

The BRI Inquiry into Paediatric Cardiac Surgery in Bristol (1984-1995)

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I have been asked to provide a statement concerning my work as a social worker at the BRI linked to the cardiac unit (ward 5) between the years 1975-1983. I cannot therefore comment on the period covered by the Inquiry (1984-1995) but provide this statement as a source of background information in order to assist the Inquiry.

In the introduction, I set out details of my training and work before, during and since I worked at the BRI. I then provide some background information on particular issues.

Introduction

1. In 1970 I obtained a B.Sc Econ (Hons.) at University College of Wales, Cardiff. In 1971 I qualified as a social worker with a Diploma of Applied Social Studies. In 1971 I became a social worker for Cheshire County Council. This post was district based, where I carried a generic case-load with a special interest in child care. In 1974 I moved to Bristol and became a social worker for Avon County Council at the BRI.
2. I became a senior social worker in 1975. I left the BRI in 1983 to become a principal social worker at Manor Park Hospital, subsequently known as Blackberry Hill, which was a geriatric hospital. I remained in that post (which in 1987 was re-designated 'Team Manager' due to a restructuring of social services) until 13 January 1997 where I became a Team Manager at the Clifton Area Office. I am presently in this post which is a job-share.
3. From 1974-1975 I dealt with referrals from the General Medical Wards, particularly from dermatology and rheumatology in the BRI. In 1975 I was appointed as a 'Senior medical social worker' and I became responsible for a case-load drawn from the General Medical Wards and

from the Regional Cardiac Surgery Unit (i.e. Ward 5). My duties as a senior social worker included the supervision of two basic grade social workers, as well as management of my own caseload. The basic grade social worker drew their work-load from other wards within the hospital. I also occasionally supervised pre-professional social work students who undertook placements at the BRI for 3-4 months at a time. I estimate, on average, that I supervised about 3 such students between 1975 and 1983. I also had the opportunity while in this post of teaching medical students but this only represented a small proportion of my time. I would estimate that 85% of my time was spent on my case-work which was ward based.

4. Whilst in post at the BRI [*both as social worker and as Senior Social Worker*] I reported to my principal social worker. Initially, this was Alison Cheal who was followed by Joan Morrison Lyden, and then Pauline Hurst. I left whilst she was still in post. Unfortunately, I cannot remember the dates when these principal social workers took up post. The principal social workers reported to the HDSSO (Health District Social Services Officer) initially Margaret Eggleton and then Frank Pearce. **[I attach as Annex 1 a diagram which I confirm accurately identifies the social worker structure within the hospital as identified during the period I was in post, 1974-1983.**

Issue B: The BRI and its Paediatric Cardiac Surgery Unit

Issue B10: Complaints procedures available to referring clinicians, and to members of the public, on the standards of treatment and care attained at the BRI

5. I cannot provide any relevant information in relation to this issue.

Issue B12: The culture of the BRI, as expressed in such matters as:

(f) the attitudes towards patients who complained of poor service or care;

6. I cannot recall any complaints being made to me by parents. I cannot provide any information in respect of this issue [save to say that the attitude of the nursing and clinical staff with whom I came into contact appeared sensitive to the needs of their patients and families of patients.]

Issue E: Pre-Operative Management of Cases

Issue E15: Liaison of staff with parents; and the participation of parents in the assessment and care of their child

7. All the nursing staff appeared sensitive to the parents' and families' needs.

Parents were actually encouraged by nursing staff to get involved in their child's care, for

example, bathing, washing and feeding. Mr Wisheart, with whom I had the most contact, made himself available to see parents whenever possible. He was particularly supportive.

Issue G: Post-Operative Care

Issue G12: Liaison of staff with parents; and the participation of parents in the assessment and care of their child

8. I cannot provide any further information apart from that stated above at E15.

Issue H: The Split Site

Issue H : Liaison of staff with parents; and the participation of parents in the assessment and care of their child

H1 The extent to which (if at all) the quality of care offered was adversely affected by the fact that paediatric cardiac surgery and immediate post-operative care were carried out within a cardiac theatre and ICU catering for both adults and children.

H2 Communication and collaboration between the ICU of the BRI and the paediatric ICU of the Children's Hospital; and transfer of children between the two sites.

H3 The response of the clinicians and the management of the BRI to any problems created by the split site.

9. Please refer to my comments under 11, paragraph 9 to 24. I do recall nursing staff having some concerns. I recall the nursing staff mentioning situations when ambulances carrying children urgently from the BCH to the BRI could not get through because of the presence of parked cars. I also recall that there were some discussions and tension between nursing staff at the two hospitals as to when it would be best to transfer children on occasion. However, I do not have any knowledge of these discussions.

Issue I: Treatment of Families, including the Bereaved

Issue 11: The nature, extent and adequacy of the services that were established to inform, support and counsel families with children receiving surgical cardiac care at the BRI, whether before, during and after surgery

The information in the following paragraphs is given as background to information others will provide for the years 1984-1995, and covers only the period up to 1983 when I left the BRI.

10. When I first took up post in 1974 as a social worker within the BRI I had discretion, as did all other social workers, on how I organised and dealt with my caseload. It was largely up to the social worker to take responsibility for their caseload with regular supervision from their line manager.
11. In respect of the cardiac unit I was more pro-active in seeking out social work referrals. Following discussion between myself and the secretary on the cardiac unit, the admissions letter confirmed that alternative accommodation could be arranged on request so that parents could contact the social work department if necessary. I also received the admissions list on a regular basis so that I could identify those patients coming from a distance who might need accommodation and additional support. I retained a list of landladies and I would try and accommodate parents as near to the hospital as I could. This was something that was not necessary on the General Medical wards as their patients were primarily drawn from the Bristol area.
12. Jean Williams was the ward clerk and she would also see parents when they came into the hospital and provide them my name and outline my role so that they could come to me when necessary. She in effect was my safety net for any parents I had not met directly as were nursing staff who would also make referral/pass on concerns as appropriate.
13. When the parents arrived I would meet with them so that I could introduce myself and explain my role. I explained that if they had any worries or concerns, I was available to share those and I would show them where my office was located so that they could find me. My office was on the same floor as the cardiac unit. We had a small suite of offices used by the three social workers, including myself and the two social workers I supervised, together with two secretaries. I would explain that if I was not in my office, the secretaries would know where I was and could take a message/contact me if necessary. I would explain that I would try and help with any problems they might have. For example, if they had financial difficulties. Lastly I would inform them of the other support agencies that were available to them. These were essentially the hospital Chaplains and the Bristol and Southwest Childrens Heart Circle which was founded by Jean Pratten.
14. The Bristol and South West Childrens Heart Circle was an outstanding group which provided considerable support for parents. Often Jean Pratten would have known the parents before admission because of the links with other Heart Circles branches in other areas. Jean Pratten had a daughter who had had cardiac surgery herself. She had felt at that time that there was a lack of support for parents. Therefore when her daughter grew up she founded this group to provide support for families in a less formal role. As Jean had been in the same position as many

of the parents she could appreciate what they were going through and the parents could identify with her. I worked very closely with Jean to provide a comprehensive service. As well as providing emotional support and being there to listen to the parents, the Heart Circle also provided financial support where necessary. It also later provided accommodation in hostels. It refurbished and furnished one or two houses on St Michael's Hill which were owned by the Health Authority but which were made available to the Heart Circle. This enabled parents who lived together in the hostel (a communal living area, but separate family bedrooms) to provide support for each other. The drawback of this was that if someone's child was unwell following surgery all parents felt their distress and anguish.

15. Before these hostels were opened I relied on landladies for accommodation. I sought landladies out, for instance by speaking to local vicars to see if there was anyone in their congregation who could assist.
16. Sometimes parents came to me before surgery to discuss any concerns they had. These could range from discussion of financial difficulties to general concerns about surgery at which time they might make reference to information given in the pre-op talk. Such pre-op talks regarding children were mostly with James Wisheart. I was aware that James Wisheart saw the parents of all children on his operating list and took the time to draw diagrams and seemed generally supportive. I did not sit in on the pre-op talk as I regarded it as a private meeting but if the parents had informed me of particular concerns that were appropriate to convey to the surgeon I would have done so. Particularly on the General Medical wards, I would discuss relevant problems with medical staff and where necessary try and arrange a meeting between carers and medical staff, sitting in on those meetings where appropriate.
17. On the day of surgery I would try and be around and I would ring in to the ward to see how surgery was going. I would try to be there after the child had come out of surgery and if the surgery was not going well I would intercept the families. Medical staff would of course see the families post-op to give them feedback. When those families were already in my office such feedback would be given then. If it did not take place in my office it would take place on the ward and I would take parents there to meet the surgeon. On days when I was not available the nursing staff would greet the parents and be there when the surgeons saw them. Jean Pratten would sometimes arrange to see parents on the day of surgery and would often be there both pre and post-operatively but if not, parents usually had a telephone number which meant that either they or I could contact her.
18. I worked 9 a.m. to 5 p.m. and outside these hours I could be contacted at home as I left my telephone number on the unit. I remember only being called two or three times out of hours whilst I was there. I was normally called if I had a particularly close relationship with the family. Jean Pratten was also contactable at night and attended much more frequently than I did.

19. On discharge, if social services had been involved with the family before admission I would contact the local Social Services office and speak to the social worker in question and provide them with an update of what had happened whilst they were in hospital. It may have been necessary in other situations to liaise with local social services, for example to provide some kind of help at home for the parents but I cannot recall any particular instance in relation to the cardiac unit. Contact with Social Services' colleagues in locality offices was more likely to arise following admissions to the general medical wards, when services would need to be co-ordinated on discharge or action taken following an admission. One such case concerned a lady admitted with a brain haemorrhage who had five children. Four of the children went to family members but in respect of the youngest child we arranged fostering whilst the mother recouped.
20. Families who lived some distance away, would often, on discharge, return home on the same day. Where appropriate if they were not already known to her. I would refer them to Jean Pratten from the Heart Circle who would know someone in the local Heart Circle branch who could provide support for the family.
21. The way in which I dealt with the cardiac unit was different to that on the medical wards as mentioned above. On the medical wards I relied more on staff making referrals and I had weekly ward meetings with members of the multi-disciplinary team to discuss any referrals and provide feedback. In respect of the cardiac ward I was in contact with the senior sisters and in their absence one of the appropriate staff almost every day. If they were concerned about a particular patient they would come to me and vice versa and we would discuss a particular patient when necessary. My involvement was therefore more proactive on ward 5.
22. Within the BRI we had a pairing system in respect of social workers, so that if a social worker was on leave the other social worker would offer urgent cover and vice versa. In addition during my time there I provided temporary social work cover to the BEH for roughly two to three weeks and the BGH for a longer period alongside my own caseload.
23. The departmental structure in place meant that Social Workers based at the BRI dealt with parents or families who were at the BRI while Social Workers at BCH dealt with the families or parents at the BCH. This clearly had potential implications for continuity as, depending on the circumstances some parents might find it difficult to unburden themselves to a different Social Worker at a time of personal crisis. However, on rare occasions I did carry on dealing with a family once the child had been transferred to the BCH. At other times I would liaise with relevant Social Work staff at BCH generally by telephone. Where circumstances warranted it, a meeting would be arranged to introduce the incoming Social Worker. I cannot recall the number of children transferred to BCH after surgery but they were in the minority.
24. Apart from the above, a small part of my role was supporting staff on the unit when morale was

low. Staff primarily supported each other but if a member of staff looked distressed or upset I would try and talk with them.

25. Over the years the Social Work referral system has become more formalized and criteria has changed. I was also conscious that I could not expect some parts of my role to be adopted by Social Workers who followed me. For example, providing my telephone number so that staff could contact me during the night was my own choice, there could be no expectation that other Social Workers would follow suit. Similarly, arranging viewing and taking the parents to register the death might not be seen as Social Work tasks as nursing and portering staff also had a role to play.
26. In summary therefore support on ward 5 was provided by the Chaplains, The Heart Circle, Myself, the Clinicians and Nursing Staff, some of the latter being trained in paediatric care.

Issue 12: The nature, extent and adequacy of the services that were established to inform, support and counsel families with children who died or suffered permanent disability after receiving cardiac care at the BRI, including liaison with community and social services

27. If a child died, and this was the case in respect of adults too, I would become involved in taking the families to view the deceased and I felt this was an important part of the grieving process. I would liaise with the head porter, who at the time was Clifford Winter, who would know when the body was ready to view. In addition, on occasion, I took parents down to the registry office to register the death. It was not always me who explained the process of registering the death. It depended on who was the main support role for the family and this could often be a member of ward staff. Sometimes families would register a death on their own and on occasion the landladies they stayed with did take them down. In particular I remember Thora and Tom Perkins were particularly helpful in this respect.
28. When a patient died I would on occasion, although this was rare, put the parents in touch with an organisation such as CRUSE. However more often than not Jean Patten would know someone in the local Heart Circle branch who would provide support.

Issue 13: The Financing of the support and Counselling services

29. I was not involved in the financing of services or any budget. I do know however that the Heart Circle funded to the first counsellor who was employed after I had left the BRI.

Issue 14: The priority afforded to support and counselling work by hospital management and clinical staff

30. I did not have any significant contact with the hospital management team. The only contact I had was when I needed to take a major sum from the Samaritan fund which would need to be authorised by management. I felt that staff were supportive and generally mentioned my services when appropriate. They would often make referrals although on occasion they were not appropriate. I learnt that some ward sisters were better at identifying appropriate referrals than others and some had more of an understanding of what I was there to do. In those wards where I felt referrals were not made so well I would check the wards more often. I provided feedback to those who made referrals to try and ensure they knew what was appropriate to refer.
31. Although, I cannot recall this happened on the cardiac surgery ward, there were occasions when clinicians wished to discharge patients when I believed delaying discharge was appropriate for a variety of reasons which might include referral to other hospital based clinicians or therapists, availability of domiciliary support services or carers ill-prepared to resume this role. In these situations it was necessary for me to put my arguments forward to ensure that such factors were taken into account and time allowed for the necessary arrangements to be made.

Issue 15: Whether staff coming into contact with parents who were under stress because of the nature and severity of their child's condition, or who had lost children, showed appropriate sensitivity in their dealings with such parents; and, if not, the importance and effect of any such failures

32. Nursing staff and some of the medical staff appeared supportive and sympathetic. They encouraged parents to get involved in the care of their child including washing and dressing. Nursing staff also got involved in supporting the Heart Circle and I can remember occasions when they received cheques raised by Heart Circle supporters, attended their social functions and gave talks on the work of the unit. They gave a lot of their time outside work and were very committed to supporting the patients and parents in any way they could.

Issue J: Post-Mortems and Inquests

J4: Whether consent (if required by law) to:

(a) hospital or coronial autopsies; and/or

(b) the retention of tissue and/or organs of the body

was properly and sensitively sought; and if consent was not required, whether proper and adequate information about this matter was given to parents, in an appropriate fashion

33. Discussions in respect of consent were with medical staff and did not involve me. I can therefore provide no information in respect of this issue.

Issue L: Informed Consent

- a. Were the risk of surgery properly and adequately assessed?
- b. How was informed consent obtained?

L1 How, and when, parents, guardians or (if appropriate) children should be informed of the risks associated with surgery.

L2 The use to be made of:

- a. national data;
- b. international data;
- c. the institutional record;
- d. the surgeon's own personal record;
- e. information upon the condition of the child;
- f. the opinion of the children's team;
- g. the opinion of any specialist nurses and/or family support services;
- h. any ethical advisory committee that may exist;
- i. written information or leaflets;

to the extent that all these are or should be available to the surgeon or others advising on procedures and risks

L3 The nature of the obligation of a surgeon, or other advisor, to refer to factors such as:

- a. the extent of the institution's experience in performing the procedure in question;
- b. the extent of the surgeon's personal experience in performing the procedure in question;
- c. the fact that other institutions within the UK are known to have higher or lower risk records in the procedure in question that those that the surgeon would be obliged to quote as the risk if the procedure were carried out at his own place of work

10.

L4 The professional guidance (if any) available to surgeons, or other advisors, upon the subject of informed consent and quoting for risk.

- L5** How the paediatric cardiac surgeons at the BRI, or other advisors, treated for various factors referred to at (L2) and (L3) above, when giving estimates of risk. The factors that were used, and how, to arrive at any estimates given; and their adequacy.
- L6** What parents and guardians attending the BRI were told, and how were they informed, as to the risks associated with surgery, including the risks of:
- a. mortality;
 - b. morbidity, especially neurological deficit;
 - c. likelihood of future surgery or protracted drug requires being needed;
 - d. other side effects or complications of surgery; and/or alternative treatment methods or the merits of non-intervention.

Issues L5 and L6

34. I did not attend pre-op talks but I do recall parents feeding back information they had been given such as percentage rates of success, and provided with diagrams, and I was aware that they knew even when the percentage rates were good they realised there was a risk of mortality.

SIGNED



Edna Culverhouse

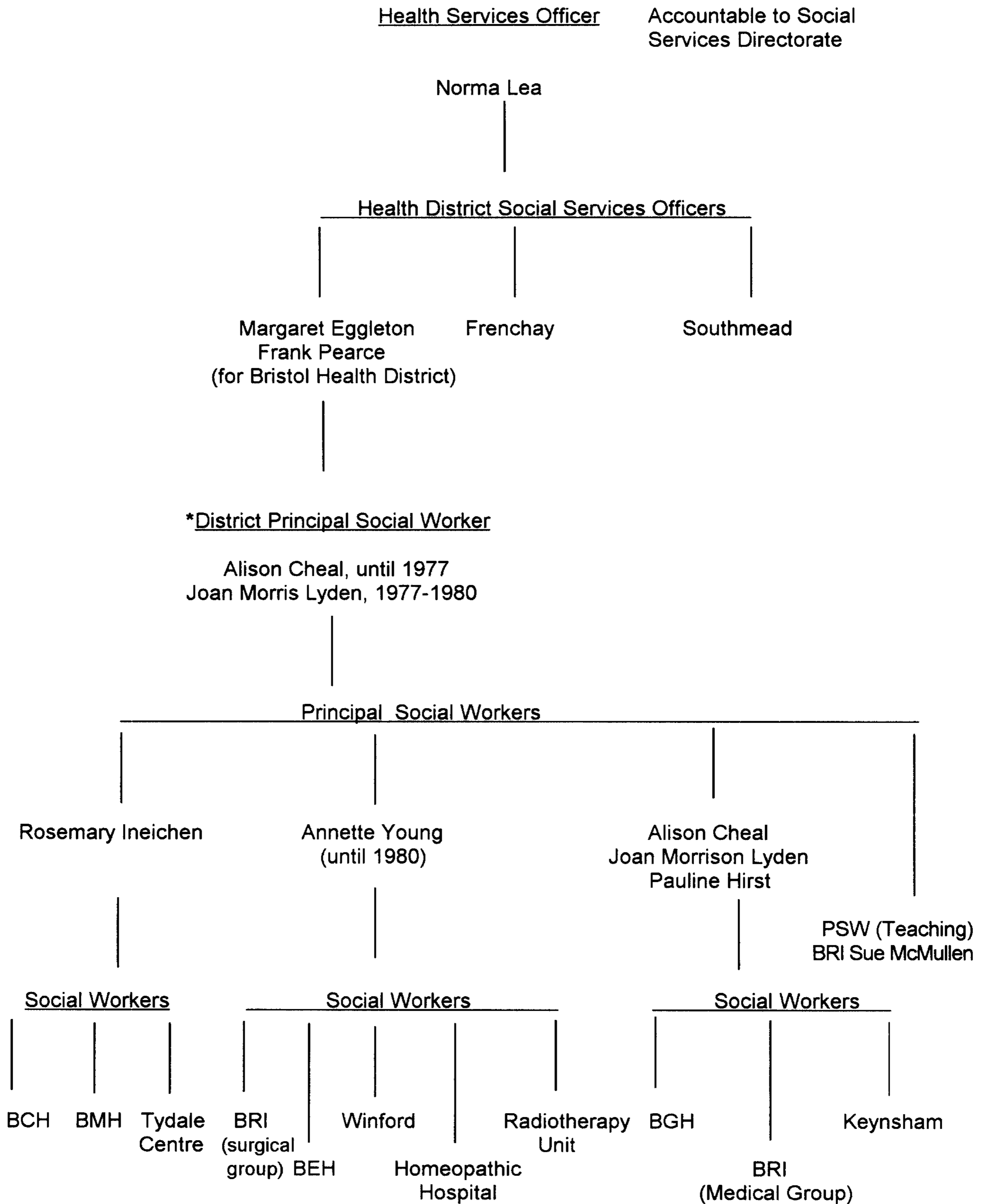
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Social Services Department Structure

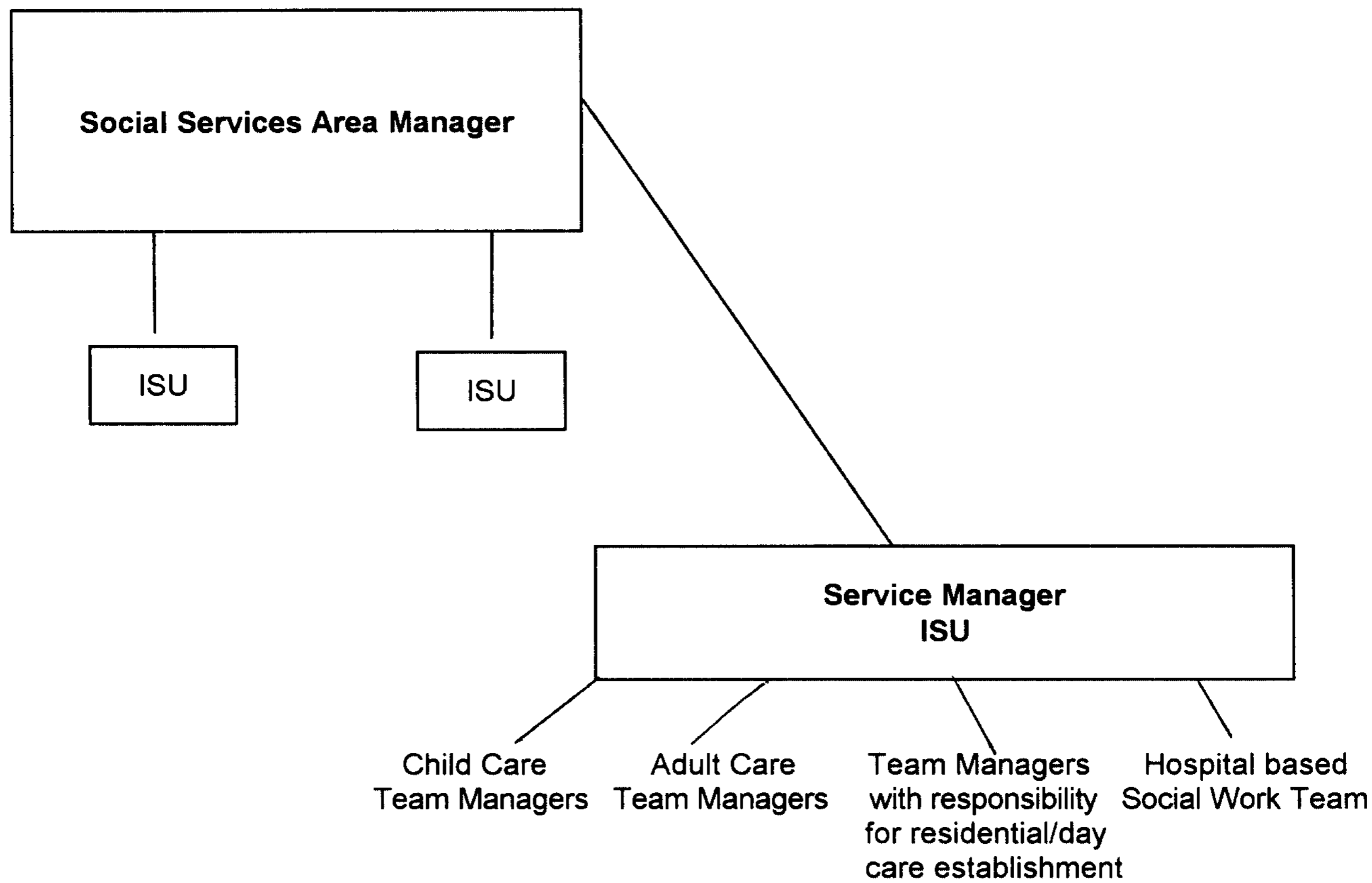
1974 - 1983: Hospital Based Social Work Service



* This post responsible for co-ordination and overall management.
Post deleted approximately 1980

Post 1987

STRUCTURE OF SOCIAL SERVICES MANAGEMENT



ISU = Integrated Service Unit