

REPORT OF HEALTH IN HACKNEY SCRUTINY COMMISSION

Sickle Cell and Thalassaemia Services	Classification Public	Enclosures
	Ward(s) affected All	

1. FOREWORD BY THE CHAIR OF THE HEALTH IN HACKNEY SCRUTINY COMMISSION: COUNCILLOR MURIEL PURKISS

- 1.1 One of the most encouraging features of the meetings of the Commission has been the participation of service users of widely differing ages. They have spoken of their experiences including those causing anxiety and even distress. These latter concerned difficulties with London Buses and the London Ambulance Service.
- 1.2 In both cases these organisations have responded positively and with understanding. (See 7.8 and 7.9 below.)
- 1.3 The Commission has also taken up concerns about the needs of affected asylum seekers and refugees.
- 1.4 In addition, even as services have been examined, changes have taken place
- 1.5 I hope that the members of the Commission and officers who have participated so willingly have appreciated the insights that service users have brought to us and that this will give the recommendations greater authority.

2. INTRODUCTION

- 2.1 The focus of Health Scrutiny is described in the Department of Health's guidance as being 'on health improvement, bringing together the responsibilities of local authorities to promote social, environmental and economic well-being and the power to scrutinise local services provided and commissioned by the NHS'.

The Health Improvement and Modernisation Programme, produced by the City and Hackney Health and Social Care Partnership Board is a key document for the Scrutiny Commission. It was the reference made in the 2002-2005 document to the needs of those with sickle cell and related disorders that prompted the Commission's scrutiny of this topic.

In Hackney, from a population of around 203,000, 23 per cent are of African/Caribbean heritage (Census 2001). It is this section of Hackney's community that is predominantly affected by inherited disorders of haemoglobin,

the oxygen-carrying substance in red blood cells. These disorders cause a proportion of red cells to be mis-shapen, 'sickled', thus shortening their life.

These are the commonest worldwide single-gene disorders. Whilst such disorders vary in form as many as 7 per cent of the world population may be carriers ^{*(1)}. Carriers may pass on an affected gene to a child even though they do not experience health problems themselves. Those who have the disorder, and not just a trait (the way a carrier is described), always pass an affected gene to a child.

Sickle cell is by far the commonest of these haemoglobin disorders in Hackney with some five hundred people thought to be affected. In contrast, fewer than twenty are known to have thalassaemia.

The Health in Hackney Scrutiny Commission met six times between January and June 2004 at Hackney Town Hall with one exception when we were guests of the Learning Trust at the Technology and Learning Centre.

In addition a visit was made to the Sickle Cell and Thalassaemia Centre and the Schoolroom on Ann Riches Ward at the Royal London Hospital. Aspects of the Scrutiny process were separately discussed with staff of the local NHS Trusts and the Learning Trust. We have been grateful for the collaboration that has been extended to us.

2.2 The Terms of reference for the Commission's investigation were:

- To seek to understand the implications of sickle cell and thalassaemia for affected people from birth to adulthood and for those upon whom they depend
- To hear and record the experiences of a variety of users of the sickle cell and thalassaemia services
- To determine the extent to which the support systems promote the care of children and young people
- To review the input of statutory agencies and their inter-relationships as well as those with their clients.
- To determine the extent to which the existing support systems promote the care of affected children
- To make recommendations for structural, funding and organisational changes as is found to be appropriate.

Preparation for this scrutiny exercise showed how complex an investigation of this topic would be. This very fact underlined the importance of collaboration between the many agencies involved, from those who give clinical care to those giving advice on home improvements.

It was pleasing to the Commission that the meetings drew together those who had not before met and indeed about whose service each was not fully informed.

^{*(1)} Sourced from evidence received from Dr Amos, Consultant Haematologist of the Homerton University Hospital, on 9/2/04

Perhaps the most outstanding and encouraging finding was that Hackney leads the way through its Sickle Cell and Thalassaemia Centre at 457 Queensbridge Road E8. The Centre's emphasis is on management in the community.

3. SUMMARY & RECOMMENDATIONS

During the Scrutiny Investigation the Health in Hackney Scrutiny Commission has discovered much about the way services for those with sickle cell disorders are accessed and received as well as about the organisational and structural means enabling this to happen.

The Commission believes it has learned of ways in which these services may be improved but in so doing recognises the limitations of its own expertise. Where scope for improvement or a different way of doing things has been reasonably identified it is for the statutory authorities and their partners to decide if and when these might be addressed. The recommendations include those that are specific as well as some that are more general.

The Commission proposes that its recommendations be put out for consultation with partners, accompanied by a request for a response which will explain whether such proposals are accepted and, if so, identify how they will be financed and which of the various funding partners will be responsible for implementation. It is envisaged that such a response would be received in time for the Commission's scheduled September meeting (13/9/04) and would not only allow Members to be informed how and if their recommendations will be taken forward but also fulfil the Council's requirement for financial probity and prudence.

This Commission recommends;

Recommendation 1

The Commission has learned that in some affected populations there can be fear and shame relating to sickle cell. This can lead to concealment. Children at school may not have appropriate support, resulting in distress and potential harm. Adults may not even wish to disclose their carrier state, quite apart from the disorder itself, so leading to relationship problems. Affected communities need to be helped to a greater understanding of sickle cell disorder so that their well being may be promoted.

Recommendation:

The Commission recommends that suitable literature be developed and widely disseminated under the auspices of the Sickle Cell Centre as considered appropriate by the professionals and partners associated with service delivery. The wider dissemination of such information should include the consideration of newer information sharing mediums including the world wide web.

Recommendation 2

Sickle cell disorders, A Guide for Teachers and Carers of Children, was produced locally several years ago, funded by Hackney Council and the Government's Urban Programme. Its usefulness is widely acknowledged but it is now in very short supply. It also needs some updating. The Commission recognises that detailed costings for the reproduction of this leaflet will need to be completed by health partners and have received assurances that such work will be undertaken.

Recommendation:

The Commission recommends that this booklet is re-issued in readiness for the beginning of the Spring term 2005.

Recommendation 3

There is a national shortage of blood and marrow donors from people of black and ethnic minority heritage.

Recommendation:

The Commission recommends that Hackney Council should demonstrate its commitment to reducing inequalities and improving the health of its black and ethnic minority residents by supporting an annual promotional and blood donor event in the town centre. The Council should be seen to support those employees wishing to donate blood during this event.

Recommendation 4

The Commission has learned that except for children with a developmental problem there is no Community Child Psychology Service. (It is acknowledged that funding was offered for a two-session post at the Sickle Cell Centre but the post could not be filled.) Adolescent young people are in special need of such a service; family support would be the focus for younger clients. This service is widely agreed to be necessary. Special induction would be needed so that the post-holder could be fully integrated with the team based at the Centre.

Recommendation:

The Commission recommends that a full-time Child Psychology post is created to serve all children with chronic conditions. This would enable a service for children with sickle cell and related disorders to be established.

The Commission recognises that detailed costings for this proposal will need to be completed and has received assurances from the relevant health partners that this will be undertaken.

Recommendation 5

The work of the Specialist Haemoglobinopathy Midwife at the Homerton Hospital is of inestimable benefit. The midwife formerly attended one session a week at the Sickle Cell Centre where Hackney has pioneered a community based service. It is important that both adults and children with sickle cell disorder or trait should have

secure links with the Centre.

Recommendation:

The Commission recommends that the Midwife session is restored at the Centre as soon as possible thus facilitating improved communication and co-operation between all health partners.

Recommendation 6

Those with sickle cell are in need of homes that can be kept warm and dry and which are preferably not above the second floor in case of lift breakdown. Stairs can be challenging for an affected person. A number of approaches can be employed in order to provide the most beneficial conditions for residents of both council and non council owned properties. A requirement exists for these differing procedures and qualification requirements to be made widely known.

Recommendation:

The Commission recommends that information about installation of central heating and application for re-housing on medical grounds be more widely disseminated by the relevant Council departments to all partnership organisations and in particular to NHS Hospital Trusts.

Recommendation 7

The effect of sickle cell disorder is unpredictable both in regard to the severity of symptoms and their frequency. It is possible that an affected parent can become ill suddenly. When this happens, whether or not admission to hospital is needed, both the care of the children and their schooling can be disrupted.

The Commission understands that in many circumstances such challenges may be overcome through the development of a variety of care packages (both short and longer term) and that such care packages would need to be both prepared by, and accessible jointly to, all health partners. The Commission has received evidence that the need for further developments in this area is acknowledged by health partners.

Those that are in need of such support are encouraged to make themselves known to the Sickle Cell and Thalassaemia Centre.

Recommendation:

The Commission recommends that through the Sickle Cell Centre care packages are made ready in preparation for any crisis, and agreed by the parent, so that children may be supported in their own home or at a nearby foster carer's home. The key requirement is that such arrangements can be made active quickly.

Recommendation 8

Prompt access to welfare benefits is of importance for people with chronic disorders. Their support, both in the application process and in understanding their entitlements is of great importance.

Recommendation:

The Commission recommends that the appropriate health partners should consider developing and enhancing the welfare adviser post.

Recommendation 9

The Commission recognises that the Borough has a responsibility for the care of Looked After Children and also, in a different way, for its workforce. In both these populations there are those from communities particularly at risk from sickle cell and related disorders and yet at present it is not possible to know how many are affected.

Recommendation

That a database is established in relation to Looked After Children. This will enable the Council to be confident that access to the services they require is timely and that it is maintained. The Commission also recommends that appropriate support, advice and guidance be offered to LBH employees who are affected by these conditions.

4. COMMENTS OF THE FINANCIAL CONTROLLER

- 4.1 The recommendations in this report, if implemented will have a financial impact. In particular, the annual promotional event in Recommendation 3 and the additional staff resources in Recommendations 4, 5, 7 and 8 are likely to have a budgetary impact on the funding body. These costs and the source of funding will need to be established by the funding bodies and reported back to the scrutiny commission and Cabinet before the implementation of these can be agreed.

5. COMMENTS OF THE MONITORING OFFICER

- 5.1 Section 21 of The Local Government Act 2000 as amended by The Health and Social Care Act 2001 and the Regulations, provides that Health Scrutiny Commissions are to review and scrutinise matters relating to the health service in an authority's area and to make reports and recommendations.

The report makes a number of recommendations to the Council and our health partners to improve the sickle cell and thalassaemia services offered to individuals with this condition, who live or work within the Borough. Some of the recommendations detailed in the report will have cost implications for the Council and our partners within the health service.

In relation to recommendation 9, the Council has a legal duty to safeguard and promote the welfare of looked after children under The Children Act 1989 and this would also include their health needs. Under Employment and Health and Safety legislation the Council are under a duty to provide a safe working environment and in particular cases may be under a specific obligation to make reasonable adjustments to an employee's working arrangements and or premises to avoid discrimination against particular employees.

The recommendations within this report should be brought to the attention of the Lead Cabinet Member for Children and Young People and the Lead Cabinet Member for Equalities, Health and Social Care.

6. COMMENTS OF THE HEAD OF PAID SERVICE

6.1 The Chief Executive has nothing to add to this report.

7. FINDINGS

7.1 This Commission received evidence from a variety of sources throughout the course of its investigation. The findings, as documented below, are not intended to match fully every shred of evidence presented to the Commission. Extensive information can be found recorded and documented in the Commission's minutes.

7.2 The statutory services involved in the provision of services to those with sickle cell are the City and Hackney Teaching Primary Care Trust, London Borough of Hackney, The Homerton University Hospital NHS Trust, Bart's and the London NHS Trust and the Learning Trust. The London Ambulance Service NHS Trust is also involved from time to time.

7.3 The conditions and their local context

The Commission learned that disorders of haemoglobin, which include sickle cell, thalassaemia and other much rarer conditions, are the commonest gene disorders worldwide. Sickle cell is most commonly found in tropical Africa, Arabia and the Indian sub-continent. Thalassaemia is most commonly found around the Mediterranean, the Middle East and the Far East. This illness is found less frequently in Hackney owing to the current ethnic make-up of the Borough.

In Hackney it is estimated that about 500 people have sickle cell disorder. Fewer than 20 have other disorders of haemoglobin.

46% of the employees of the London Borough of Hackney are from black and visible ethnic minority communities. It is planned to raise this proportion to 50%. (LBH Performance Plan 2004 /05). Some of the workforce must be affected by sickle cell or related disorders but at present there is no means of knowing how many there are. It is anticipated that the new Occupational Health Service will be able to develop a better understanding of the health profile of the workforce.

The Commission was informed that Newham and Hackney have the highest sickle cell birth rates in the country. In 2003 fourteen affected babies were born with sickle cell in the Hackney area (approximately 3.4 per 1000 births). Only two babies have been found to have thalassaemia major since 1988.

It is anticipated that the number of those affected by thalassaemia in Hackney may increase over time because of demographic changes.

7.4 *Clinical issues and medical complaints*

Neo-natal testing has only recently been implemented nationally but has been in place in East London and the City for over twenty years.

The most common reason causing a person affected by sickle cell to contact a physician relates to pain management. The severity and frequency of problems experienced usually increase with age. From about the age of thirty patients may, for example, develop problems resulting from damage to joints and the kidneys. These complications have become more common recently as patients survive longer because of better treatment in childhood and early adulthood than was once possible.

The development of new treatments for sickle cell and thalassaemia is being pursued that in the long run is hoped to bring a reduction in the amount of pain experienced and thus treatment required. There has been a noticeable improvement in the general health of people affected by sickle cell and thalassaemia.

Those with sickle cell disorder often suffer from chronic anaemia which is not normally so severe that regular blood transfusions are needed. They may also experience pains in their bones or joints, though sickle cell 'crises' can affect any part of the body. Those with beta thalassaemia require regular blood transfusions (at least every 3-4 weeks) in order to remain well. A side effect of regular blood transfusions is a build up of iron in the body that may need treatment.

Alternative treatment options exist. Bone marrow transplant, similar in technique to that used in the treatment of some leukaemias, can be carried out in those with thalassaemia major and sickle cell conditions as long as the patient has a suitable bone marrow donor. If successful this procedure will cure both conditions. The unpredictability of sickle cell makes it difficult to determine whether there is an ethical basis for marrow transplant, a process which in itself is potentially life-threatening. Thalassaemia has an appreciable mortality so a bone marrow transplant may be the best treatment option. This would normally take place at the Hammersmith Hospital.

7.5 Regional Organisation

The services offered to those with sickle cell and thalassaemia in the Hackney area are delivered in a fragmented fashion.

Hackney children are treated at the Royal London Hospital. Most affected people who are over sixteen are seen at the Homerton Hospital.

Issues identified throughout the course of the Commission's investigation as potential weaknesses within the current care structure offered to those with sickle cell and thalassaemia were as follows;

1. Fragmented nature of the services

- Geographically fragmented.
- Three NHS trusts are involved: Homerton University Hospital, Bart's and the London and City & Hackney Teaching Primary Care Trust. Efforts are made to overcome problems which arise through the Sickle Cell and Thalassaemia Centre, its advisory group and the East London Haemoglobinopathy Network.

One of the most difficult areas for staff at the Royal London Hospital was associated with the multi-sited, cross-borough nature of patient management. A paediatric patient is medically managed in Tower Hamlets whereas the Housing and Social Services needs are managed in Hackney. A challenging issue is poor access to information and knowledge of local contacts. Hospitals treat a population of patients; local authorities serve people living in a geographical area. Such issues may be resolved through improved commitment by LBH and CHPTCT to the sourcing and commissioning of services.

- It was reported that in the USA services are offered through universal Comprehensive Care Centres, where help is given with clinical matters but also with benefit entitlements etc. A service of this type is offered in the UK to people with haemophilia.

2. Service standard variables

- There are concerns about the emotional well-being of affected people and their relations. Hackney does not currently offer them a dedicated psychological service. Attempts to provide a tri-borough service, with shared funding, had been made in the past. The Sickle Cell Centre provides some forms of psychological support and help but the establishment of a dedicated, easily accessible service would be of great benefit.
- Local clinicians believed that over fifty per cent of sufferers were first generation immigrants. The Commission was concerned to learn that the medical conditions experienced by refugees or those seeking

asylum are not always taken into account when their dispersal is being arranged. In London, services for those with sickle cell and related disorders are readily available. Outside London they are more widely dispersed, reflecting the needs of the population. It is of great importance that those who need this service are placed as near as possible to the places where it is available. The unpredictability of the clinical course of some of these disorders can mean that life-threatening emergencies may arise that need accurate diagnosis and urgent skilled care. It is essential that affected people should be placed within reasonable distance of those who are best placed to help them. The Commission is in correspondence with the appropriate authorities.

The Commission also heard about a number of voluntary sickle cell and thalassaemia support groups. The National Sickle Cell Society was notable for its help with, for example, childcare and other support.

7.6 *Local Hospitals - Homerton University Hospital*

Children from Hackney are usually treated at the Royal London Hospital. Emergency assessment and care would be received at the Homerton as required. Adults would usually attend Homerton University Hospital.

Homerton University Hospital offers a comprehensive laboratory service (DNA work is outsourced), delivered through a compact team. Its work is supplemented by that of other specialists as needed. Diagnostic testing is offered to newborns, before pregnancy or surgery and can be requested at any other stage. Through this team the Homerton provides a number of services, which include:

- Adult Services – A full out-patient service, which reviews every patient at least once every three months.
- A day care centre which is open Monday to Friday 9-5pm.
- In-patient facilities, with the support of specialist nurses.
- Specialist Consultant Services
- Neo-natal – co-operation between the obstetrics team and the specialist haematology team.
- If, through foetal testing, diagnosis takes place before birth, parents are offered a reproductive choice and accompanying counselling.
- When a newborn child is identified as suffering from sickle cell three early treatments are offered. These are penicillin and vaccination against infection by haemophilus influenzae and streptococcus pneumoniae. Mothers are also taught to monitor the size of their child's spleen because an enlarged spleen increases the chances that a child will need medical attention in the near future.

Within 3-4 years all children in the UK will be screened using the Guthrie Card technique. The North Thames area was the first region in the whole country to adopt this system of testing. Processing of all such tests has been centralised at Great Ormond Street Hospital and Central Middlesex Hospital.

7.7 *Local hospitals – The Royal London Hospital*

The haematology service at the Royal London Hospital offers an out-patient clinic and an in-patient service dedicated to sickle cell. The Sickle Cell and Thalassaemia Centre based in Hackney is regarded as an essential part of the joint working required to treat children in the area.

The team operating from the Royal London had one hospital based Nurse Specialist who has a heavy work load. A Clinical Psychologist is also part of the Royal London haematology team. This post was not specifically part of the sickle cell service; nevertheless it is of great importance.

In the three-year period to 2003 around 2,800 patients with sickle cell disorder have attended Bart's and the London NHS Trust. These patients came from the whole of East London and include Hackney children. Their experience would have mirrored that of all the child patients with the primary diagnosis of sickle cell disorder whose average length of stay was five days.

The Haematology department at the Royal London Hospital has a dedicated ward, which although not solely for the use of children with sickle cell and thalassaemia is staffed by skilled and experienced nurses. The out-patient centre helps to monitor a patient's health and educational needs as well as assisting in picking up other health concerns early and making appropriate referrals. At any one time the Buxton Ward (out-patient ward) might have twenty patients attending in order to receive blood transfusions etc, although the children treated on this ward will have a variety of conditions.

The condition most commonly dealt with in the acute ward is pain. It is imperative for physicians to minimise the excessive use of drugs such as morphine whilst seeking to reduce pain as rapidly as possible. New modes of treatment have in recent years reduced the number of admissions for pain control.

Parents often face a period of significant shock after their child had been diagnosed with sickle cell or thalassaemia. Normally a new parent would be invited to visit the Sickle Cell and Thalassaemia Centre in order to meet the Clinical Nurse Specialist.

The Community Nurse based at the Sickle Cell and Thalassaemia Centre regularly attends the outpatient clinic at the Royal London Hospital and the Haematology team meetings. Through this regular contact it is possible for the LBH Community Nurse to follow up the needs of Hackney families and to help with issues around the needs of teenagers who must at some point leave behind the paediatric services to which they will have become attached.

The style of care and the environment in which it is provided is particularly critical at the time of adolescence. This is especially true for boys with sickle cell who are more likely to suffer from pain associated with their illness, coupled with a desire to be independent. Such behavioural issues had in the past resulted in frequent hospital treatment for pain leading to drug dependency.

Educational performance was an important issue in relation to the treatment of those with sickle cell and thalassaemia. These conditions could have an effect on a child's concentration, memory and attention span, all of which mean that a child might not achieve its potential. Common parental complaints in relation to school included a lack of understanding of the child's need, for example, to keep warm indoors and out and to have ready access to drinking water.

7.8 *Ambulances*

The Commission was informed that it is usual paramedic policy for a patient to be taken to the nearest hospital for treatment, although in the case of those with sickle cell this was not always the best for the patient as only their usual hospital would have access to their medical records. At times the requirement for an ambulance was not related to a patient's sickle cell status.

Part of the problem for patients being treated at a variety of hospitals or locations, was not so much a lack of information on the patient but the differing forms of treatment employed and the unsettling effects this had or might have on a patient.

The Commission has been in touch with the London Ambulance Service through its Development Manager. Central Ambulance Control must give permission if a patient is not being taken to the nearest Accident and Emergency Department. However, an assurance has been given that within the East London Boroughs sickle cell patients will be taken to the hospital where they usually receive treatment if their emergency is sickle cell related. It would be helpful if patients would carry their haemoglobinopathy card with them always. The Commission's concerns have been passed on to local LAS managers.

7.9 *Access to Transport*

People with sickle cell would not normally qualify for a Freedom Travel Pass.

Those who were issued with a Pass had to meet stringent criteria concerning permanent mobility problems or had reached the age of sixty.

For pupils without a Statement of Educational Need support with home to school travel is provided according to specified distances between home and school by the shortest walking route that varies according to age. When appropriate medical evidence is provided the qualifying distance may be waived. Most children with sickle cell will not have Statements of Educational Need but it would be worth while applying to the Learning Trust for assistance if the distance travelled is proving a challenge to their physical capability. The Learning Trust has a published policy on this and each child is assessed individually.

The Commission learned that in separate incidents a bus driver had refused to accept that the passes carried by boys were being used honestly. The police had been called.

The Commission was in contact with Transport for London and a profound apology offered. Bus drivers must all undertake the BTEC Intermediate Award in Delivering

a Bus Service in London. The Commission's letter will be used in training to illustrate the fact that disabilities are not always visible.

7.10 *Housing.*

The Commission received information on the Council's re-housing policy and system of medical prioritisation.

Legislation dating back to the Public Health Act 1936 requires the Council to provide housing that was non-prejudicial to an individual's health. People who are not Council tenants are not the responsibility of the local authority. Living conditions have improved within recent years and the improvement is likely to continue with the adoption by 2010 of the Government's 'decent homes standard'.

The medical priority applied by the Council is now referred to as zero, A or B. Tenants are awarded medical priority A if they suffer from serious health problems on which their current housing is thought to have a negative effect. Recommendations made on discharge from hospital would be taken into account. Medical priority does not apply to homeless families because the Council already has a duty to provide them with suitable accommodation.

After receiving a medical referral the Advice and Access Unit would conduct an assessment of the client's needs, the impact of their current home environment on their life and assess the scope for improving or adapting their home.

Even when achieving priority re-housing grade A, a client could not expect to be swiftly re-housed. Most require ground floor properties.

In some circumstances, individuals with sickle cell and thalassaemia requiring re-housing may be able to apply for grants for providing central heating to their homes. Such an improvement might mean that re-housing would not be needed. Applicants would normally be referred to the occupational therapy team of the local authority. Better means of communicating the services and options available would result in improved take up and access to information and resources.

The clinicians' view is that at least half of their patients are suffering adverse effects as a result of poor housing. It was noted that cold, damp and poorly ventilated properties make things worse for them and lead to an increase in frequency of 'crises' which may cause admission to hospital. These patients may be in poor financial circumstances, in particular if they are refugees or asylum seekers.

7.11 *National Blood Service*

The National Blood Service (NBS) is currently undertaking a number of initiatives with the aim being to increase levels of donation, briefly described as 'Working Together to Save Lives'.

Two forms of promotional activity were undertaken by the NBS. Session specific – where blood donating occurs and is promoted through banners and posters and also

events which revolve around recruitment campaigns, TV advertising and general promotional activities at different locations.

It was stated that the NBS was about to embark upon an Ethnic Recruitment Campaign, because donation rates were proportionately much lower amongst the majority of ethnic groups.

The currently planned campaign was thought likely to focus on promotional activity undertaken by sports and music stars, thus making the event resonate with the youth culture of various ethnic groups. The NBS always seeks to work in partnership with interested organisations.

Most people between the ages of 16 and 60 years can donate blood (with other exceptions existing). They must weigh 110 lbs and be in good health. The age limit for bone marrow donation is 45. Only six per cent of the UK population donates blood. Hospitals use 10,000 units of blood every day and would be unable to carry out routine procedures without a sufficient supply. Transfused blood needs to match that of the recipient as closely as possible, hence the importance of having donors from all backgrounds.

Those with sickle trait could donate blood whereas those with sickle cell disorder could not. It was also noted that a national 'Sickle Cell Week' takes place each July. On the invitation of the Commission the NBS is to have a promotional event at the Town Hall on July 4 and July 6 with the aim of recruiting donors. There is to be a further publicity and donor event in October in central Hackney for which the Commission has been pleased to obtain the support of the Speaker and the Mayor.

The support of such an occasion is one way of contributing to the Council's aim to reduce health inequalities as expressed in its Community Strategy.

7.12 *Sickle Cell and Thalassaemia Centre*

The service provided by the Sickle Cell and Thalassaemia Centre had been operating from its current premises for three years. It is funded jointly by the CHTPCT and the LBH. The joint management arrangement evolved following extensive consultation with service users.

The Centre has the following staff:

- Two Specialist Nurse Counsellors
- A Welfare Rights Advisor
- Care and Assessment Manager
- Community Development Officer (LBH Seconded)
- Service Director (with Nurse Experience)
- Administrative Post

The services offered by the Centre include;

- *Genetic Advice and Counselling* – in particular after detection of sickle cell trait or disorder.
- *Education & Training* – Focused upon schools and communities.
- *Assessment and Care Package* – Providing a social care focus, allowing for both GP and self-referrals. The Centre liaises with neighbouring borough's services in order to promote and maintain common standards
- *Blood Testing / Screening Advice* – An off-the-street walk in service is offered. The Centre would offer a pre-conception screening programme, which it is hoped would be widely acceptable to trait carriers.
- *Advice relating to welfare benefits* – This post was noted as being part-time but with a heavy workload, reflecting the socio-economic make up of Hackney.
- *Client and Family Support* – After medical diagnosis, helping those affected understand the condition, reducing the feeling of being stigmatised and avoiding denial.
- *Community Development Officer* – Providing those in the community with access to information relating to service provision.

In order to educate the population the Centre is active in National Sickle Week, each July, when it seeks to promote awareness amongst the public, employers and relatives of affected people. About 500 people in Hackney are currently estimated to have sickle cell and thalassaemia. All are in need of holistic care. Not all those attending the Centre are resident in Hackney. The Centre acts as a forum to canvass opinion for service changes or improvements, by using its advisory group a quarter of whose membership are service users.

The Centre is in touch with about 240 children and young people and about 150 older teenagers and adults.

The Sickle Cell and Thalassaemia Centre has scored numerous achievements since its re-launch, which include receiving a modernisation award from North East London Strategic Health Authority and coming runner up at national level.

The Centre has produced appropriate literature for its wide audience in French, Spanish, Portuguese and Swahili. It has produced a leaflet about nutrition.

It is notable that the Centre has been approached by Tower Hamlets PCT to recruit and manage staff for a similar Sickle Cell and Thalassaemia Service in their area in order that the Bangladeshi population, in particular, may have an improved service.

The Centre's relationship with the CHTPCT is developing by establishing service links with their staff such as health visitors. Closer and more effective links with all the service providers are constantly being explored.

The Centre undertakes a great deal of work in the community and usually targets specific areas within a three-month period raising awareness in schools as deemed appropriate. The Centre provides sessions in school assemblies, at teacher training events or with specific classes. Such work could be hindered by a

parent's unwillingness to disclose the status of their child to a school, relatives, friends or sometimes even the child itself.

Although some parents choose not to disclose their child's medical status because of cultural sensitivities and a fear of social stigma, it was noted that the development of Children's Service Directors would lead to increased sharing of individuals' details where it could be presumed to be for their benefit. In future the requirement of statutory bodies to help a child is likely to be paramount so that issues of confidentiality do not obstruct action being taken that is in the child's best interests.

7.13 *Schooling*

There are two codes of practice; one relating to special educational needs (SEN) the other being the Disability Discrimination Act (DDA). Both of these codes relate to making schools accessible to pupils so that there may be the provision of a full education for those with disabilities and medical needs.

All schools within Hackney had now been briefed on the issues associated with inclusion as noted above.

The Department for Education and Skills publication entitled 'Access to Education', details the Government's desire to provide continuity of education even when the child cannot attend their usual school. The guidelines outlined within this document set out how children with medical needs could expect to have their needs met in a comprehensive fashion. Each school is now asked to have a named individual who is responsible for the well-being of children at that school. Schools also have an obligation to provide work to children who are out of school for a period of time due to illness.

The Learning Trust was in the process of publishing a revised Health and Safety Policy. Section 11 of this policy provides help and advice for issues related to the medical needs of children. It was also noted that the LSS team was in the process of developing its own guidance relating to children with medical needs, condition by condition, in co-operation with school nurses and their local health partners. The guidance about those with sickle cell will be brought forward. This will note, for example, that in order for children with sickle cell disorders to feel confident in the classroom the successful management of their condition depends upon easy access to drinking water and permission to take regular toilet breaks.

It was observed that a critical pillar of the LSS team's work was the collaborative approach adopted by the Manager for Inclusion who, for example, will work with community nurses, occupational therapy teams, speech and language therapists, ensuring that confidence exists between them in order to serve the needs of the child.

The LSS team provides training in a variety of forms; for example, a course is usually run at the end of each term to enhance the skills of the employees of the Learning Trust. Training provided at such sessions includes reviewing the requirements of those with special needs, medical needs and disabilities.

Hospitals have an obligation to inform schools that a child has been an in-patient so that provision can be made for the child to have or continue with schoolwork. Similar guidelines exist for those individuals older than sixteen who are in further education. Most problems emerge around the fact that the system responds to a child's need when three weeks of absence is predicted or experienced, whereas in the case of sickle cell disorder a pupil may only be absent from school for a day or two – triggered perhaps by a change in the weather. Such incidences of absence on a semi-regular basis can prove to be just as disruptive to a child's education over the longer term. This puts an additional responsibility on both parents and the school as falling behind in achievement may not be correctly attributed to the child's absences.

CONCLUSION

- 8.1 This has been the second investigation conducted by the Health in Hackney Scrutiny Commission. The review has aimed not only to identify and understand the service delivered but also the effects the present service has on those affected, their family or carer. The Commission's perception of the difficulties currently being faced has been increased and the recommendations have been made bearing these in mind.
- 8.2 The recommendations mirror the needs perceived by the Commission and to that extent may be incomplete. The Commission recognises that the capacity of the Local Authority alone to tackle some of these needs is limited. The Commission acknowledges the partnership that is constantly required between the relevant authorities and intends to hold ongoing dialogue with those on whom the report's recommendations have an impact.
- 8.3 The Commission's Chair and the Scrutiny Officer will therefore, over the coming months, liaise with the bodies identified above and other organisations in order to establish how this report's recommendations can best be implemented.
- 8.4 The Commission appreciates that the Sickle Cell and Thalassaemia service is always evolving. This report is a contribution to that evolution. The recommendations included herein are therefore intended to build upon the significant successes already achieved.

Lead Councillor: Cllr Muriel Purkiss

Scrutiny Officer: Ben Vinter, ☎ 020-8356 3441

Agreed by the Health in Hackney Scrutiny Commission July 5 2004

9 CONTRIBUTORS

The following attended the Commission meetings and gave evidence. Informal contributions were made by others present including members of the sickle cell support group and other service users.

Those who provided information separately from the meetings are also listed.

All the contributions were of value and the Commission is grateful to all participants. Any omissions or errors are the responsibility of the Commission.

- Dr Roger Amos, Consultant Haematologist, Homerton University Hospital NHS Trust - 9 February & 10 March
- Evodian Fonyonga, Haematology Clinical Nurse Specialist - 9 February
- Cynthia Dickson, Community Development Officer, Hackney Sickle Cell and Thalassaemia Centre - 9 February
- Dr K Cinkotai, Consultant Haematologist, The Royal London Hospital - 10 March
- Dr Paul Telfer, Consultant Haematologist, The Royal London Hospital - 10 March
- Amit Vaja, Marketing Co-ordinator, National Blood Service - 10 March
- Andrew Wilkes, Head of Access and Advice, LBH (Housing) - 10 March
- Nita Patel, Special Needs Housing Manager, LBH - 10 March
- Ursula Beckford, School Nurse Team Manager, CH(T) PCT - 14 April
- Steve Rowlands, Director of Specialist Community Health Services, City and Hackney Teaching Primary Care Trust - 14 April & 4 May
- Beverley Smalling, Service Director, Hackney Sickle Cell and Thalassaemia Centre -14 April
- Elaine White, School Nurse -14 April, 4 May
- Cora Woolcock, Chair, Hackney Sickle Cell Support Group -14 April
- Sue Davies, Manager for Inclusion, The Learning Trust - 4 May
- Lizzy Yauner, Head of the Learning Support Service, The Learning Trust - 4 May

The following provided information outside the meetings of the Commission either in person, by correspondence or by telephone:

- Tolu Ahmed, Specialist Haematology Midwife, Homerton University Hospital
- Susan Crocker, Principal Psychologist, Donald Winnicott Centre
- Valerie John-Charles, Practice Nurse Manager, The Sanctuary, John Scott Health Centre
- Phillip Sharpe, Head of Assessment and Care Management, Social Services Department, LBH
- Hilary Smith, Strategic Support Officer (Pupil Services) The Learning Trust
- Margaret Vander, Development Manager, London Ambulance Service
- Andrew Wieland, School Teacher, Royal London Hospital
- Dr Farid Fouladinejad Partnerships and Planning Manager, Bart's and the London NHS Trust

- Steve Goodman, Assistant Director. Children and Families Services, LBH
Keith Miller Head of the Corporate Health and Safety Unit, LBH
- Peter Hendy, Managing Director, Surface Transport, Transport for London
- Peter-John Wilkinson Director, Pupil Services, The Learning Trust

10. Membership of the Scrutiny Commission

10.1 Elected Members up to 12/05/04

- Councillor Muriel Purkiss (Chair)
- Councillor Vivian Amaran (Vice Chair)
- Councillor Lindsay Montgomery
- Councillor Sally Mulready
- Councillor Sharon Patrick
- Councillor Ian Rathbone
- Councillor Muttalip Unluer

- Scrutiny Officer; Ben Vinter

10.2 Elected members from 12/05/04

- Councillor Muriel Purkiss (Chair)
- Councillor Ian Rathbone (vice -chair),
- Councillor Vivian Amaran
- Councillor Daniel Kemp
- Councillor Alan Laing
- Councillor Lindsay Montgomery,
- Councillor Sharon Patrick
- Councillor Joseph Stauber

- Scrutiny Officer; Ben Vinter

10.3 Co-opted Members

- Bill Marks

10.4 External Advisers

- Mrs Elizabeth Taylor

Background papers

The following documents have been relied upon in the preparation of this report or were presented to the Scrutiny Commission as part of the investigation:

- City and Hackney Health Improvement and Modernisation Programme 2002-2005
- Homerton Sickle Cell Handbook, Dept of Haematology, Homerton University Hospital NHS Trust
- Procedure for the Conveyance of Patients. London Ambulance Service NHS Trust 2002
- Department for Transport Guidance on Concessionary Fares for Disabled People under the Transport Act 2000. DETR 2001
- Home to School Transport Policy for Children & Young People with Special Educational Needs and with Medical Needs. The Learning Trust 2003
- London Buses: BTEC Professional Qualifications for Drivers, Conductors and Service Controllers 2004
- Access to Education for children and young people with Medical Needs. Department of Education and Skills 2001