to suffer, significant harm, the authority shall make, or cause to be made, such enquiries as they consider necessary to enable them to decide whether they should take any action to safeguard or promote the child's welfare'*.
- 5.15.3 This responsibility comes into play when there is 'reasonable cause to suspect' and not when there is evidence. Professionals had such suspicions over much of the period under review, and especially as the children got older and were living in Kingston.

- 5.15.4 When there are such suspicions, Working Together to Safeguard Children²¹ and the London Child Protection Procedures²² provide the expected response to be taken, of a multi-agency strategy discussion / meeting to decide whether or not to initiate a s.47 enquiry and then to plan the subsequent investigation.
- 5.15.5 This suspicion met the child protection threshold at times, when the family first moved into Wandsworth and health were struggling with the parents' expressed intention for the children not to be resuscitated in hospital. Again during 2013 Mother's behaviour at two different hospitals gave rise to specific concerns. The refusal to contemplate medical intervention could also have triggered this threshold during 2013.
- 5.15.6 Instead of using the entire child protection process, the use of legal intervention was repeatedly debated and at times mentioned to the parents. This included legal intervention within health in relation to specific medical interventions, as well as legal intervention by children's social care.
- 5.15.7 When the family moved into Wandsworth in 2011 consideration was given to using the child protection process: the designated doctor advised the consultant paediatrician to make a referral to children's social care and request a strategy meeting was held. The advice was followed but the consultant paediatrician wanted to speak to the parents before the strategy meeting was held. Difficulty in seeing the parents followed by a reduction in the level of concern (after the parents accepted emergency medical treatment when P was unwell) and a positive social work assessment led to no further action on a strategy meeting.
- 5.15.8 Within Kingston children's social care the child protection threshold was reached in 2013 but the focus became on legal proceedings with this being mentioned several times:
- directly to the family in February, when a team manager (not in line management of the case) visited the home;
 - in a supervision session with the social worker following Mother's outbursts at RBH in April and again
 - in July 2013 when there were concerns about Mother's behaviour at hospital.
- 5.15.9 On none of these occasions was there any thought of a strategy discussion and a s.47 enquiry, although the named nurse from Your Healthcare did advocate for this in July 2013.
- 5.15.10 Legal intervention should have been the last stage, preceded by the use of strategy discussion, child protection enquiry, child protection conference, child protection plan and ultimately, if no other option legal proceedings.

5.15.11 It is understood that the leap to legal proceedings was at least in part because of a view that the use of multi-agency meetings and professional discussions had replaced the need for the child protection process. In fact, by missing out the child protection process the view of the professional network was not explained openly to the family, there was no clear statement about what was expected of them and most critically no independent conference chair to ensure the focus remained on the children's welfare.

5.15.12 However, the moving into the child protection framework would have achieved more than just the existing multi-agency collaboration. It would have provided:

- s.47 enquiries to 'bottom out' exactly what the evidence was for concern in relation to specific incidents - instead the suspicions were never investigated adequately
- the involvement of an independent conference chair: someone not involved with the family, expert at chairing such meetings and ensuring the focus remains on the children's needs
- assurance that a holistic assessment was undertaken, with direct input from the children concerned (this had not yet happened, although was in process at the time the children died)
- openness and clarity between professionals and parents about the 'bottom line' - although this was provided in different formats at various times, there needed to be consistent clarity within the professional network and to the parents
- support for the parents to obtain any second opinions if required about the need or not for medical intervention
- child protection plans, with explicit contingency arrangements and timescales
- support to the social worker in being able to undertake the assessment, see the children and monitor progress

5.15.13 The lack of moving into child protection procedures, despite all the concerns, gave mixed messages to the parents and other professionals. Whilst the parents were constantly aware of veiled criticism of their views, this was not clarified formally. The father has expressed to the authors that he wanted such clarification and wanted the opportunity to be able to resolve the fundamental differences between the parents' beliefs and the medical standpoint. Although the parents would have been shocked at the prospect, the use of the child protection process would have been the first step in reaching the clarification they wanted and the professionals needed.

Recommendation 14

Kingston LSCB to establish if the practice in this case about wanting to go straight to legal proceedings without going through the child protection process is unusual, or representative of a misunderstanding of the child protection process in the children with disability service.

Glossary of Terms & Abbreviations

BiPAP	Bi-level postural airway pressure
Brearely Risk Assessment	Brearely P (1982) Risk and Social Work assessment.
CAF	Common Assessment Framework
Carer's Assessment	A carer has an entitlement to an assessment if they provide substantial regular care under the Care Act 2014.
CCG	Clinical Commissioning Group
RCCPH growth charts	Royal College of Paediatrics and Child Health Charts: indicate a child's size compared with children of the same age and sex. The centile lines show the range of heights and weights for age.
Child Protection Procedures	London Child Protection Procedures 2015
CIN	Child in Need
Core Assessment	An in depth assessment to inform the enquiry process and establish whether action is required to safeguarding or promote the welfare of a child.
CPAP	Continuous positive airway pressure
CSC	Children's Social Care
Direct Payments	UK Government initiative to gives users money directly to pay for their care.
DNA Testing	Testing
DNR	Do Not Resuscitate
GOSH	Great Ormond Street Hospital
GP	General Practitioner
Hospital Order	Section 37 Hospital Order of the Mental Health Act 1983 given by Crown Court
IDCS	Integrated Disabled children's Service
IMR	Individual Management Review
ITAC	Integrated Team around the Child Meetings
KAFO	Knee Ankle Foot Orthoses
Lead Professional	Single point of contact for the child, family or young person to coordinate delivery of integrated support. Children's Workforce Development Council.
LSCB	Local Safeguarding Children Board
MDT	Multi Disciplinary Team
NHS	National Health Service
Ofsted	Office for Standards in education, Children's Services and Skills
PICU	Paediatric Intensive Care Unit
RBH	Royal Brompton Hospital
SALT	Speech and Language Therapy
SCIE	Social Care Institute of Excellence
SCR	Serious Case Review
Section 47	A child protection investigation under the Children Act 1989.
SGH	St George's Hospital
Significant Harm	Threshold that justifies compulsory intervention in family life in the best interests of children. Children Act 1989.
SMA	Spinal Muscular Atrophy
TAC	Team Around the Child
YHC	Your Healthcare
Young Carer	Someone aged under 18 who helps looks after a relative. They have a right to assessment under the Care Act 2014 and Children and Families Act 2014.

Panel Members

The review panel consisted of the following members:

Nicky Walker-Hall: Independent Chair, Lead Review and Author
Edi Carmi: Independent Chair, Lead Review and Author
Designated Doctor Safeguarding Children Brent CCG (Clinical Commissioning Group)
Designated Nurse Safeguarding Children Kingston CCG
LSCB Legal Adviser
Head of Service, Safeguarding Standards, Wandsworth CSC from June 2015
Head of Family & Community Services, Wandsworth CSC (Children's Social Care) to June 2015
Director of Kingston CSC
Director of Performance and Standards, Kingston CSC
Associate Director, SEND, Kingston CSC
Safeguarding Children Lead NHS England to Dec 2014
Detective Chief Inspector, Local Territorial Police
Specialist Crime Review Group, Metropolitan Police
Deputy Director of Quality & Lead Nurse, Wandsworth CCG
Kingston LSCB Professional Adviser