SCOTTISH HEALTH ADVISORY SERVICE

SERVICES FOR PEOPLE WITH LEARNING DISABILITIES IN LOTHIAN
Review of

Services for People with Learning Disabilities in Lothian

21 – 25 February 2000
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**The Scottish Health Advisory Service thanks the following people:**

The people who use the services we reviewed  
The relatives and carers we met during our visit  
General Practitioners  
Lothian Primary Care NHS Trust, West Lothian Primary Care NHS Trust, Lothian  
University Hospitals NHS Trust  
Lothian Health  
City of Edinburgh, East Lothian, West Lothian, Midlothian Social Work Departments  
Representatives from Voluntary Organisations and Groups  
Representatives from social care providers  
Advocacy Services
Executive Summary

The Scottish Health Advisory Service visited services for children and adults with learning disabilities provided by Lothian Primary Care, Lothian University Hospitals and West Lothian Healthcare NHS Trusts between 21\textsuperscript{st} and 25\textsuperscript{th} February 2000. This report covers the community and inpatient learning disability services provided across Lothian.

Since 1994 the hospital reprovision programme in Lothian has successfully achieved the closures of the Hopetoun Unit in Haddington, St. Joseph’s Hospital in Midlothian and Gogarburn Hospital in Edinburgh. A comprehensive range of new services has developed in the community. However there are some issues that need to be addressed if the full benefits of innovative work are to be realised.

There is a need for the health board and the trusts, in association with local authorities and other agencies, to build on the excellent work to date and develop a strategic framework for learning disability services in Lothian. This should include a review of current provision.

Particular issues were identified in relation to the planning and delivery of services to children with learning disabilities that need to be addressed with some urgency.

Services provided by community nurses, other members of the community learning disability teams and the specialist community based services are exemplary although issues of equity require to be resolved.

This report details the findings of the SHAS visit to Lothian and Lothian Health Board, Lothian Primary Care, Lothian University Hospitals and West Lothian Healthcare NHS Trusts are asked to:

- note the contents of this report; and
- action the recommendations contained within the report.
Contents

Introduction .................................................................................................................. 1
Planning services ......................................................................................................... 4
Learning Disability Strategy ....................................................................................... 4
Children’s services ....................................................................................................... 6
Needs assessment ......................................................................................................... 8
Service user involvement in planning ....................................................................... 10
Evaluation .................................................................................................................... 10
Hospital closure and service reprovision .................................................................. 11
Social care providers/Voluntary organisations ......................................................... 13
Independent advocacy ............................................................................................... 14
Leadership and management .................................................................................... 15
Clinical governance ................................................................................................... 17
Staff training and appraisal ....................................................................................... 18
Services to Children and Young People With Learning Disabilities ....................... 18
Respite care................................................................................................................ 21
Cairdean and Douglas House .................................................................................... 22
Meeting the Health Needs of People in the Community .......................................... 24
Primary care services ............................................................................................... 24
General health/hospital services ............................................................................... 25
Health promotion ....................................................................................................... 27
Specialist health services ......................................................................................... 28
Community learning disability services .................................................................... 28
Regional epilepsy service ........................................................................................... 30
Services for people with profound and multiple disabilities ................................... 31
  Special needs clinic ................................................................................................. 32
  Murraypark .............................................................................................................. 32
Services for people with challenging behaviour ..................................................... 33
  Challenging Behaviour Team ............................................................................ 34
  Greenbank Centre ................................................................................................. 35
Services for people with mental illness .................................................................... 36
Services for people who offend ................................................................................ 37
Services for people with learning disabilities .......................................................... 38
Homeless service ....................................................................................................... 38
Quality of care and services – inpatient services ..................................................... 39
Assessing and meeting individual needs ................................................................... 39
Accommodation .......................................................................................................... 41
Day activities and opportunities ............................................................................... 41
Managing the funds of INCAPAX residents .............................................................. 42
Support services ........................................................................................................ 43
Clinical services ......................................................................................................... 43
Administration and clerical ....................................................................................... 43
Clinical psychology ................................................................................................... 44
Creative therapies ...................................................................................................... 45
Dietetics ..................................................................................................................... 45
Nursing ....................................................................................................................... 46
Occupational therapy ............................................................................................... 47
Physiotherapy ............................................................................................................ 47
Psychiatry services .................................................................................................... 48
Social work ................................................................................................................ 49
Speech and language therapy .................................................................................. 49
Conclusions ............................................................................................................... 51
Good practice ............................................................................................................ 54
Main recommendations ............................................................................................. 55
Appendix 1 .................................................................................................................. 55
Appendix 2 .................................................................................................................. 55
Introduction

1. This visit provided the first opportunity for a Lothian-wide review of services to people with learning disabilities and to visit services following the reprovisioning of all long stay hospital services. The Scottish Health Advisory Service last visited the learning disability services provided by the then Edinburgh Healthcare NHS Trust in June 1998. Services in East Lothian were visited in 1994, that being a joint visit to the Hopetoun Unit with Social Work Services Inspectorate, and St. Joseph’s Hospital (an independent hospital) in Midlothian was visited in December 1993. Table 1 below provides information on the inpatient population in Edinburgh, East Lothian and Midlothian at the time of the SHAS visits in 1998, 1994 and 1993 respectively. Since these visits, many changes have taken place.

Table 1

Inpatient Population - Lothian Learning Disability Services in 1993 and at the time of previous SHAS Visits

<table>
<thead>
<tr>
<th></th>
<th>Hopetoun Unit</th>
<th>St. Joseph’s Hospital</th>
<th>Gogarburn Hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1993</td>
<td>60</td>
<td>95</td>
<td>351</td>
<td>511</td>
</tr>
<tr>
<td>SHAS Visit (1994)</td>
<td>55</td>
<td>95</td>
<td>120</td>
<td></td>
</tr>
</tbody>
</table>

*Nursing Home status under contract with Lothian Health

2. In 1992, the former Hopetoun Unit in Haddington became a nursing home managed by East Lothian Care and Accommodation Project (ELCAP) under contract to Lothian Health. ELCAP managed the resettlement of 60 residents into a range of community based services and the reprovision of the Hopetoun Unit was achieved in January 1998. Lothian Health continued to contract directly with ELCAP for these services until July 1999 when the commissioning role was transferred to East Lothian Local Authority Social Work Department.

3. At the time of the last SHAS visit to Midlothian, St. Joseph’s Hospital had 95 residents – some of whom came from outwith Lothian. St. Joseph’s had a contract with Lothian Health for the provision of 50 continuing care beds and six respite beds. A number of other health boards contracted for the remaining beds.
4. The 1994 Lothian hospital closure and service reprovision strategy, supported by £14m of bridging finance, established the framework for the closure of Gogarburn and St. Joseph’s Hospitals and the resettlement of the remaining long-stay patients from the Hopetoun Unit, Herdmanflat Hospital. St. Joseph’s Hospital closed in March 1999. Gogarburn Hospital closed in May 1999 leading to the discharge of 302 people to a range of social care and health provision in the community. (Appendix 1 provides further detail).

5. Since the 1st April 1999, Lothian Primary Care NHS Trust has had the responsibility for the inpatient and specialist community-based health services for people with learning disabilities across Lothian. Two inpatient assessment and treatment units provide short-term assessment and intensive treatment for 24 people. The Greenbank Centre provides 12 beds for people with severe challenging behaviours and the William Fraser Centre provides 12 beds for people with dual diagnosis (learning disability and mental illness) and offending problems. Five Healthcare Houses with 36 inpatient beds were commissioned as part of the hospital programme for medium to long-term care and rehabilitation for people assessed as requiring continuing NHS care. One house is located in West Lothian, one in Midlothian and the remaining three in Central Edinburgh.

6. The primary care trust is also responsible for Murraypark which is located in the grounds of Corstorphine Hospital. This accommodation provides services across three interconnecting 6-bedded units for people with profound and multiple disabilities. Plans to transfer the service to nursing home status with services purchased by the local authorities have been delayed pending clarification of the legal position by the Scottish Executive. This follows a change of view by the Central Legal Office (CLO). Table 2 below provides details of the current adult learning disability inpatient provision in Lothian.

**Table 2**

<table>
<thead>
<tr>
<th>Type of Residence</th>
<th>Number of Beds</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>William Fraser assessment and treatment</td>
<td>12</td>
<td>Dual Diagnoses and Forensic</td>
</tr>
<tr>
<td>Greenbank Centre assessment and treatment</td>
<td>12</td>
<td>Challenging Behaviour</td>
</tr>
<tr>
<td>5 Healthcare Houses continuing care/ rehabilitation</td>
<td>36</td>
<td>Dual Diagnoses, Forensic, Challenging Behaviour</td>
</tr>
<tr>
<td>Murraypark * continuing care</td>
<td>18</td>
<td>Profound and Multiple Disability</td>
</tr>
</tbody>
</table>

*Registered as a nursing home but currently inpatient status
7. The primary care trust is responsible for eight community learning disability teams based in West Lothian, East Lothian, Midlothian and five teams covering Edinburgh city. There are seven local healthcare co-operatives (LHCCs) within the Lothian Primary Care NHS Trust and these are coterminus with the learning disability teams. West Lothian Healthcare NHS Trust has a Director of Primary Care responsible for primary and community services.

8. The primary care trust is also responsible for a challenging behaviour team that provides specialist assessment and treatment for people with severe challenging behaviour across Lothian in support of the local teams.

9. Inpatient and community child health services are the responsibility of the Lothian University Hospitals and West Lothian Healthcare NHS Trusts. There are two inpatient units for children with learning disabilities and complex health care needs. Douglas House and Cairdean provide residential and respite care for up to 19 children. These units are based in Edinburgh but provide a service to children across Lothian. The primary care and West Lothian trusts are responsible for child and adolescent mental health services.

10. The principal focus of this review was the provision of health services to people with learning disabilities in the community. The significant changes in the profile of service provision from long-stay hospitals to dispersed social and healthcare services in the community provided SHAS with a unique opportunity to review services in a community context.

11. While SHAS has no remit to review services provided by other agencies, the opportunity was given to visit former residents and other people with learning disabilities in a range of community-based residential and day care services.

12. Meetings were held with staff from the health board, the Lothian Primary Care, West Lothian Healthcare and Lothian University Hospitals NHS Trusts, City of Edinburgh, West Lothian, East Lothian and Midlothian Social Work Departments, representatives from primary care services and independent service providers. The team also met with carers, advocacy services, voluntary groups and user groups. SHAS is grateful to these people who gave their time to help complete this review. A list of the social care provision visited and voluntary and user groups who met with SHAS during the visit is included in Appendix 2.
13. The SHAS reports of 1993, 1994 and 1998 made a number of recommendations. A number of these have been achieved and some are no longer relevant given the closure of Gogarburn and St. Joseph’s Hospitals. However, some issues still need to be progressed and these will be referred to in the main body of the report. During the visit, there was evidence of a number of examples of high quality care and innovative practice which the SHAS team was pleased to note.

Planning services

Learning Disability Strategy

14. The Health Improvement Programme (HIP) sets out a number of priorities for learning disability services. SHAS welcomes the focus on transitional issues, the needs of adults with complex needs, ageing, access to quality general medical services and short breaks. SHAS is aware of a number of initiatives being taken forward by staff at a local level that are relevant to these priorities. There is a need to integrate local developments with the HIP and ensure HIP objectives inform local initiatives. There is also a need to consider other priority areas.

15. As in 1998, SHAS recommends that a Lothian-wide learning disability strategy is taken forward with due attention to the work in progress in the different local authority council areas. There is a need to involve all three Lothian trusts, local authority social work departments, voluntary organisations and advocacy and user representation. The model of working adopted for the hospital reprovision programme serves as a good example for taking forward a broad strategy to meet the needs of people with learning disabilities in the community. The Scottish Executive’s review of learning disability services will provide a policy context for the development of strategy at a local level.

16. The role and function of the current inpatient assessment and treatment and continuing care services will need to be reviewed as part of a joint strategic framework. There is a need to consider the role of the Healthcare Houses and the future policy on admissions and discharges. SHAS is aware that the current inpatient provision is full and there is little flexibility in the service to meet the needs of people currently living in the community. Likewise, some people currently in healthcare provision could move to community settings, with the appropriate support.

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17. The development of a new medium secure unit for mentally disordered offenders in Edinburgh will not meet the needs of people with a learning disability and offending behaviour. Agreement should be reached as to how the needs of people with learning disabilities and mental illness who offend are addressed. There are problems in securing appropriate provision and services for a small number of people with “borderline” learning disabilities who have historically been involved in learning disability services. The health board and the primary care trust should ensure that the needs of this group are addressed.

18. Recent discussions have taken place involving the health board, primary care trust and the four local authorities on the needs of people with Autistic Spectrum Disorder. This should involve representation from the child health services in the Lothian University Hospitals and West Lothian Healthcare NHS Trusts. Consideration should be given to the needs of both adults and children with learning disabilities. It is of interest that there is a reported increase in the recognition of Autistic Spectrum Disorder. The Learning Disability Review Report provides specific guidance on service development in this area.

19. SHAS was pleased to note the work being taken forward in identifying people with learning disabilities who may be homeless. A project is under way that should inform service planning for this group.

20. The primary care trust has continued to fund an initiative that aims to support people with learning disabilities in general hospital settings. This is referred further to in paragraphs 115 - 116. There is a need for the health board to consider how such a service should be commissioned across Lothian and to build on the excellent work that has taken place to date.

21. The SHAS team was very concerned to find that there is no current health funding for advocacy services for people with learning disabilities in hospital or the community. This is unacceptable. The health board contributed funding to Powerful Partnerships Advocacy Project as a temporary element of the reprovision programme. In the 1998 SHAS report it was recommended that the provision of advocacy be considered beyond the hospital closure programme. At the time of the latest SHAS visit there was no evidence of any agreed strategy for the development and delivery of advocacy services to people with learning disabilities, particularly those in health service facilities. It is recommended that Lothian Health, in association with the primary care trust and social work colleagues, commission advocacy services at an early date. There is an opportunity to involve Advocacy 2000 in this work. The independent evaluation of the Powerful Partnerships Advocacy Service, commissioned by PACT, should inform the process.\(^3\)

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22. Social work is the lead agency for the development of community care planning in respective local council areas. There are learning disability planning groups in all four council areas and a number of planning issues and developments are being progressed. The SHAS team were told by representatives from a number of voluntary sector organisations that the planning structures are not considered to be effective in enabling the views of providers and voluntary groups to be taken into account in the planning and delivery of healthcare. It is recognised that the presence of four local authorities and three trusts makes the planning process quite complex. There needs to be a clearer mechanism for engaging the views of service users, relatives, carers and social care providers in the planning and development of healthcare services.

23. Lothian Health, in association with the four local authorities, has developed criteria for people requiring continuing care. SHAS welcomes this approach. However, during the visit, a number of issues relating to people requiring significant health and social care input and the funding of such packages were identified. These should be considered in a strategic context and Lothian Health should ensure an evaluation of the implementation of the continuing care criteria is undertaken.

24. Appropriate Adult Schemes 4 are in place, one covering Edinburgh City, East Lothian and Midlothian, and one covering West Lothian. Social work is the identified lead agency for both schemes, with Edinburgh City co-ordinating the service for Edinburgh, East Lothian and Midlothian. An interagency policy for the protection of vulnerable adults and sexual abuse guidelines is also in place. It is of interest that the majority of requests for Appropriate Adults relate to people with learning disabilities.

Children’s services

25. The needs of children with learning disabilities are referred to in a number of strategic documents and are identified as an area to be included in a Learning Disability Strategy. Children’s plans are also developed in each of the four local authority areas although there is little involvement of learning disability clinicians. Lothian Health needs to decide how strategic planning for children with learning disabilities is to be taken forward and in what forum.

4 Scottish Office (1998): Interviewing People who are Mentally Disordered: Appropriate Adult Schemes
26. Services to children and young people with learning disabilities are referred to in the Lothian Health ‘Children and Young People’s Strategy’ and the draft ‘Joint Strategy for Children and Adolescent Mental Health Services for Lothian’. The Children’s Strategy makes reference to the needs of children with autism and children with learning disabilities who also have mental health problems. The recent draft joint strategy for children and adolescent mental health services for Lothian also makes reference to the mental health needs of children with learning disabilities, although the strategy does not adequately deal with the range and scale of the issues.

27. While reference is made to the prevalence of mental health problems in the child and adolescent population, there is no mention of the significant higher prevalence of mental health problems in children with learning disabilities. This is referred to in a position paper prepared by East Lothian and Midlothian community team for people with learning disabilities (CTLD) regarding a proposal to develop local child mental health services for people with learning disabilities.

28. SHAS found no evidence of constructive planning being taken forward to ensure provision of an adequate mental health service for children and young people with learning disabilities. This issue was highlighted in the 1998 SHAS report and, despite references to the needs of this group in strategic documents, there is currently no appropriate or adequate service in place. It is recommended that the medical director of the primary care trust in association with the health board, West Lothian trust and Community Child Health Services in the Lothian University Hospitals NHS Trust agree how mental health services to this group should be provided at an early date. SHAS will follow up on this issue within three months.

29. A new inpatient facility for children and young people with mental health problems is due to open in Edinburgh later this year. There is a need to agree how the needs of children and young people with mild learning disabilities are to be met and if they can access the inpatient facility if appropriate. The SHAS team was aware of different views on this and Lothian Health should reach agreement with the clinicians on clear referral criteria for the service.

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5 Lothian Health, December 1997: Children and Young People’s Health Strategy
30. SHAS was pleased to see the joint commissioning approach taken to the development of the National Children Home (NCH) respite service for children with challenging behaviour that is jointly funded by Lothian Health and the four local authorities’ social work departments. This service needs to be considered in the wider context of service provision for this group with appropriate involvement of the learning disability services. SHAS notes that the HIP states that an evaluation is to be undertaken and issues of equity to be addressed.

31. Plans for the reprovisioning of Douglas House and Cairdean have been under discussion for a number of years. It has long been recognised that Douglas House and Cairdean are inappropriate facilities for this group of children. An outline business case was approved by the Lothian University Hospitals NHS Trust in September 1999 for two units located in different parts of Edinburgh. The Douglas House and Cairdean parents’ group was actively involved in this work. It is proposed that both units will provide residential and respite beds in two separate houses for four and five. SHAS is concerned about a recent option to have one 18-bed development rather than a smaller dispersed model. SHAS recommends that Lothian University Hospitals NHS Trust progresses plans to ensure small homely and safe environments for these vulnerable children and young people. An 18-bed development would be unacceptable for this group.

32. The needs of children and young people with complex needs who do not require the specialist nursing provision at Douglas House should be addressed in association with the local authorities. There should be a spectrum of provision and plans developed to ensure appropriate input from health staff in community settings. Lothian Health has recently transferred the budget for children requiring complex care packages to the Lothian University Hospitals NHS Trust. Clinicians expressed concern about the resource implications for new cases and have indicated that no new care packages can be resourced. Lothian Health and the trust will need to review this and ensure that appropriate services and resources are in place.

**Needs assessment**

33. Health boards are responsible for assessing the health needs of people in a catchment area and there should be a comprehensive approach to identifying the health needs of people with learning disabilities. This should be taken forward with social work colleagues to ensure the development of an integrated needs assessment.
34. Adults with learning disabilities have higher levels of health problems, examples of which include:

- sight and hearing problems;
- nutritional problems;
- communication difficulties;
- mobility problems;
- thyroid disorder;
- dental disease;
- side effects of medication;
- epilepsy; and
- mental health problems.

34. They also have less access to services. A number of papers have identified the issues in this area and are useful reference points for planning and commissioning services.7, 8, 9.

35. Lothian Health covers a population of 774,528. On the basis of national prevalence data there are approximately 15-20,000 people with learning disabilities living in Lothian. Of these 2-3,000 will have a severe learning disability. In the United Kingdom it is estimated that there has been an increase of 1.2%10 a year since 1960 of people with severe learning disabilities. Research suggests that the number of people with severe learning disabilities will continue to grow by over 1% a year over the next 10 years.

36. No formal needs assessment has been carried out across Lothian. The SHAS team was made aware of some innovative work being undertaken by community learning disability nurses, psychologists and primary care colleagues in relation to identification of health needs in certain areas. Community care plans also identify a number of people using services and known to the different agencies. SHAS was informed that there is an over-representation of children with learning disabilities in West Lothian compared with the national average. Likewise, Midlothian has a higher number of adults with learning disabilities living in the local community compared to the expected numbers based on general prevalence rates. This has come about as a consequence of the reprovisioning of St. Joseph’s Hospital services, largely to Midlothian communities.

9 The Royal College of Nursing (1998): Health Strategy for People with Learning Disabilities
37. Some needs assessment work is being progressed by the Midlothian LHCC with the development of a morbidity register. In East Lothian the community learning disability team is working closely with social work and education colleagues to ascertain numbers of people with learning disabilities living in the area. However, there is a need for a comprehensive Lothian-wide needs assessment to be carried out. There is an opportunity for local healthcare co-operatives (LHCCs) to be involved in locality needs assessment and it is recommended that work is taken forward in this area.

38. Child health services are involved in the Scottish National Special Needs Database System, which holds relevant information on children and young people with special needs. There is a need for Lothian Health to utilise this information in association with the Lothian Primary Care NHS Trust and social work departments to inform future planning for adult services.

Service user involvement in planning

39. SHAS found little evidence of active service user involvement in planning. Lothian Health and Lothian Primary Care NHS Trust do not have a service user strategy, although the need for one is recognised. There is some involvement of service users in local projects but limited opportunities for them, their carers and/or advocates to be involved in a proactive way. A recent publication by BILD \(^{11}\) identifies how to promote the development and participation of people with a learning disability in the commissioning of services.

Evaluation

40. SHAS welcomes the proposal by Lothian Health (Health Implementation Programme 2000-2005) to monitor and evaluate the new community-based health services for people with learning disabilities. Lothian Health, the primary care trust, West Lothian trust and the four local authorities, in association with all stakeholders, should agree how such evaluation can be taken forward on a multi-agency basis.

41. There is an opportunity to build on an earlier research study, which was funded by Edinburgh Healthcare NHS Trust, examining aspects of service provision for a number of people who had moved from Gogarburn Hospital.

42. SHAS is aware that the previous clinical director for learning disability services is involved in a research study relevant to the hospital programme. This should inform the evaluation process.

\(^{11}\) BILD (2000): A Place at the Table. *BILD publications*
ELCAP funded and commissioned an independent evaluation of their services in East Lothian. This report makes some reference to the provision of health services and the experiences of users. This is a useful piece of work and the recommendations should be considered on an interagency basis.

A number of small scale studies have been carried out by clinical psychologists and others that could usefully inform planning and developments. The Lothian Primary Care NHS Trust should ensure appropriate mechanisms are in place to utilise and disseminate the findings of this research.

Hospital closure and service reprovision

SHAS notes the significant achievement of the successful closure of all long-stay hospital beds in Gogarburn and St. Joseph’s Hospitals and the development of new community based models of health and social care services (see Appendix 1). The resettlement of people from the Hopetoun Unit and those in non-learning disability hospitals outwith Lothian completes the service reprovision learning disability strategy agreed in 1994. The Purchasing and Commissioning Team (PACT) overviewed the strategy and completed this task in June 1999. The team was chaired by the Director of the City of Edinburgh Social Work Department and involved representatives from the health board, Edinburgh Healthcare and East and Midlothian NHS Trusts, (latterly Lothian Primary Care NHS Trust), the four local authority social work departments, Scottish Homes, voluntary organisations and others. This is a successful model for joint working and implementing strategic change, and serves as a model of good practice for services elsewhere in Scotland.

The challenge of matching existing skills to new posts in the community was generally well met by the director of human resources and the personnel department training development team in the final months of the Gogarburn Hospital reprovision programme. The main training aims of making motivated staff more skilled for community posts and more attractive to new providers, has been largely achieved for the vast majority of staff. Good lines of communication with trade union officials and the Royal College of Nursing have also helped maintain a smooth transition for many staff in a time of great upheaval. The transition and what has been achieved to date, would be of great interest to those involved in future reprovision programmes.

A comprehensive evaluation of the effectiveness of the staff training in equipping staff for new posts would have been very useful, taking into account the relocation of staff and staff perception of the effectiveness of training. Such an evaluation would have guided new training and may still be possible, if staff can be tracked.

48. The plans for the development of Murraypark as a nursing home have run into some difficulty. There is an additional cost to Lothian Health of £100,000 a year while the residents remain inpatients. SHAS supports the aims to have this service commissioned as a social care resource and notes that the health board and the primary care trust are working towards a resolution to the current problem.

49. Lothian Health contributes £300,000 per annum as part of resource transfer money for care management across the four local authority areas. An additional £900,000 was made available for the development of the Community Learning Disability Teams.

50. SHAS was pleased to hear the very positive experience from users, relatives, GPs and other staff on the outcome of the hospital reprovision programme in Lothian. SHAS met with 39 relatives at one meeting in Midlothian all of whom were complimentary of the new services in place in the community. SHAS is aware that many relatives have anxieties and concerns during a hospital resettlement programme and the work done with relatives to support them in this process is evident.

51. The reconfigured healthcare provision should be reviewed on an ongoing basis in close discussion with social work colleagues. There are concerns about blocked beds, throughput for individuals and how the needs of people in the community are to be addressed in the future.

52. SHAS supports the need for ongoing social work attachment to healthcare provision and the involvement of social work in annual reviews of people in Healthcare Houses in order to plan for their future care.

53. There is a need for robust monitoring of the quality of new provision across health and social care. Lothian Health retains responsibility for monitoring the use of resource transfer money and joint evaluation with social work should be put in place.

54. SHAS notes that there have been some developments for community learning disability services as part of the Gogarburn reprovision programme. While there have been increases in staffing in all disciplines since 1994, there is a need to keep this under review given the increasing workload reported by the community teams and the additional complexities in supporting people in a diverse range of community settings. Some specific resource deficiencies are identified elsewhere in the report.
55. Of particular concern to SHAS was the difficulty for people discharged from Gogarburn Hospital to West Lothian in accessing equipment from the West Lothian joint equipment store. There are difficulties also in agreeing how repairs and maintenance of existing equipment is to be carried out and financed. There is an urgent need for the West Lothian trust and the primary care trust to agree how equipment should be provided to people discharged from Gogarburn.

Social care providers/Voluntary organisations

56. The SHAS team met with representatives from a range of social care providers and voluntary sector organisations in Lothian. The team also visited residential day care and nursing home provision.

57. SHAS was impressed with the quality of provision provided by the social care providers visited (see Appendix 2 for details). The network of social care providers for people with a learning disability in Lothian has been greatly expanded by the Gogarburn reprovisioning programme. New providers have come into the region to complement existing ones. Most provide residential (predominantly small group homes) and day care services. In Midlothian the closure of St. Joseph’s Hospital involved the resettlement of people into small homes managed by St. Joseph’s Services. In East Lothian, ELCAP was the provider organisation involved in the resettlement of people from the Hopetoun Unit.

58. Providers generally perceived the community learning disability teams as providing a good service that is responsive and accessible. Primary healthcare services are seen as responsive and of good quality. The learning disability liaison nurse project at the Western General hospital is seen as good practice that should be expanded to other hospitals.

59. Of significant concern to social care providers is the apparent lack of resources for addressing the changing needs of individuals once they are living in the community. The resource transfer funds carried no contingency. A number of providers are experiencing real difficulties in managing situations that were not foreseen at the time of the initial assessment for the move from hospital to the community. This is a major strategic matter for the health board and local authorities, and it is also an issue to be considered by other hospital reprovisioning programmes.

60. The downward pressure on social care funding, caused partly by a lack of annual uprating in recent years and partly by financial pressures during the latter stages of the Gogarburning programme, is reported to be causing an increase in staff turnover in social care services. This is seen as a significant problem by the community health services as well as social care providers, voluntary groups and carers.
61. Social care staff play an important role in supporting people to access community health services. Staff work closely with community teams to promote physical and mental health, and to develop skills through training to support people with epilepsy, mental health problems, challenging behaviour, sensory deficits, communication difficulties, dietary issues and a range of physical disabilities. The issue of staff turnover should be of joint concern to board, trust and local authorities and should be reviewed within a strategic context.

62. In Lothian there is a well-developed and articulate voluntary sector that has great potential for complementing and supporting statutory services for people with learning disabilities. It is important for the primary care trust to engage this sector in developing its new strategy for delivering community-based services.

Independent advocacy

63. At the time of the last visit there were three advocacy groups involved with residents in Gogarburn Hospital. ‘Powerful Partnerships’, an advocacy service, managed by ENABLE services, which was commissioned by PACT as a means of addressing at least some of the advocacy issues arising out of the rep rovision programme. ‘Partners in Advocacy’ was also supporting a number of Gogarburn residents and ‘People First’ was involved in the provision of a self-advocacy group for interested residents in hospital.

64. ‘Powerful Partnerships’ has continued to support a number of individuals in Greenbank, William Fraser and the Healthcare Houses, despite the lack of any funding from Lothian Health or the Lothian Primary Care NHS Trust. SHAS recognises the efforts made by ‘Powerful Partnerships’ to maintain its contact with individual residents.

65. SHAS is aware of plans by the Lothian Primary Care NHS Trust to work with social work departments in developing an advocacy service for people with learning disabilities. However, no detailed work has been carried out on this proposal and there is a lack of clarity as to how this may be funded. This issue is referred to earlier in the report.

66. At the time of the SHAS visit ‘Powerful Partnerships’ was in receipt of funding from the City of Edinburgh Social Work Department but on going funding arrangements had not been agreed. ‘Powerful Partnerships’ has received Lottery funding of £180,000 over a 3-year period for the development of community focused advocacy work. This is not linked to the current inpatient provision and will only cover North West Edinburgh.
67. ‘Partners in Advocacy’ has been commissioned by the City of Edinburgh Social Work Department to support residents as part of the reprovisioning programme for a large hostel. While this is welcomed, some concerns were expressed to the SHAS team that this does not address the long-term needs of people with learning disabilities with regard to relationships and support in the community.

68. ‘Sticking Up for your Rights’ is a self-advocacy group that receives financial support from the City of Edinburgh Social Work Department. The group has identified a number of areas of concern regarding the provision of healthcare services and has been involved in some discussions with Lothian Health and members of the community learning disability team on relevant matters. The involvement of user groups, such as ‘Sticking Up for your Rights’ should be encouraged and there is a need to develop a robust strategy for the involvement of service users generally. This is referred to in paragraph 39.

Leadership and management

69. Since 1st April 1999 the Lothian Primary Care NHS Trust, West Lothian Healthcare NHS Trust and the Lothian University Hospitals NHS Trust provide health services in Lothian. Specialist learning disability services for adults are provided by the primary care trust although services to children with learning disabilities, in the main, are the responsibility of the Lothian University Hospitals and West Lothian Healthcare NHS Trusts.

70. The closure of Gogarburn and St. Joseph’s Hospitals along with the development of local healthcare co-operatives (LHCCs) has brought about significant change to the management and organisation of learning disability services. Since 1999 a clinical director, who is a consultant psychiatrist, is the identified clinical leader for learning disability services across Lothian and reports to the chief executive of the primary care trust. This role is supported by a general manager (hospital services) who is the overall budget holder for the Edinburgh and West Lothian Learning Disability Services. Two clinical services development managers manage the inpatient and community services respectively and report to the general manager. Support services are the responsibility of the general manager. Human Resources and Finance are managed on a trust-wide basis.

71. Community nursing, clinical psychology and Professions Allied to Medicine (PAM) services in East Lothian and Midlothian are managed as part of a locality structure and report through the LHCCs. A recent change has seen the community learning disability nursing in Midlothian linking to the clinical services development manager for professional issues.
72. The closure of Gogarburn Hospital resulted in clinical staff groups losing a professional base and associated support. Clinical staff, other than the medical staff, are now based in the community areas in which they work. Medical staff are in temporary accommodation pending plans for new premises. The resultant change in organisational structure and support following the closure of Gogarburn, along with the changes brought about by the introduction of the LHCCs, has meant that many clinical staff are unsure about management and reporting arrangements. A number of people are undertaking ‘acting’ duties with little clarity as to the role and function of such posts. A decision on the final gradings for the senior nursing posts has still to be taken in the light of the new primary care trust structures.

73. There are plans to appoint a lead therapist for each of the professional groups for learning disability services across Lothian. The lead therapists will be involved with the clinical director, clinical service development managers and general manager (hospital services) in a directorate management team.

74. Lothian Primary Care NHS Trust has appointed a professional adviser for each discipline across all care groups. The advisers have responsibility for professional development and clinical strategy and link to the medical director. The respective roles and responsibilities for the professional adviser and lead therapist need to be made clear to staff and an early decision taken about the implementation of the management arrangements to avoid further confusion and uncertainty.

75. There is a need for the Lothian Primary Care NHS Trust to balance the historical locality focus in East Lothian and Midlothian with the more central focus in Edinburgh City and West Lothian in relation to learning disability services. The appointment of one lead therapist for each clinical speciality seems appropriate and should provide continuity and consistency across the different Lothian localities. SHAS was aware of the tensions regarding the separate management arrangements for East Lothian and Midlothian compared to the remaining Lothian services. The development of a Directorate Management Team involving appropriate representation for East Lothian and Midlothian LHCCs, along with other relevant managers and lead therapists, should enable a consistent approach to the management delivery of learning disability services across Lothian.

76. The clinical director should be invested with the responsibility for clinical leadership across all Lothian services. SHAS was concerned about the limited time available for the post holder in relation to this role. The chief executive of the primary care trust should consider the need for additional resources and support to enable the clinical director to take forward the significant change agenda.
77. The clinical director has established clinical networking lunches to involve staff including social work staff across learning disability services and LHCCs. Staff spoke positively of this development which provides an opportunity for people across Lothian to meet on a regular basis.

Clinical governance

78. In the Lothian Primary Care NHS Trust the development of clinical governance has led to the establishment of a clinical governance committee, and a clinical governance reference group is headed up by the medical director. Five areas are identified that cover:

- clinical effectiveness, including clinical audit;
- research and development;
- partnerships in practice and public involvement;
- staff development; and
- risk assessment – including complaints.

79. The LHCCs are developing a focus on clinical governance as are the different professional groups. SHAS was impressed with the work on research and audit within the different clinical groups. The primary care trust was recently successful in applying for £935,000 from the Research and Development Support Funding for NHS Providers.

80. There are good operational policies and procedures for the inpatient services covering risk assessment to care planning, care standards, information on admission, discharge checklists and policies for most clinical interventions.

81. There is a trust complaints procedure and the management of complaints is identified as one of the areas in the clinical governance programme. Only a small number of complaints have been made in relation to learning disability services and some of these relate to community provision. The trust has developed a user-friendly leaflet to help people with learning disabilities understand the complaints procedure. There is a need to ensure that this is readily available to users and their families. As people with learning disabilities and their families seldom make complaints, there is a need to encourage views about aspects of service provision, particularly for those in inpatient services. Regular meetings with relatives and the active involvement of advocates can assist with this.

82. There is a procedure for the recording of incidents and reporting them to the trust board. SHAS recommends that the Directorate Management Team ensures that information is reviewed regularly with a view to considering appropriate proactive measures.
Staff training and appraisal

83. Statutory health and safety training is ongoing. There is a staff appraisal and staff development programme across Lothian Primary Care NHS Trust, although SHAS found it to be patchy and in places non-existent. The director of human resources is currently reviewing the staff appraisal system and there is a need to ensure that this is integrated across the diverse, largely community-based, services. There is a need to:

- identify staff training needs in the new provision, through training needs analysis;
- establish a staff training system for all staff;
- establish a mechanism for informing and updating all staff on available training, locally and elsewhere; and
- clearly define and locally devolve training budgets.

84. Clinical supervision is carried out by peer review and this seems to work well.

Services to Children and Young People With Learning Disabilities

85. The Lothian University Hospitals NHS Trust is responsible for Lothian-wide specialised residential and respite care services for children with profound complex health care needs (including learning disabilities) in Douglas House and Cairdean. The trust is also responsible for the provision of community paediatric services for Edinburgh City, East Lothian and Midlothian. There are 7.4 consultant community paediatricians, one having Lothian-wide responsibility for co-ordinating services to young people with profound and multiple disabilities. This includes responsibility for Douglas House and the respite unit at Cairdean. The community paediatric service to children and young people with learning disabilities provides early support to children and their families. In addition the service is involved in training staff from other agencies involved with the care of children with profound and multiple learning disabilities. There are close links with the hospital neurology department.

86. West Lothian Healthcare NHS Trust provides child health and community paediatric services to children and young people in West Lothian. There are two consultants community paediatricians both covering hospital and community services. There is a child development centre in West Lothian that has input from health, social work and education. The child development centre is based in Livingston and aims to provide an accessible focus for the provision of services to young children with significant developmental problems and their families. This includes multidisciplinary assessment and investigation and management of all forms of development delay. The service is primarily
for pre-school children but can also be accessed by children identified as having difficulties in their early school years.

87. Services in Edinburgh are currently provided on a peripatetic basis to preschool children with clinics for children with developmental disorders based in the Royal Hospital for Sick Children, Craigroyston Clinic, Sighthill Health Centre and Leith Hospital.

88. Community learning disability nurses spend on average between 30% and 35% of their time providing services to children with learning disabilities, although some nurses reported having higher levels of contact with children. This service is highly regarded by the community paediatric service, GPs, carers and other agencies. Community learning disability nurses work closely with school nurses and the community paediatric service and have taken part in a number of child health training initiatives. Community nurses also provide a vital link between children and adult services. The transition from one service to another is often a very difficult and problematic time for young people and their families. While community learning disability nurses have close multidisciplinary involvement with child health services, there is no corresponding involvement from the child and family mental health services or adult learning disability services. The nurses can, therefore, be working in somewhat isolated situations with a lack of multidisciplinary support for children and young people who have significant emotional, behavioural and mental health problems.

89. In the context of identifying appropriate services for children with learning disabilities the primary care trust should agree an appropriate structure to support the community learning disability nurses in this work, with appropriate focus on supervision, training needs and specialisation of roles. The demand for a service for children with learning disabilities is increasing and SHAS is aware of concerns that this may be deterring from work with adults. Following close discussion, the primary care trust and the child health service should agree the level of service provision and how this is to be supported. The Children’s Strategy (1997) makes reference to the need to address equity issues of access to learning disability nurses across Lothian. No work appears to have been taken forward in this area. SHAS recommends that this is progressed at an early stage to inform the overall service provision for this group.

90. Provision of PAM services to children with learning disabilities remains the responsibility of the Lothian University Hospitals and West Lothian NHS Trusts. Services are provided within schools and in the home. In Edinburgh paediatric PAMs identify a key therapist for each child who takes responsibility for co-ordination and appropriate liaison with other disciplines.
91. Lothian Health has increased the funding for the provision of paediatric PAMs with some recent investment (£334,000 1999/2000) from waiting list money. However, clinicians reported that there remains a degree of unmet needs for therapy services in the community. While waiting times have decreased, there can be lengthy delays in providing active treatment and support for children and young people on an ongoing basis. Recent investment by Lothian Health was conditional upon further work by therapists to examine patient protocols and practice with a view to ensuring cost effective, equitable, treatment across Lothian. The reported gaps in service provision require to be considered in this context. Lothian Health in association with the Lothian University Hospitals and West Lothian Healthcare NHS Trusts should conduct a review of paediatric PAM services for children and young people with learning disabilities. This could also inform planning for adult services and how the needs of young people are to be met in the future.

92. As noted earlier, there is no mental health provision for the majority of children and young people with learning disabilities from psychiatry or clinical psychology across Lothian. In Edinburgh a consultant child psychiatrist provides a limited service to the special schools, mainly for children with a mild or moderate degree of learning disability. However, there is no multidisciplinary support for this work and many children and young people are unable to get a service. In West Lothian clinical psychology provides a limited service to children and young people with learning disabilities.

93. There is no child psychiatrist with a specialist role for children with autistic spectrum disorder. A consultant community paediatrician has an interest in this area specifically in relation to speech and language disorders. The need for psychiatric input has been identified for some time and this service gap needs to be considered in the wider context of mental health services to children and young people with learning disabilities.

94. SHAS was pleased to see the identification of transitional issues as a priority in the HIP. The arrangements for transition to adult services is facilitated by the involvement of the community learning disability nurses as noted above. There is close liaison between the community paediatricians and the adult psychiatrists in learning disabilities to ensure appropriate referrals are made at an early stage. A special needs clinic, which is provided by the primary care trust, involving psychiatrists, nursing and PAM services, also provides support for the transition to adult services. The PAMs involved in adult learning disability services liaise with the paediatric PAMs and recognise the need to have clear policies in place. Appropriate information held by the child health services on the special needs register is now routinely transferred to adult learning disability services. This will certainly facilitate continuity of information for people and their families.
95. Despite these arrangements, service users and their families still experience major difficulties at times of transition. SHAS recommends that the arrangements for transition from child to adult services need to be supported by clear policies and procedures across all disciplines with the involvement of GPs and other specialities as appropriate e.g. community rehabilitation service. The Director of Patient Services for Children (Lothian University Hospitals NHS Trust) has initiated discharge case conferences for people moving on from child health services and SHAS supports this initiative.

Respite care

96. There is a range of respite care provision for children and young people with learning disabilities, although this area is still identified as a significant gap in terms of meeting unmet needs, particularly for children with complex needs. Few children are now admitted to the Royal Hospital for Sick Children for respite care, although some children are routinely admitted to St. John’s Hospital, usually because of a lack of available appropriate provision in the area for children with complex physical healthcare needs. Lothian Health and the West Lothian trust, in association with the West Lothian Council social work department, should review the use of paediatric wards for respite care and examine options for alternative provision in the community.

97. Lothian Health and the four Lothian local authority social work departments jointly fund a respite resource provided by the National Children’s Homes (NCH). The resource was commissioned for children with challenging behaviour and opened in 1998. The unit has four respite beds and one emergency assessment bed. In addition, an outreach service is provided. At the time of the SHAS visit, approximately 50 families were being supported by this service.

98. While offering respite care, the NCH unit also provides comprehensive assessment and support for families in their own home. A half-time clinical psychologist is employed by NCH in addition to staff from social work, health and education backgrounds. The initial proposals for the service identified a sessional commitment from a consultant psychiatrist. However, no separate funding was made available for this and the service has not been provided. At the time of the SHAS visit, a senior registrar in learning disabilities was providing some ad hoc input to the unit although this was only on a temporary basis. The lack of psychiatry services to the NCH resource is of concern. The consultant paediatrician supervises medication such as major tranquillisers in the absence of psychiatry input. This is an unsatisfactory situation and needs to be resolved. This is an issue across Lothian.
99. The unit provides respite care for young people up to the age of 19. Appropriate arrangements will need to be in place for those young people who will require respite provision when they move to adult services. Lothian Health has identified a need to evaluate and review the role of the NCH unit and SHAS recommends that this is considered in the context of the provision of mental health services to this group across Lothian.

Cairdean and Douglas House

100. Cairdean and Douglas House provide respite and residential provision for children with profound and complex health needs including learning disability. A clinical nurse manager, who has responsibility for staffing across the two units, manages the services. The service has its own bank staff and this provides a degree of flexibility in meeting the needs of the children and young people.

101. There is an active staff training programme with opportunities for secondments and exchanges with other areas of the Royal Hospital for Sick Children. There is a good clinical supervision programme in place for ongoing appraisal and development of staff.

102. Cairdean provides respite care and opened in 1994. The unit has seven respite beds plus one emergency bed. Cairdean is presently located in temporary rented accommodation which is not appropriate as a long term resource. A number of the children also access other forms of respite care such as shared care schemes, although their needs are such that they require regular and ongoing involvement of nursing staff.

103. Douglas House is a 12 bedded unit in a large Victorian House in Edinburgh and provides residential and respite. At the time of the SHAS visit, there were seven children on a long-term residential basis, two on a shared care basis i.e. the child is resident more than 50% of the time and three beds available for respite.

104. The children in Douglas House are inpatients and under the responsibility of the consultant community paediatrician. The trust contracts with a GP practice to provide out-of-hours cover for Douglas House. Children in Cairdean are not inpatients and the children are registered as temporary residents with the local GP practice who provide any necessary medical input and an out-of-hours service.

105. While the units provide care for children there is one resident who is 19 years old and is awaiting a place in Murraypark. There is a recognised gap in service provision for young people over the age of 16 who have significant health needs and will require complex social and healthcare packages. There is also a significant gap in service provision for children whose health needs have improved and who could move on from the
specialised respite care provision provided at Douglas House and Cairdean although still require significant healthcare input. Some successful placements have been made by social work. However, five children currently receiving respite at Cairdean could be provided for in other less specialised settings.

106. Plans for the reprovisioning of Douglas House have been considered for over 10 years and this is referred to in paragraph 31. The service is now accommodated on the ground floor only and significant investment has been made in the building in recent years to maintain an acceptable standard. Nevertheless, it is recognised that it is not suitable for the needs of children and young people.

107. SHAS was impressed with the efforts staff had made to make the environment as homely as possible, with bedrooms decorated to meet the individual needs of the different children. There are problems with storage of equipment, particularly at Cairdean, as every child has personalised seating, wheelchairs and standing frames. For those children attending on a respite basis, families are required to transport the equipment or else the children have access to non-personalised equipment in the units.

108. Children attend school during the day and a home teaching service is available for those children who are unable to attend through illness. Parents are actively encouraged to be involved in the care planning process and to attend regular reviews. There is ongoing social work involvement with a number of the children, and successful long-term placements have been secured for a small number of children whose health needs improved.

109. The hospital is appointee for three children and the management of patient funds is linked with the Royal Edinburgh Hospital’s Patient Funds Department because of their expertise in this area. It was of concern to the SHAS team that there are no funds available for clothing for children who are in Douglas House on a long-term residential basis and who have little or no contact with family. Until recently, nursing staff were able to apply to endowments for funds to purchase necessary clothing but this is no longer the case. SHAS recommends that the Lothian University Hospitals NHS Trust makes available appropriate funds for necessary clothing for those children who have limited or no access to funds.

110. Children who are resident in Douglas House on a permanent basis access dental services at the Royal Hospital for Sick Children. There is good multidisciplinary involvement in both units with significant involvement of physiotherapists and other PAMs. Other services are available on a referral basis e.g. dietetics, speech and language therapy. There is close liaison with the paediatric PAMs who work in educational settings but there is no dedicated PAM input to Douglas House or Cairdean. A case for additional PAM staff was made for the Units but this was not funded. The trust should review this in the context of the
planned new developments. Hydrotherapy is accessed at Graysmill School, although a lack of physiotherapy has meant that weekly sessions have recently been cancelled. It is unclear how long the sessions will be unavailable for and the trust should explore ways of ensuring children have access to these regular weekly sessions.

111. Staff in Douglas House and Cairdean have raised funds to purchase a specially adapted mini bus that provides transport to a variety of outings and activities. Staff have also raised funds to provide resources for a play scheme that runs during the summer holidays at Douglas House. Any child accessing respite care at Douglas House or Cairdean is able to attend the summer play scheme and this is of tremendous benefit to children and parents. SHAS commends these initiatives which have been taken forward by the staff and aim to improve the quality of life and experiences for this very vulnerable group of children. In addition to the play scheme, the parents group raised funds to purchase a specially adapted chalet near Aviemore that children, parents and staff can use at any time of the year.

Meeting the Health Needs of People in the Community

Primary care services

112. SHAS met with representatives of LHCCs in East Lothian, Midlothian, West Lothian and Edinburgh. SHAS was pleased to note the positive attitude and experience of primary care staff in relation to the hospital reprovision programme. Early work by the trust and regular liaison by the community services development manager has assisted with this process. In the context of the Gogarburn Hospital reprovisioning programme, Lothian Health agreed to provide additional funding to primary care for 140 people identified as having high healthcare needs. Concerns from GPs in Midlothian regarding the closure of St. Joseph’s Hospital were assuaged by the involvement of the community rehabilitation consultant who provided an assessment of the physical healthcare needs of people moving into the community.

113. In general, primary care services appear responsive to meeting the healthcare needs of people with learning disabilities in the community. Developments, particularly in East Lothian, have assisted with the identification and recognition of needs of people with learning disabilities and how community learning disability staff can support primary care colleagues. SHAS found varying degrees of awareness amongst GPs about the role of the community learning disability teams and the services available. In East Lothian and Midlothian the links between the learning disability teams and primary care staff are well developed. They are less well developed in Edinburgh although recent meetings with the community services development manager have helped to raise the profile. One LHCC in Edinburgh has a lead GP for learning disabilities.
The primary care and West Lothian trusts should consider the extension of such a role to all LHCCs and to ensure that learning disability services has a focus at LHCC level.

114. The learning disability community nurses are involved in routine health screening for all people referred to the service. SHAS supports this approach and recommends the early involvement of primary care staff in this area. This is important given that only a small percentage of people with learning disabilities in any given area will be referred to the community learning disability services and therefore have access to routine health screening. For example, in south-east Edinburgh it is estimated that only 18% of people with learning disabilities in the area are being seen by members of the community learning disability team. Developing awareness amongst primary care professionals and utilising expertise in primary care in areas such as health promotion and health screening is therefore a major objective for the service.

General health/hospital services

115. A link nurse project in the Western General Hospital has been funded and developed by the Lothian Primary Care NHS Trust in association with the Lothian University Hospitals NHS Trust. A community learning disability liaison nurse provides training and support to general nurses in the hospital. The project has been running on a pilot basis since 1998 and Lothian Primary Care NHS Trust has recently approved funding for a further year. It is hoped to expand the service to the Royal Infirmary. The project aims to ensure that admissions for acute episodes of care for people with learning disabilities are well planned and the support needs of people using the service are identified. The project is highly valued by the staff involved and SHAS received very positive feedback from carers and clinicians. The pilot project has been well evaluated and is recognised as good practice nationally.

116. SHAS was made aware of a complaint relating to an admission to the Western General Hospital. Despite the link nurse project there were difficulties for the person with a learning disability and his family. Feedback from patients and carers should be incorporated on a routine basis to inform future provision and support. SHAS was also aware of another inpatient with a learning disability where members of the CTLD were expressing concerns about aftercare arrangements. Appropriate care plans should be in place for people with a learning disability being discharged from acute hospital wards.

117. Some problems were reported to SHAS in relation to “step-down” services from the acute hospital for a small number of people with learning disabilities since the closure of Gogarburn Hospital. Gogarburn Hospital had an infirmary ward, which enabled people with learning disabilities to receive nursing and medical care following discharge from an acute ward. Two people with learning disabilities were admitted to
Ward 8 at the Royal Edinburgh Hospital, which has a similar “infirmary” role. This provision may not always be appropriate or available for people with learning disabilities and consideration needs to be given as to how such a service can be provided for people - preferably in a community setting.

118. Palliative care needs for people with learning disabilities are also recognised as a gap in current service provision. SHAS was pleased to hear of recent discussions between the learning disability services and the hospice regarding support and training for staff around the needs of people with learning disabilities.

119. SHAS was pleased to note the involvement of the community rehabilitation consultant in assessing the healthcare needs of people who were being discharged from St. Joseph’s Hospital. The primary care trust and the West Lothian trust should ensure effective communication between learning disability services and other specialist services, in particular the rehabilitation services who have a valuable role in the assessment and treatment of people with significant physically disabling conditions.

120. Access to neurology services in West Lothian was reported to be a problem, with waiting times of up to seven months. No such problems were reported for Edinburgh.

121. SHAS welcomes the PACT Healthcare Procedure Document which makes recommendations on healthcare procedures and specifies those tasks that can be undertaken by non-nursing staff. The PACT procedure has been taken forward by the four local authorities and adopted as policy. However, SHAS was made aware of some unresolved issues relating to peg feeding, insulin and enemas. There is an opportunity for the PACT policy to be reviewed and additional areas of concerns to be addressed.

122. Community pharmacists are now working across LHCC boundaries and are organised as a co-operative, which offers a good framework for joint working. Some funding has been made available to encourage primary care pharmacists and community care pharmacists to work together in a number of schemes. SHAS was made aware of the proposals for the development of a community learning disability pharmacist that would enable ongoing training to social care staff and carers on aspects of administration of medication, side effects etc. Such a post could also provide specialist support to the learning disability teams. SHAS supports this proposal to develop the community pharmacist role specifically for learning disability services.

123. There is an excellent community dental service, which provides a comprehensive service to people with learning disabilities. A special needs team provides outreach preventative and remedial dental service through the use of mobile units and clinics. The mobile units visit schools
and adult resource centres. People discharged from Gogarburn Hospital have been supported to access local dental practitioner services or, where appropriate, to continue accessing the service provided by the community dental service. The service is actively involved in health promotion work aimed at individuals and their carers. The service is seeking to identify people with a learning disability not currently registered with a local dental practitioner who are not accessing the community dental service. SHAS heard of some problems in accessing specialised services for extractions with waiting times reported, for some people, to be up to one year.

124. Users and staff in the John Chant Centre in Penicuik are working closely with the community dental service special needs team to develop a proactive approach to oral hygiene. This is an example of good practice that could usefully be developed in other areas.

125. The chiropody services are provided by community chiropodists who are attached to LHCCs. The needs of people with learning disabilities in the community are met in a range of ways – by direct input to training centres, residential units and provision of services at clinics and health centres.

126. SHAS was made aware of some particular problems in West Lothian and East Lothian regarding access to chiropody services and, in particular, waiting times for review appointments. Because of this problem, some residents are paying for private chiropody. The provision of chiropody services to people with learning disabilities should be reviewed to identify any gaps in the current service provision.

**Health promotion**

127. One of the priorities identified in the HIP relates to the general healthcare needs of people with learning disabilities being met through mainstream services. Critical to achieving this objective is the accessibility of health services and the availability of appropriate health promotion and material for people with learning disabilities. While there are some excellent examples of work being taken forward in this area, in general, developments are ad hoc and there is no overall health promotion strategy for people with learning disabilities.

128. There are some basic courses on health, personal and social development run through local adult training/resource centres and by community nurses. The Bonnington Resource Centre in Edinburgh has a day care officer with a specific health promotion remit. However, there is no co-ordinated information strategy to promote better health for people with learning disabilities.
129. FAIR (Family Advice and Information Resource), a voluntary organisation, has produced excellent health awareness booklets in conjunction with community learning disability nurses but disappointingly were unable to attract funding from the trust or the health board. Funding was awarded from the National Lotteries Charities Board.

130. A Health Promotion Report “Health Matters” is being taken forward by a team led by a clinical psychologist and involving members of the North-East Edinburgh Learning Disability Team and Jewel and Esk Valley College. The project has secured one year’s funding from the primary care development fund. Its aim is to pilot a method for people with learning disabilities to find out and tell their peers about resources, health service personnel and procedures that can help them stay healthy and to enable feedback from users to service providers. A small group of people with learning disabilities are taking part in an 18 week college-based course that will produce individual health portfolios, and a video that will form the basis of a second shorter course for subsequent groups. Following review of the pilot, it is hoped that the course can be included in the college programme.

131. The involvement of a communication therapist in the project team has enhanced the involvement of service users. The potential exists for further course on topics such as smoking, healthy eating and dental health. This initiative is to be commended and, subject to positive evaluation, SHAS would urge that it be supported by the board and trust to develop and widen its scope and range.

132. Service users reported some difficulties in accessing information on health services in an understandable format. The excellent work carried out by FAIR in developing health promotion leaflets could be usefully expanded to provide general information on health related services for users.

Specialist health services

Community learning disability services

133. Lothian Primary Care NHS Trust is now responsible for all community learning disability services across Lothian. There are eight teams providing services in West Lothian, East Lothian, Midlothian and five for Edinburgh City. The number of teams in Edinburgh has increased by one since the last SHAS visit in 1998 to match the LHCC boundaries. Table 3 below provides information on the teams, population covered and number of people registered on Psymon (an information database) with a diagnosis of a learning disability since September 1998. This information is incomplete and it is recognised that a considerable
number of people known to CTLDs are not registered on the Psymon system. The trust is in the process of implementing the PIMs (Patient Information Management System) and this will assist in the accurate and consistent recording of information across the trust.

Table 3
Lothian Local Healthcare Co-operatives
Population and numbers of people with learning disabilities using services

<table>
<thead>
<tr>
<th>District</th>
<th>LHCC Population (approx.)</th>
<th>Community Nursing Caseload</th>
<th>People registered on PSYMON with Diagnosis of Learning Disability (Sept 1998)</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Lothian</td>
<td>145,000</td>
<td>131</td>
<td>260</td>
</tr>
<tr>
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</tr>
<tr>
<td>Midlothian</td>
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</tr>
<tr>
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<tr>
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<tr>
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<tr>
<td>SC Edinburgh</td>
<td>86,800</td>
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PIMS (Project Information Management System) replace Community Information System this year

135. Co-ordinators are appointed to each of the CTLDs and the role and function of team co-ordinators needs to be reviewed in the context of other management changes. At present there is no additional time allocated for this role and its function is more one of co-ordination than of direct management.

136. The community learning disability teams have been in existence since the early eighties, although in recent years they have become more multidisciplinary in focus, with involvement from community nurses, psychiatrists, clinical psychologists, occupational therapists, art therapists, speech therapists, physiotherapists, speech and language therapists and dieticians. There has been an increase in resources across all disciplines since 1994, although there is an issue about equity of services across Lothian. The teams in East Lothian and Midlothian have significantly less community nursing staff compared to Edinburgh City teams and the West Lothian team. There is very limited dietetic input across all the teams, which makes it difficult for the dietetic staff to attend regular multidisciplinary meetings. One dietician covers all five Edinburgh teams. The primary care trust should review the staffing across all the teams and ensure as equitable a service as possible.
137. There are link social workers identified for all the community learning disability teams and in East Lothian and Midlothian there are dedicated care managers for learning disability services. While there are clear benefits in having linked social workers to the teams, in many cases the social worker is unable to respond directly to referrals. These need to be channelled through the relevant social work team. There is an opportunity for the planning partners to review the social work role in relation to services for people with learning disabilities and to ensure that relevant expertise in learning disabilities is retained within care management. The recommendations in the Learning Disability Review should assist with this.

138. There are developing links with primary care services in the context of LHCCs since the reorganisation of trusts on 1st April last year.

139. Community teams work closely with social care providers across Lothian. SHAS was made aware of the very positive impact of community learning disability teams, and in particular community nursing in supporting people in the community.

140. Community learning disability nurses provide an out-of-hours service for Edinburgh and West Lothian that has been in operation for many years. Referrals can be made by families, clients and other providers via the Royal Edinburgh Hospital switchboard. The service is accessible and responsive. Advice can be provided by telephone or in some circumstances the nurse will make a home visit. It is of interest that the demand for the service has decreased in recent years, although the service is still seen as providing a valuable role and assisting in avoiding crisis situations develop. The on call service is currently being reviewed following this amalgamation of Edinburgh Healthcare and East Lothian and Midlothian trusts, and recommendations will be made regarding the future provision of the service.

Regional epilepsy service

141. The learning disability directorate is responsible for the provision of a regional epilepsy service for Lothian. Clinics are held in community health centres in Edinburgh, West Lothian and Midlothian. The service has a full-time associate specialist and full-time community learning disability nurse. In addition, a consultant psychiatrist and a community nurse provide a service to East Lothian and a staff grade doctor supports the West Lothian clinic. There are medical clinics and nursing clinics held in addition to home visiting where appropriate.
142. The service has been developed over many years and provides an excellent specialist epilepsy service to people with learning disabilities in addition to supporting and training GPs and carers. The service is primarily for people with learning disabilities aged 16 and over and there is close liaison with the paediatric service in relation to transitional issues. The regional specialist epilepsy service targets its resources at people with problematic epilepsy, with support being provided to GPs to manage patients with epilepsy that is considered non-problematic. There are close links with community learning disability teams, with joint working where appropriate. There is no dedicated clinic in East Lothian and it is recognised that there is a potential need to expand the service to ensure equity of service across Lothian. Lothian Health and Lothian Primary Care NHS Trust should ensure that the needs of people with epilepsy are considered in the context of a learning disability strategy.

143. The epilepsy service is involved in a comprehensive training programme for staff working in social care provider organisations. This covers general epilepsy awareness and the administration of rectal diazepam. The work in Lothian is recognised as best practice across Scotland.

Services for people with profound and multiple disabilities

144. People with profound and multiple disabilities are supported in a variety of settings, mainly in the community and often with family carers. SHAS is impressed with the range of needs being supported in social care provision with appropriate input from community learning disability teams and other health services. The closures of Gogarburn and St. Joseph’s Hospitals have brought about the development of a range of social care and health provision for people with profound and multiple disabilities. Community nurses and PAMs provide dedicated specialist health services to three day centres for people with complex health needs.

145. The needs of people with profound and multiple disabilities should be considered in a strategic context, in particular, the provision of day care and respite care for this group. The increasing incidence of children and young people with very complex needs now living into adulthood will need to be considered in relation to future models of service provision.

Special needs clinic

146. Lothian Primary Care NHS Trust provides a regional special needs clinic for people with learning disabilities aged 16 years and over who have multiple and complex physical needs that require long-term follow-up and surveillance. Staffing for the clinic includes an associate specialist, physiotherapist and input from three community disability nurses for West Lothian, North Edinburgh and South Edinburgh. The clinics are held in two community health centres in the City and in St. John’s hospital in West Lothian. A visiting clinic attends the Murraypark Unit. There are plans to provide a special needs service to Midlothian in the very near future. However, there is no service as yet for East Lothian and this should be addressed. There is close liaison with acute neurological and hospital services.

147. There are development proposals for this service that include the establishment of a liaison service to effect a smooth transition for patients between paediatrics and adult services and community monitoring and liaison between the clinic and patients at home or at day centres. A proposal to develop a dysphagia clinic as a sub-speciality of the special needs clinic is under discussion. SHAS supports these initiatives to target services in the community for people with profound and multiple disabilities.

Murraypark

148. In the context of the Gogarburn reprovision programme and the resettlement of people in out-of-Lothian hospitals, an 18 bed nursing home, Murraypark, was commissioned in the grounds of Corstorphine Hospital. At the time of the SHAS visit, the home had achieved nursing home registration. The residents are still inpatients of the primary care trust pending negotiations with the Scottish Executive on the legal status of the home.

149. Murraypark provides care for people with profound learning disabilities and multiple complex physical health needs. The unit accommodation comprises three linked six-bedded houses in the grounds of Corstorphine Hospital with all single room accommodation. Seven residents moved from Gogarburn Hospital, with nine Lothian residents returning from out-of-Lothian hospital placements. One resident was admitted from home and there is one bed that is used for respite. The location of the home provides easy access to local community facilities and amenities.
150. Two of the units have qualified nursing staff on duty at all time with the third unit having access to supervision and support from qualified staff. The residents are inpatients and they remain the responsibility of a consultant psychiatrist. General medical needs are met by the local general practitioner service and there is close involvement with the associate specialist.

151. There is dedicated physiotherapy input to the unit and weekly input from the dietician. Other specialist health staff are accessed on a referral basis via the local community learning disability team. There is involvement, as appropriate, from the local social work team.

152. At the time of the SHAS visit the management of the unit had transferred from the general manager for mental health and learning disabilities to the hospital manager responsible for Corstorphine and Astley Ainslie Hospitals. Because of the uncertainty over the current status of the unit, nursing staff were concerned about future management arrangements and links with learning disability services. There is a need for the Lothian Primary Care NHS Trust to consider the professional learning disability links for nursing, given that the service is now managed outwith the learning disability directorate.

153. There was a lack of clarity amongst nursing staff about the arrangements for the maintenance of equipment. This needs to be resolved to ensure that there is appropriate monitoring and review of equipment in the unit.

154. SHAS recommends annual multidisciplinary reviews of all residents in Murraypark with the involvement of social work. Consideration should be given to long-term planning for those residents who have less significant health needs and how these are to be met in the future.

Services for people with challenging behaviour

155. The needs of people with learning disabilities and challenging behaviour are met in a range of settings. A number of people are supported in social care provision and at home with family carers with input from community learning disability teams and the challenging behaviour team. The Greenbank Centre provides inpatient care for up to 12 people for assessment and treatment and also provides a day service for a small number of people living in other settings. The Healthcare Houses provide continuing care for a small number of people with challenging behaviour.
Challenging Behaviour Team

156. The challenging behaviour team has been operational as an outreach service from Gogarburn Hospital since 1989. Proposals for the development of a challenging behaviour service were agreed by PACT in 1997 and the current service was formally commissioned by Lothian Health in 1998.

157. The challenging behaviour team is a regional service providing a range of specialist support services to people with challenging behaviour and their carers in the community. The team is multidisciplinary providing a range of skills, competencies and experiences. Nurses and an assistant psychologist are based with the team on a full-time basis. There are two sessions from a consultant psychiatrist, five sessions from clinical psychology (one from a consultant clinical psychologist) and three sessions from a speech and language therapist. All the sessional staff are members of the community learning disability teams, as are some of the nursing staff. There is limited involvement from the consultant clinical psychologist and this should be reviewed to ensure appropriate clinical expertise in this area.

158. There is no social work involvement with the team and SHAS recommends that links with social work should be established. The involvement of a social work representative on the team would be an advantage.

159. The team provides services to people with learning disabilities aged 16 and above. There are requests to see younger people and, over the past year, six individuals aged under 16 have been referred and taken on by the team. A number of other referrals relating to children and young people were not accepted and redirected as appropriate. The gap in challenging behaviour services for children with learning disabilities is referred to in paragraph 92.

160. The team has been fully operational since March 1999 and at the time of the SHAS visit was supporting 24 people in a range of community settings. There is an important focus on training for social care staff although some difficulties are experienced with staff turnover in social care provision and the need to provide training for new staff. This also has an impact on individual residents, with the potential for a lack of continuity and inconsistent approaches to the management of challenging behaviour. In East Lothian members of the CTLD provide training on challenging behaviour to staff in social care settings.
161. There are good links with the community learning disability teams and this has improved significantly since the last SHAS visit in 1998. The challenging behaviour service acts as a specialist resource to the CTLDs although referrals can be made directly to the team by carers, social work, families etc. The links and respective roles of the CTLDs and the challenging behaviour team should be reviewed in due course.

162. The team is considering the use of money from unfilled posts to develop a flexible budget to enable the recruitment of bank staff to support people in their own home setting. SHAS supports this proposal.

163. The challenging behaviour service does not offer an out-of-hours service at present. This should be considered in the context of the role and function of the community nursing out-of-hours service and links with other agencies.

164. The team is working on an evaluation protocol for the service and this will be useful in informing future service provision and development.

Greenbank Centre

165. The Greenbank Centre is a purpose-built, 12-bedded inpatient unit for the assessment and treatment of people with severe challenging behaviour aged 16 and over. The centre also provides a day hospital service for six people living in the community.

166. There is good multidisciplinary input to the unit, with dedicated sessions from speech and language therapy, clinical psychology, occupational therapy and art therapy. Other specialist health services can be accessed on a referral basis.

167. While the centre functions as an assessment unit, six patients have been resident for two years with two being resident for over four years. There have been no recent admissions and while it is recognised that there may be some people that could benefit from short stay admission, this is not possible at the present time.

168. There is social work involvement with a number of the residents in the Greenbank Centre. There are some difficulties in identifying appropriate supports and settings for people to move on to. There needs to be ongoing multi-agency assessment and planning for individuals to ensure that people can be discharged to appropriate placements.
Services for people with mental illness

169. Psychiatrists and members of the community learning disability teams support people with dual diagnosis (mental illness and learning disability) in community settings. A small number of people with a mild learning disability, who have not historically accessed learning disability services, may be involved with adult mental health services.

170. Specialist inpatient services for people with a mild to moderate learning disability and mental illness are provided in the William Fraser Centre, which is also a new purpose-built unit. Six of the 12 beds in the William Fraser Centre are designated for this group, with the remaining beds for people with offending behaviour. In addition to the inpatient facility, there is a day hospital for 15 people that is currently split between forensic and dual diagnosis. At the time of the SHAS visit, three days were identified for people with mental health problems.

171. There have been a small number of admissions to the Royal Edinburgh Hospital because of the lack of available provision in the William Fraser Centre. Information provided to SHAS indicated that in the last year approximately four people were admitted to the Royal Edinburgh hospital who would have been admitted to William Fraser if beds had been available. However, these four admissions only accounted for 20 occupied bed days. The clinical director is monitoring this. The average length of stay for people with dual diagnosis in William Fraser is between two and 12 weeks.

172. There is good multidisciplinary involvement in the William Fraser Centre with input from clinical psychology, speech and language therapy, art therapy, occupational therapy and other professions as required. There is input from local social work area teams if there is direct involvement with the resident, but there is a lack of overall co-ordination of social work input for the service. SHAS was pleased to hear that the City of Edinburgh Social Work Department will be providing a dedicated social work manager for the Edinburgh inpatient services.

173. The operation of multidisciplinary case files is currently being evaluated.

174. In addition to the inpatient services, a small number of people with chronic mental health problems and other difficulties are supported in Healthcare Houses. These services are described further in paragraphs 188–224.
Services for people who offend

175. Specialist inpatient provision for people with learning disabilities and offending behaviour is based at the William Fraser Centre. There are six beds located in the forensic unit providing assessment and treatment for people with a mild and moderate degree of learning disability. The accommodation is provided in single rooms. At the time of the SHAS visit, five out of the six patients were detained under the Mental Health Act. In addition to the inpatient facility, there is a day hospital facility located in the William Fraser Centre. This day hospital is split between forensic and dual diagnosis – as described earlier. Two days are identified for forensic services.

176. In relation to the inpatient accommodation, the length of stay is variable from about six months to two years, with one individual who has been in the unit for three years. There are a few individuals in the State Hospital who could be accommodated in the William Fraser Centre or a similar facility. However, patient mix is also an issue and the William Fraser Centre may not be an appropriate provision for some more able individuals.

177. There is social work involvement with most of the residents. There is good multidisciplinary input from psychology, occupational therapy, art therapy and speech and language therapy.

178. There is a need for Lothian Health and the Lothian Primary Care NHS Trust to review the forensic provision to ensure that there is adequate and appropriate access to specialist inpatient admission and treatment facilities as well as to day hospital services and community support. The allocation of two days a week for the day hospital for this group is inadequate, although SHAS recognises the need to keep the dual diagnosis and forensic services separate. SHAS is aware that discussions are under way about the development of a seven day day hospital for this group and supports this initiative.

179. In addition to the assessment and treatment facility at the William Fraser Centre there are a small number of people with offending problems resident in the healthcare houses. As with people in the William Fraser Centre there is a need to develop a joint plan with social worker colleagues for people to move on to supported accommodation or other provision in the community. It is concerning that one resident has been in the unit for four years and another for over two years.

180. The clinical psychology service provides a Lothian-wide forensic psychology service for people living in the community. The service is actively engaged in research and evaluation.
Services for older people with learning disabilities

181. An older people’s working group has recently been established to focus on the needs of older people with learning disabilities and those with dementia. The group is a Lothian-wide group with representatives from psychiatry, clinical psychology, nursing and social work. The group initially focused on people with learning disabilities and Down’s Syndrome but has broadened its remit to focus on the needs of older people in general. A two-year project funded by the East Lothian and Midlothian trust led to the identification of 96 people with learning disabilities and Down’s Syndrome. A care pathway programme has been developed for people with learning disabilities and Down’s Syndrome over the age of 30 involving appropriate assessment and screening. This is an example of good practice.

182. Of the 302 people who were discharged from Gogarburn, 100 were aged 65 and above. A number of people were discharged to nursing home and Part 4 accommodation and there is variable involvement from community learning disability specialists in relation to follow-up.

183. It is recognised that there is a need to develop appropriate training for staff in nursing homes and residential homes regarding specific aspects of learning disabilities and ageing and also for staff in the general learning disability services. Training should also be extended to GPs in this area.

184. A number of social care providers are supporting older people and those with dementia. Where possible, efforts are made to maintain someone in their own setting and this can lead to higher care costs. SHAS was pleased to note that in some individual cases additional resources had been made available from social work to support people in the community. This issue will need to be considered in the development of a Learning Disability Strategy.

185. There is a need for the work of the older people’s group to link with the development of the learning disability strategy and community care planning.

Homeless service

186. The homeless outreach project has been in existence for eight years and has a focus on the mental health needs of people who are homeless. The recent involvement of a specialist registrar in psychiatry of learning disabilities has enabled a focus on the needs of people with a learning disability who may be homeless. A street survey carried out in June indicated that approximately 17% of people surveyed identified themselves as having a learning disability. A study is currently under
way to identify the prevalence of learning disability in the homeless population in Edinburgh and this is due to be completed in the autumn. A small number of individuals have already come to the attention of the learning disability services and it is expected that once the study is completed there may be a need for a more focused input from learning disability nurses, psychiatry and other disciplines.

187. There is a link learning disability nurse for the Edinburgh homeless practice and this should facilitate early involvement of learning disability services where appropriate. SHAS commends this initiative and the work being undertaken in Edinburgh should inform local and national planning for this group. Lothian Health and Lothian Primary Care NHS Trust need to consider the resource implication of providing a focused service for people with learning disabilities who are homeless. SHAS is interested in hearing of the progress in this area.

Quality of care and services – inpatient services

188. Since the closure of Gogarburn and St. Joseph’s Hospitals, inpatient services for people with learning disabilities consist of 24 assessment and treatment beds for people with dual diagnosis, forensic, offending behaviour and challenging behaviour. These services were referred to earlier.

189. The Lothian Primary Care NHS Trust is also responsible for five Healthcare Houses that were developed in the context of the Gogarburn Hospital closure. The five houses provide medium to long-term care and rehabilitation for 36 residents, some of whom are detained under the Mental Health Act. The Healthcare Houses were developed as part of the health infrastructure to provide services for people who may move on from the William Fraser and Greenbank Centres but who still require a significant input from health staff for chronic mental health problems, offending behaviour and for challenging behaviour. Three of the houses are based in Central Edinburgh, one in Midlothian and one in West Lothian. One of the houses in Edinburgh and the West and Midlothian houses are new build units catering for eight residents. The remaining two houses are for six residents each. One of the Healthcare Houses has been open for three years with the other houses coming on stream during 1999 prior to the closure of Gogarburn Hospital.

Assessing and meeting individual needs

190. A system of care planning is in place for residents in the inpatient services. Care plans are generally developed in the context of multidisciplinary working and there is a standard format for recording care aims and outcomes. The William Fraser Centre has developed a care plan format that has been taken on by the Greenbank Centre and the Healthcare Houses. There is a need for the clinical development manager for inpatient services to ensure that there is appropriate
consistency across the Healthcare houses and to implement an ongoing audit of care plans.

191. General medical services to the inpatient services are provided by the senior house officers and staff grade doctors. The out-of-hours GP service covers the Healthcare House in West Lothian. Previous SHAS reports have recommended that consideration is given to GP involvement in the provision of general medical services. The primary care trust in association with the West Lothian trust should consider how this service could be more appropriately provided by a general practitioner service.

192. There is very limited social work involvement in reviews of people in the Healthcare Houses other than routine mental health officer involvement for those people detained under the Mental Health Act. In Midlothian there is a dedicated care manager for learning disabilities linking to the home. In Edinburgh there are plans to have a social work presence in an overview and co-ordinating role.

193. There is a need to consider, in close collaboration with social work colleagues, the long-term plans for people in the Healthcare Houses. SHAS recommends that all residents should have regular multidisciplinary care assessment to ensure that those people who no longer require to live in an NHS continuing care setting have the opportunity to move to appropriate alternative accommodation with adequate health and social care support. Plans should be reviewed on, at least, an annual basis.

194. The Lothian Primary Care NHS Trust has developed protocols to ensure that appropriate health screening is available to male and female patients on a routine basis. This includes cervical and mammography screening and attention is also being given to Wellman services.

195. Individual referrals are made for audiology and ophthalmology services although there is no routine screening for this.

196. There is limited pharmacy input and this has decreased since the closure of Gogarburn Hospital; this is referred to further in paragraph 122.

197. There is variable input to the Healthcare Houses from members of the multidisciplinary team. Vacancies in clinical psychology and speech and language therapy meant that one House has had no regular input for several months. There is a need to ensure that there is appropriate therapeutic assessment and intervention available to all people in healthcare provision and any resource implications should be
addressed. SHAS is aware that seclusion is used for one individual on a very regular basis. There is appropriate recording and procedures in place. However, there should be regular and intensive input as required from the multidisciplinary team and clinical psychology in particular, to plan and implement alternative strategies as far as is possible.

Accommodation

198. The accommodation provided for all the inpatient services is of a generally good standard. There is single room accommodation for all patients and this is a significant improvement on the accommodation latterly available in Gogarburn Hospital. The Healthcare Houses providing accommodation for eight people have limited space and there is little access to outdoor areas, particularly in Carnethy House.

199. While the Healthcare houses have only recently opened, SHAS was aware that the environment of Carnethy was somewhat shabby and there is clear evidence of wear and tear. The trust will need to ensure that the original standard of accommodation is maintained as far as possible.

200. SHAS found that many of the internal and external doors were locked. It is recognised that there needs to be vigilance regarding security and safety of residents, although this should be balanced with ensuring that the least restrictive environment possible is being provided. The trust should ensure that there is a locked door policy that is appropriate to the current community-based accommodation and is reviewed regularly.

Day activities and opportunities

201. A number of residents from the William Fraser Centre and the Healthcare Houses attend adult resource centres on a sessional basis. There are good links between the William Fraser Centre and the Columcille day centre. This enables a number of residents to attend sessions as part of their care plan. However, in the Healthcare Houses the main daytime activities are delivered by the DART (Day and Recreational Team) and there is a link worker responsible for planning the DART input. The funding for DART is with the local authorities who commission the services from the primary care trust.

202. Approximately 250 client sessions are provided monthly. Activities include: drama, visual art work, gardening and outdoor activities. The services that are available are of a good standard, with committed staff and a belief in the value of the services for those receiving them.
203. There are five whole time equivalent (wte) posts and the head art therapist manages the team. The team now has a full staff complement for the first time since the hospital closures. There is no devolved budget for supplies, which have to be requisitioned centrally. This reduces the flexibility and responsiveness of the service. There was no evidence that the DART manager was involved in the planning of services or had professional representation in the senior management team. This should be considered in the context of the new management arrangements.

204. The availability of structured day time activities in the Healthcare houses is variable. In addition to the DART team, nursing staff are involved in day time and evening activities. The activities are a mixture of 1:1 and small group activity. The general aim of these activities is to provide a positive experience for residents rather than any long-term therapeutic objective.

205. There are large variations in the amount of time each resident is engaged in meaningful activities in and out of the houses. A few of the residents appear to have fewer day opportunities in the new services than they did while resident in Gogarburn and spent more time in their homes than they did previously.

206. The Healthcare houses have access to a mini bus, although this is somewhat limited and depends on the demand for transport at the time.

207. SHAS recommends that the trust and local authorities review how the DART team is resourced and funded. The trust should clarify the balance of day therapy and day services they provide.

208. SHAS was disappointed to see that the post of volunteer co-ordinator/client service community co-ordinator was not extended beyond the closure of Gogarburn Hospital, contrary to recommendations made in ‘Volunteering in Edinburgh Healthcare Trust’, the research done by Edinburgh Voluntary Exchange. The primary care trust should review this given the need for building links in the new communities where people are now living.

Managing the funds of INCAPAX residents

209. Most of the residents in the inpatient Lothian Primary Care NHS Trust facilities are assessed as INCAPAX (unable to manage their own finances). Of the 60 residents in William Fraser, Greenbank and the Healthcare houses, 53 are INCAPAX. Only six residents in Murraypark were identified as INCAPAX despite the fact that all 18 residents are unable to manage their financial affairs. This requires should be addressed.
210. The patients funds manager for the Lothian Primary Care NHS Trust also takes responsibility for the residents in Douglas House – the children’s unit provided by the Lothian University Hospitals NHS Trust. The hospital is appointee for three residents who receive disability living allowance. The hospital also administers £2 a week ‘pocket money’ to the residents of Douglas House.

211. Multidisciplinary six-monthly reviews are established. The patients funds manager plans to be involved in the reviews along with other members of the multidisciplinary team.

212. The recent amendment to the Mental Health Act has legislated for hospital managers to retain the responsibility for managing funds of residents identified as INCAPAX when discharged to the community. This is interim legislation pending the implementation of the Adults with Incapacity Bill. The Lothian Primary Care NHS Trust needs to ensure that the appropriate arrangements are in place to ensure timely and easy access of funds for patients discharged into the community.

Support services

222. The trust facilities across the wide geographical area were generally well managed. This was both evidenced and supported by the views of a range of staff. Some maintenance problems arose in some of the healthcare houses, which were the responsibility of the contractors, and this led to unacceptably long delays in minor repairs to the accommodation and fittings. In general, those repairs that are the responsibility of the trust are carried out in a reasonable timescale, and urgent repairs are carried out as required.

223. The arrangements for catering vary across the inpatient provision. Some food is cooked on site whereas in other units, food is brought in. There is limited opportunity for residents to be involved in meal preparation.

224. SHAS was aware that staff had recently requested more flexibility and locally devolved budgets and a scheme has been piloted in the Healthcare house in West Lothian. In an agreement with The Royal Bank of Scotland, staff will have a credit card allowing them to withdraw money from central funds for petty cash and food items.

Clinical services

Administration and clerical

225. There are 4 wte administrative/secretarial for the medical staff, clinical services development managers and all the inpatient services. In addition, there are 5 wte. secretarial staff covering the eight CTLDs.

14 INCAPAX Mental Health (amendment) (Scotland) Act 1999, the Clark Act
226. A significant issue raised by many staff we met during the visit was the lack of secretarial/clerical support. This has become more of an issue since the closure of Gogarburn Hospital and the loss of “departmental secretaries”. The trust is planning an administrative review of clerical services and administration support to the CTLDs. The administration support to the clinical director and consultants should also be included in this review.

Clinical psychology

227. The learning disability psychology services are an adult service and in general referrals are only accepted for people aged 16 and above. Historically the service had a role in providing services to children with learning disabilities, although this changed when children services became the responsibility of the Edinburgh Sick Children's NHS Trust. The lack of clinical psychology provision to children was noted in the last SHAS report and there is still no service for this group. The NCH Respite Care service for children with challenging behaviour employs a clinical psychologist for five sessions, although there are no formal links with the learning disability service.

228. The Edinburgh City and West Lothian service has an acting head of service, 4.1 wte clinical psychologist and 3 assistant psychologists. Since the closure of Gogarburn Hospital, staff are based within the geographical area they cover. The department also provides a Lothian-wide psychology service to the challenging behaviour team and the specialist forensic service. East Lothian and Midlothian has a head of speciality for learning disabilities (.8 sessions) covering East Lothian and .6 sessions for Midlothian. In addition, there is an assistant psychologist post funded from endowment funds for six months.

229. The psychology services are involved in a number of developments such as work with older adults with a learning disability and a programme on developing parenting skills for people with learning disabilities who are parents. There is a well-developed forensic psychology service which provides input to the William Fraser Centre and to people living in Lothian. The East Lothian and Midlothian services have taken forward a project for Down’s Syndrome and Dementia screening and are working closely with their primary care colleagues on a number of issues relevant to the client group.

230. The psychology services across Lothian are actively involved in supporting and training carers and social care providers in areas such as challenging behaviour.
231. The service is actively involved in a number of research projects such as assessment of dementia for people with Down’s Syndrome and evaluating treatment approaches for people with learning disabilities and offending behaviour, access to primary care services and management of challenging behaviour. Both departments have an impressive range of publications. There is an opportunity for this work to inform service developments.

Creative therapies

232. There is one head art therapist and 1.2 (wte.) senior art therapists. At the time of the SHAS visit, the head art therapist was seconded to do some research on the effectiveness of art therapy. The head art therapist is responsible for the DART Team.

233. The art therapy service provides input to the Greenbank and William Fraser Centres as part of a multidisciplinary team.

234. Staff in the DART Team are involved in providing therapy and day services to residents in the Healthcare houses. The art therapists are also involved with the community learning disability teams although the resources available limit the involvement of individual work with people in the community.

235. Since the closure of Gogarburn Hospital there have been some problems with the availability and access of storage space for materials and activities. This needs to be addressed.

236. A separate Artlink programme involves ex hospital residents in creative video work. Service users spoke highly of this opportunity. The service is an example of good practice.

Dietetics

237. Specialist dietetic services for people with learning disabilities are provided on a Lothian-wide basis. The service has 1.8 wte for the inpatient and community services. The current resource allocation is two sessions for East Lothian and Midlothian, four sessions for West Lothian and 1.2 wte for Edinburgh and the inpatient services. While there has been a small increase in the establishment of dietetic services for people with learning disabilities since 1994, the resources available make it very difficult for a comprehensive service to be provided across Lothian. While dieticians are attached to community learning disability teams, it is difficult to have input to multidisciplinary case discussions on a regular basis (given the workload and the areas covered). This is particularly the case for the dietician covering the Edinburgh City CTLDs.
238. The service is involved in providing advice and information on menu planning, special diets and training and education of carers. There are major nutritional needs for this group, such as problems with significant underweight, overweight and swallowing problems. The dieticians have introduced weight monitoring forms that allow care staff to monitor changes in weight and identify when referral to the dietician might be appropriate.

239. The dieticians reported problems with the range of knowledge and information amongst social care providers on dietary needs and nutritional issues. SHAS recommends that the National Care Standards Group considers the development of nutritional standards for care homes.

Nursing

240. There have been major changes in the organisation and management of nursing services since the closure of Gogarburn Hospital. Nursing staff in the inpatient services work 24 hour shifts, in all areas Two clinical service development managers now manage learning disability nursing, one for the inpatient services and one for the community learning disability teams. The level of staffing and skill mix allocated to the inpatient services is adequate. There is very limited use of temporary contract for sickness and maternity leave. SHAS welcomes this.

241. There is significant use of bank staff to cover absence and to provide special cover for some patients. The trust should keep this under review. The level of sickness absence has reduced from 20% at the time of the last SHAS visit in 1998 to a median of 2.5% for short-term absence and a median of 4.2% for long-term absence. This represents a considerable improvement.

242. SHAS was concerned to hear that there is no longer a post of clinical nurse specialist for inpatient services. The trust should review this and consider how such a role could be supported. There is a clinical development nurse for community services who links with the Director of Nursing.

243. There is a well developed community nursing service with 17 ‘G’ grade staff and seven ‘E’ grade staff to cover Edinburgh City, West Lothian, East Lothian and Midlothian. The service available to East Lothian and Midlothian is less well resourced than elsewhere in Lothian and issues of equity across Lothian need to be addressed. Community nurses provide a service to adults and children. Community nurses have developed a number of initiatives aimed at meeting the health needs of people with learning disabilities and these need to be supported by a community nursing strategy for learning disability services.
Occupational therapy

244. There are 8.7 wte. occupational therapists for Lothian adult learning disability services. Staff are linked to community learning disability teams and provide input to the Healthcare houses, William Fraser and Greenbank Centres. In Edinburgh there are good links between occupational therapists employed by the primary care trust and day centres, although links are less well-established in West Lothian.

245. The focus of occupational therapy input to the Healthcare Houses has seen a welcome emphasis on activities within the community which previously would have been hospital-based. There is a consequential increase in activity-related expenditure which has not been matched by a funding review. The situation is reported as less problematic in East Lothian and Midlothian where occupational therapists have access to petty cash, and it may be appropriate to review the position in Edinburgh in the light of the different practices.

246. Across the region there is inconsistency in the funding of aids and adaptations. In some areas it is accepted as a social work responsibility, in others that of the care providers. While this is not a direct issue for the trusts, it clearly has an effect on the outcomes for occupational therapy involvement and should be addressed at a strategic level between the trusts and the local authorities.

Physiotherapy

247. Physiotherapy services for people with learning disabilities consist of nine whole time equivalent (wte) physiotherapists for the City of Edinburgh, 1.5 for West Lothian and three wte staff plus a physiotherapy assistant for East Lothian and Midlothian. Some recent staffing difficulties have been experienced in relation to vacancies and maternity leave.

248. The physiotherapists are linked to community learning disability teams but tend to work around the adult training/resource centres and the trust inpatient services. The provision of services outwith the large hospital bases has resulted in some difficulties, particularly with regard to access and provision of equipment. There is a need to identify appropriate budgets for small items of equipment and to enable easy access to equipment still stored in Gogarburn Hospital. Problems regarding transport of equipment will need to be addressed.

249. The physiotherapy service is involved in supporting people with learning disabilities to access acute physiotherapy in community settings where appropriate. Some advice and training has been offered to community-based physiotherapists and appropriate support is offered to individuals with learning disabilities attending for outpatient appointments.
250. There is a good orthotic service and procedures have been put in place to enable physiotherapists to prescribe in close consultation with the orthotics staff.

251. Physiotherapists are involved in a range of training initiatives with social care providers. Initially this was set up in the context of the Gogarburn Hospital closure but there are ongoing requests because of changes in staff and the development of new services.

252. The service is involved in academic work with a number of the staff contributing to a forthcoming book on learning disabilities, physical treatment and management. The staff should be congratulated on this achievement.

**Psychiatry services**

253. Since the trust reorganisation, there are now 4.6 wte consultants and one senior lecturer post. One of the consultants is the clinical director for learning disability services. In addition to the consultant staff there is one associate specialist for the epilepsy and specialist needs services, two part-time staff grade posts (1 wte.) and two SHOs who provide input to the inpatient facilities and community services. There is one part-time senior registrar and a specialist registrar post (SpR).

254. Two consultants have responsibility for the assessment and treatment services at the William Fraser and Greenbank Centres. The consultants provide services on a geographical basis. Special interests include autism, older people, dementia and the homeless.

255. The psychiatrists do not provide a service to children and adolescents with learning disabilities under the age of 16. There is a funded half session for psychiatry input to Douglas House and very limited involvement of the SpR in the NCH respite unit for children with challenging behaviour. The issues of mental health services to children and young people are referred to in paragraph 92.

256. The consultant staff provide a 24 hour on-call service for learning disabilities with some additional on-call available from psychiatrists in the Royal Edinburgh Hospital.

257. Medical staff are involved in a number of research and audit projects including a neuroleptic audit in the community, survey of autism and identification of people with learning disabilities in the homeless population. Work on appropriate modification of SIGN guidelines for epilepsy and schizophrenia in a learning disability context is being taken forward. This work can inform practice at a national level. Audit work is also underway in relation to high dosage antipsychotic medication.
Social work

258. Prior to the closure of Gogarburn Hospital, a social work team was based in the hospital fulfilling the assessment and commissioning role over the course of the resettlement and reprovision programme. The work on the hospital reprovision programme was significant and SHAS recognises the role social work has played in this process. There is still a small team of staff involved in the assessment and commissioning work for the out-of-Lothian hospital residents who will be resettled by December this year. This will complete the Lothian hospital reprovision programme.

259. There are a number of references made to social work elsewhere in the report. SHAS was impressed with the evidence of good links between health professionals and social workers around individuals. There are dedicated care managers for learning disability services in East Lothian and Midlothian but generic care managers in Edinburgh and West Lothian. In Edinburgh, each area team has a worker with a lead responsible for learning disabilities, although this person is not in a position to take on all the relevant work.

260. The need for social work involvement in the inpatient provision is identified in the report. SHAS was pleased to hear that a care manager in Midlothian is linked to the healthcare house and involved with individuals on a regular basis. In Edinburgh there are plans to identify a social work manager as the link person for inpatient learning disability services. SHAS recommends that this post links with the challenging behaviour team and directorate management team.

Speech and language therapy

261. There are 8.2 (wte) posts for the speech and language therapy services to adults with learning disabilities in Edinburgh and West Lothian and 2.8 wte for East Lothian and Midlothian. At the time of the SHAS visit there was one vacancy and efforts were being made to recruit to this post. The departments are involved in providing a service as members of the community learning disability teams and also have input to the William Fraser and Greenbank Centres, the Healthcare houses and the challenging behaviour team.

262. The principal focus of the work is on assessment, therapy and advice to clients and their carers, about communication disorders and dysphagia. The service is involved in a number of local and national good practice initiatives, such as ‘sign-a-long’ tutoring, dysphagia training and assessment of people with Autistic Spectrum Disorder. The service is also actively involved in training staff in a number of provider agencies.
263. The reorganisation of the service in the context of the Gogarburn reprovision has created some difficulties in relation to access to equipment. This is leading to delays in diagnostic assessment and therapeutic intervention.

264. The development of a dysphagia training pack and training of carers in the community are examples of good practice and are to be commended. However, both of these initiatives would benefit from the support of a clear trust policy on dysphagia management and the dangers of choking. Such a policy would offer guidance to both trust and carers employed by service providers.

265. SHAS was pleased to see the support from endowment funds to develop information leaflets on:

- How to communicate with people with a learning disability;
- Getting help with communication and eating and drinking problems; and
- How to help people who have difficulty eating and drinking.

267. Given the crucial role of communication by and with service users in the range of service settings, SHAS recommends that the primary care trust includes in any new job description an explicit remit for staff in supporting and developing communication with service users.
Conclusions

1. Learning disability services in Lothian have undergone significant change over the last few years with the closure of three hospitals and the development of services in the community. The strategic planning to date has almost exclusively focused on hospital closure and service reprovision and there are a number of strategic issues that should be addressed by Lothian Health in association with the trusts and the local authorities.

2. The reprovisioning of the hospital services in Lothian has enabled many people to live in small community-based settings and to access local community services. Much has been achieved and the experience gained in Lothian can usefully inform other hospital reprovision programmes elsewhere in Scotland. However, there are issues arising from the programme that need to be addressed. There is a lack of clarity as to the future plans for people in the new Healthcare Houses and how these services are considered in the wider context of service provision.

3. An impressive range of community services has been developed across Lothian for people discharged from Gogarburn, St. Joseph’s Hospitals and the Hopeton Unit. There needs to be appropriate monitoring and evaluation of the new services.

4. Since the last SHAS review little progress has been made in developing plans for the provision of mental health services to children and young people with learning disabilities. The role of child and family psychiatry and learning disability services needs to be considered to ensure an appropriate multi-disciplinary service for this vulnerable group.

5. The primary care trust is now responsible for all specialist learning disability services for adults. Changes in the management structure along with the closure of Gogarburn Hospital has led to many staff in the primary care trust being unclear about the new management arrangements. The appointment of a clinical director for learning disabilities has the potential for giving clear clinical leadership to the service at a time of significant change.

6. There are some excellent services for children and young people with profound and multiple disabilities that are mainly the responsibility of the Lothian University Hospitals NHS Trust. There is a range of residential, respite and developing outreach services for this group, although there are concerns around the increasing number of very complex cases and the future resource implications. Community learning disability nurses play a major role in services for children although there is no other involvement of members of the specialist learning disability teams.
7. There are a number of initiatives that support people with learning disabilities in accessing general health services. There is an excellent link nurse project with one of the acute hospitals. There are problems in certain areas such as the provision of healthcare tasks in social care settings that agencies are working to resolve.

8. There is a well-established community learning disability team service across Lothian. This is a very good service. Community nurses, in particular, provide excellent support to people with learning disabilities in the community and their carers. With the changes in trust reorganisation there is an issue of equity in service provision that needs to be addressed. The role of the community learning disability teams needs to be considered in the context of the developing local healthcare co-operatives. There are good links with social work and evidence of good multidisciplinary working.

9. Links with primary care services are developing, although there is a variable level of awareness by GPs about learning disability services and the needs of people with learning disabilities living in the community. The clinical service development manager has done some excellent work with the LHCCs in relation to learning disability services.

10. A number of specialist services have been or are being developed to support people with additional and complex needs. These include the Regional Epilepsy Service, Special Needs Clinic, Challenging Behaviour Team and developing work in relation to older people with learning disabilities. There is excellent practice in some of these areas.

11. The inpatient services have seen the most change over recent years with a very significant reduction in the numbers of beds. There is evidence of good multidisciplinary working in the assessment and treatment units although the input from the range of clinical disciplines is more variable in the Healthcare houses, due in part to some recruitment problems. The nursing services are now in a much more stable situation with a significant reduction in staff absence and staff on temporary contracts. There is still a high dependency on bank staff to ensure appropriate staffing is in place to meet the needs of the residents.

12. There is no health funded advocacy services for people with a learning disability, including for those in inpatient accommodation. Advocacy services had been funded in the context of the hospital reprovision programme but this was discontinued in September 1999. This is a significant gap.

13. The range and availability of day services for people in the inpatient provision is variable. The continued involvement of the DART team has been very beneficial and additional resources may be required to ensure an equitable service across inpatient services.
14. The closure of all long stay hospital provision is a significant achievement for all agencies involved. There remains a number of challenges for the learning disability services in relation to the integration and development of services in a largely community-based context. These and other issues need to be taken forward by the health board, the trusts and other agencies.
Good practice

SHAS was impressed with the many examples of good practice observed during the visit. These included:

- the successful hospital closure and service reprovision programme and the work to support relatives, users, GPs and others;
- joint commissioning of the NCH respite service for children with severe challenging behaviour;
- the development of high quality health and social care provision in the community;
- the link nurse project that aims to provide training and support to general nursing staff and information on the needs of people with learning disabilities in acute hospital settings;
- the development of the FAIR health promotion leaflets and other health promotion initiatives;
- the development of information leaflets to assist people with learning disabilities;
- joint working across health and social work, as evidenced in health input to day centres and training of staff in social care provision;
- the health screening initiative that has been taken forward by community learning disability nurses in association with primary care colleagues and the developing links and work with primary care colleagues;
- the development of a care pathway for people with Down Syndrome;
- the quality of services to children with profound and multiple disabilities in Douglas House and Cairdean and the liaison role of the community paediatrician;
- provision of specialist services, in particular the Epilepsy Service and the Special Needs Clinic;
- the project being taken forward to assess the prevalence of learning disability in the homeless population;
- the range of clinical research being undertaken by the different professional groups; and
- the high standard of professional practice across the different disciplines.
Main recommendations

Several suggestions for improving the service are made throughout the text. The main recommendations are as follows:

1. The health board, in collaboration with the three Lothian trusts, social work departments and other agencies, needs to progress a comprehensive health needs assessment and to ensure the development of a learning disability strategy meets the health needs of people with learning disabilities in Lothian. Carers and service users, along with all stakeholders, need to be fully involved in the process.

2. The health board, trusts and local authorities need to address issues identified in relation to the hospital closure and service reprovision programme. Particular attention should be given to:
   - provision of advocacy services to people with learning disabilities in inpatient accommodation and for people in the community.
   - individual plans for people currently in health care provision and links with social work;
   - access to equipment for people discharged from Gogarburn Hospital to West Lothian; and
   - the issues impacting on the delivery of healthcare in social care settings.

3. The health board, Lothian Primary Care, West Lothian Healthcare and the University Hospitals NHS Trusts in association with other agencies, need to ensure that appropriate arrangements are put in place to fully meet the health needs of children and young people with learning disabilities. Particular attention should be given to the provision of mental health services and the interface between child and adult services.

4. The health board, primary care and West Lothian trusts, in association with general practitioners and social work colleagues, need to ensure appropriate and adequate healthcare provision for people with learning disabilities living in the community. There needs to be equity of access to health services and a strategic direction for the provision of healthcare to people with learning disabilities and other families.

5. The primary care trust needs to implement the new management arrangements for staff. There should be appropriate forums in place to ensure clinical staff are involved in the planning and development of services across Lothian.
6. The primary care trust should address issues in relation to inpatient provision including:

- access to advocacy services;
- availability and range of day care opportunities;
- provision of general medical services; and
- availability of clinical psychology, pharmacy and speech and language therapy.

DR SANDRA M GRANT
Chief Executive

30 May 2000
Appendix 1

Hospital reprovision and resettlement

Lothian is the first area in Scotland to have achieved reprovision of all learning disability hospital facilities and by December 2000 will have resettled all residents in out-of-Lothian hospitals. This is a significant achievement and Lothian Health, the primary care trust and local authority colleagues need to be commended for this.

Three learning disability institutions have closed. The largest, Gogarburn Hospital, closed in May 1999. 302 people have been discharged to a range of community resources since 1994. Day care and respite services were also commissioned as part of the hospital reprovision programme. Table 1 shows the detailed information on discharges. The vast majority have moved to social care provision, with 32 having moved to Healthcare provision and nine to other hospitals. There have been 13 readmissions since 1994. Figure 1 provides graphical representation of the discharges, deaths and readmissions by year from 1994.

| Table 1  
| Gogarburn Hospital  
| Discharges, Deaths, Re-admissions and Proposed Discharges  
| April 1994 to February 2000  

| Discharges, Deaths, Re-admissions and Proposed Discharges April 1994 to February 2000 |
|---|---|---|---|---|---|---|---|
| | 94/95 | 95/96 | 96/97 | 97/98 | 98/99 | 99/00 | Total |
| Residents at 01.04.94. | | | | | | | **336** |
| Deaths in hospital | 11 | 12 | 8 | 2 | 1 | 0 | 34 |
| Deaths in community (1) | 0 | 2 | 4 | 7 | 6 | 6 | 25 |
| Social Care Discharges (2) | 7 | 48 | 73 | 45 | 75 | 16 | 264 |
| HCH Discharges (3) | 6 | 18 | 8 | | | | 32 |
| Discharges to other hospitals (4) | 2 | | 7 | | | | 9 |
| General & Section 58 Re-admissions | -2 | -4 | -3 | -4 | -13 | | |
| Discharges not achieved to date(5) | | | | | 8 | 8 | |
| State Hospital & Section 58 Pats(6) | | | | | 2 | 2 | |
| Total Discharges (7) | 7 | 48 | 73 | 53 | 93 | 31 | 305 |
| Achieved + Proposed Discharges (8) | 7 | 48 | 71 | 49 | 90 | 37 | 302 |
| Total Discharges + Deaths excluding readmissions | | | | | | | **336** |

Note 1: 25 deaths in community after transfer
Note 2: Achieved discharges to community social care placements
Note 3: Achieved discharges to community Health care placements
Note 4: Achieved discharges to other hospital accommodation
Note 5: Discharges not yet achieved includes some re-admissions
Note 6: 1 person in State & 1 person admitted under Sec 58
Note 7: Total figures to 29 February 2000 not taking account of re-admissions (292 including readmissions)
Note 8: Net of re-admissions

This includes Murraypark at this stage.
The financial framework and commissioning arrangements are covered in the June 1998 SHAS report.\textsuperscript{15}

The plans for the development of Murraypark as a nursing home have run into some difficulty. There is an additional cost to Lothian Health of £100,000 a year while the residents remain inpatients. SHAS supports the aims to have this service commissioned as a social care resource and notes that the health board and trust are working towards a resolution to the current problem.

St. Joseph’s Hospital closed in March 1999 with a total of 88 people discharged to live in community-based provision, provided by St. Joseph’s Services, mainly in Midlothian and South-East Edinburgh. St. Joseph’s Services also provide residential provision for a number of people discharged from St. Joseph’s Hospital prior to the 1994 strategic agreement. The discharge arrangements have been complex in that a total of about 50 people are not from Lothian. Lothian Health provided extra funding to Midlothian Social Work Department to assist in the care management arrangements. Midlothian Social Work Department needs to negotiate with a large number of local authorities around this issue. In addition, the care needs of some individuals have exceeded the existing available resources and St. Joseph’s Services need to reach agreement with the out-of-Lothian local authorities to enable the appropriate level of support and care to be provided.

The Hopetoun Unit closed in January 1998 and 60 people were resettled in a range of small community services provided by ELCAP. Lothian Health contracted directly with ELCAP for 51 places until July 1999 when the commissioning role was transferred to East Lothian Social Work Department. In addition, a small number were out-of-Lothian people and ELCAP contracting arrangements are with the relevant local authority.

In East Lothian there was no provision within the resource transfer budget for day care provision and this has been funded by East Lothian Social Work Department. Lothian Health is continuing to provide some bridging money to support the care needs of residents in ELCAP for a period of four years.

In addition to the Lothian hospital reprovision programme, Lothian Health and the four Lothian local authority social work departments are planning for the resettlement of all Lothian patients in long-stay learning disability hospitals outwith Lothian. 50 of the 65 people have already been resettled. Most people have moved back to Lothian, with a small number remaining in the area local to their long-stay hospital. The remaining 11 individuals will be resettled in Lothian by December this year. This final phase of the hospital reprovision strategy will see all Lothian residents with a learning disability resettled from long-stay hospital provision.
## Appendix 2

**VISITS AND MEETINGS**

**VOLUNTARY ORGANISATIONS, USER GROUPS AND SOCIAL CARE PROVIDERS WHO MET WITH SHAS**

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Location</th>
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<tbody>
<tr>
<td>Action Group</td>
<td>Edinburgh</td>
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<tr>
<td>Artlink Project</td>
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<td>Ark Housing</td>
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<tr>
<td>Beatie School Campus</td>
<td>West Lothian</td>
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<tr>
<td>Blackburn Adult Training Centre</td>
<td>West Lothian</td>
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<tr>
<td>Carers Groups/representatives</td>
<td>Lothian-wide</td>
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<tr>
<td>Choices</td>
<td>Midlothian &amp; West Lothian</td>
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<td>Community Integrated care</td>
<td>Edinburgh</td>
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<td>Columcille Day Centre</td>
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<td>Church of Scotland Services</td>
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