

**SCOTTISH HEALTH ADVISORY SERVICE**

**SERVICES FOR PEOPLE WITH PHYSICAL  
DISABILITIES IN LoTHIAN**

**Review of  
Services for People with Physical Disabilities  
In Lothian**

**1 – 4 November 1999**

**This report may be photocopied or obtained from:**

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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 Health Council;

Lothian Primary Care NHS Trust, West Lothian Healthcare NHS Trust, Lothian University

Hospitals NHS Trust;

Lothian Health;

Lothian and West Lothian Social Work Department;

Representatives from Voluntary Organisations.

## EXECUTIVE SUMMARY

The Scottish Health Advisory Service visited services for younger people with physical disabilities that are provided by Lothian Primary Care and West Lothian Healthcare NHS Trusts. This report covers the specialist hospital assessment and rehabilitation services and community services across Lothian.

The range and quality of inpatient assessment and rehabilitation services is excellent as is the day care and out patient services. There is little emphasis, however, on the long-term needs of people in the community, although community rehabilitation is beginning in both trusts.

Service users experience major problems about patient transport, which has a significant impact on their access to health care. This is a problem across Lothian but particularly so for people living in rural communities.

There are difficulties for young people with complex physical disabilities and their families around the transition to adult services, with many people over 18 years being unable to get the full range of health services that are available to younger people.

There will be an impact on the service when the Princess Margaret Rose Hospital closes in two years' time, the site at the Astley Ainslie Hospital is rationalised and the new Royal Infirmary of Edinburgh is opened. These and other issues need to be considered in a strategic context.

There are many examples of good practice within the services. There are also some issues that need to be addressed to ensure equitable and accessible services for people with physical disabilities in Lothian.

Lothian Health Board and the Lothian Trusts are asked to:

- note the contents of this report; and
- take action on the recommendations contained in this report.

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## Introduction

1. Lothian Health covers a population of 772,684. Since April 1999, Lothian Primary Care NHS Trust and Lothian University Hospitals NHS Trust cover the geographic areas of Edinburgh, East Lothian and Midlothian, which have a combined population of just under 620,000. The remaining population of 153,000 is covered by the West Lothian Healthcare NHS Trust.
2. The services identified in this review (see table 1 below) include tertiary services provided on a Scotland-wide basis, services covering a number of health boards in south-east Scotland, services provided on a Lothian-wide basis and local services in the Primary Care and West Lothian trusts.

**Table 1**  
**Rehabilitation/Physical Disability Services**  
**Provided in Lothian**

<b>Scottish-wide Services/Tertiary Services Lothian Primary Healthcare NHS Trust</b>	<b>South-East Scotland Lothian Primary Care NHS Trust</b>	<b>Lothian-wide Services Lothian Primary Care NHS Trust</b>	<b>Trust Specific Services Lothian Primary Care NHS Trust West Lothian Health Care NHS Trust</b>
Brain Injury:  • Charles Bell Pavilion  • Robert Fergusson Unit	Wheelchair Service  Bioengineering and Prosthetics	Neuro-rehabilitation Cardiac rehabilitation Locomotor Disability Lanfine Unit Disabled Living Centre Chronic Pain Service * Link Nurses	Cardiac rehabilitation (West Lothian) General community services Local Health Care Co-operatives

\* Lothian University Hospitals NHS Trust

3. For the purpose of this review, services to people with physical disabilities include: the specialist rehabilitation services provided at the Astley Ainslie Hospital, the Liberton Hospital Lanfine Unit in Edinburgh, Ward 4 at St. John's Hospital and community and primary care services in Lothian.
4. Since the formation of the new trusts, specialised assessment and rehabilitation services for younger physically disabled people have been located within the Lothian Primary Care NHS Trust, although there is a close interface with the Lothian University Hospitals NHS Trust. This report refers to some of the services provided by the acute trust, in particular services to children and specialist services provided by nurses. The orthopaedic services at the Princess Margaret Rose Hospital have not been reviewed.
5. There are seven local healthcare co-operatives (LHCCs) in the Lothian Primary Care NHS Trust. West Lothian Healthcare NHS Trust provides integrated acute and community services, with primary and community services being the

responsibility of the Directorate of Primary Care. Table 2 below provides summary information on current service provision. In addition to the inpatient services, Lothian Primary Care NHS Trust provides a range of community services with a developing community rehabilitation approach for people with chronic disabilities. In West Lothian there is a new community rehabilitation team, which is jointly funded by the health board, trust and social work department. There is a range of other community services supporting people with physical disabilities in West Lothian.

**Table 2**  
**Bed Numbers by Hospital**  
**Rehabilitation/Young Physically Disabled**

	<b>Astley Ainslie Hospital</b>	<b>Lanfine Unit Liberton Hospital</b>	<b>St. John's Hospital *</b>
Brain Injury	20		
Neuro-rehabilitation	20		
Stroke	12 (< 70 years)		11 (all ages)
Cardiac Rehabilitation	8		access to beds
Limb Amputation/ Locomotor Disability	21		
Continuing Care		3	
Respite/ Rehabilitation		30	access to beds

\* access to beds in Wards 4, 8 and 9 as required

6. The health board contributes funding for a number of places in nursing homes for people with complex disabling conditions. The board also provides some funding for a small number of people living in their own homes.
7. The principal focus of this review was on health services provided for younger people (under 65) with physical disabilities by the Primary Care Trust, although attention was also given to services provided by West Lothian Healthcare NHS

Trust. A very important focus of the review was the health needs of people with long-term complex and chronic disabilities living in the community.

8. Meetings were held with people who receive services and their carers, staff from Lothian Health and Lothian Primary Care, West Lothian Healthcare and Lothian University Hospitals NHS Trusts. The team also met the Local Health Council, City of Edinburgh and West Lothian Social Work departments, representatives from primary care services and community staff and a number of voluntary organisations. SHAS is grateful to these people who gave their time to help complete the review.
9. This current visit provides the first opportunity for a review of physical disability services. There is evidence of a number of examples of high quality care and innovative practice.

### **Issues relating to a review of physical disability services**

10. The visit to Lothian services for people with physical disabilities is the first comprehensive SHAS visit to examine services for this group both in hospital and the community. A number of themes quickly emerged, including the lack of an agreed definition of physical disability. The decision was taken to concentrate on the main diagnostic groups that have dedicated specialist services. Disabling conditions such as sensory impairments were included. There was some difficulty in identifying services for people with lifelong disabling conditions and how these could best be included in the review. A number of voluntary organisations representing such groups contacted SHAS in the hope of being included and therefore getting support in arguing for better quality services. This will be considered for future visits.
11. Another important issue is the interface with services for older people. While some services are provided on an age basis, many people receiving services for a physical disability are over 65 years and some of the issues will be picked up as part of a SHAS review of services for older people. Decisions need to be taken about which services ought to be examined within the respective SHAS care groups.
12. SHAS also needs to look at the interface with services provided by the acute trust. Inpatient services provided by Lothian University Hospital NHS Trust were not included as part of this review, yet clearly there are a number of areas that are relevant to this group, such as the orthopaedic services at the Princess Margaret Rose Hospital. When does an 'acute' illness become a 'disability'?
13. Some of these issues are referred to throughout the report and SHAS would welcome feedback about how best to organise future service reviews.

## Planning services

14. Lothian Health is involved in joint planning forums with the four local authorities and other agencies. Both City of Edinburgh and West Lothian Social Work departments are leading strategy groups on services for people with physical disabilities linked to the development of joint community care plans. Midlothian and East Lothian local authorities do not have specific planning groups looking at services for people with physical disabilities but a position paper has been prepared by Lothian Health about services in Midlothian. Plans are under way to develop a focus on people with physical disabilities in East Lothian. There has been an absence of co-ordinated planning.
15. The most recent draft Health Improvement Programme (HIP) 2000-2005<sup>1</sup> states that “the health board will liaise with the four local authorities to reduce the incidence and impact of disability, and to improve services for people with physical disabilities through more effective working, focusing initially on a number of chronic conditions”.
16. There are plans to rationalise the Astley Ainslie Hospital site and to close the Princess Margaret Rose Hospital in two years’ time. The SHAS team found that managers and staff were very unclear about the role of the different groups working on this. There is a need to engage clinicians in this work at an early stage and to develop a clear vision for the future provision of services across hospital and community settings.
17. The local authorities are leading on planning at a local level, with involvement from the health board. These strategy groups have identified a number of key issues. In Edinburgh, priorities are the provision of advocacy and counselling services, integrated service provision and the provision of information.
18. West Lothian has also identified the development of advocacy services as a priority in addition to day opportunities, respite care and joint working with health services. Joint planning has led to the development of ‘Ability Services’ and a new Ability Centre to be based in Livingston. This will provide a focus for the services to younger people with physical disabilities. This integrated working is a good way forward.
19. While there is no overall strategy for physical disability services in Lothian, Lothian Health has strategies about Stroke and Cardiac services. These focus mainly on the acute stage of the illnesses, although the Cardiac Heart Disease Strategy also has a strong emphasis on rehabilitation. A cardiac rehabilitation group has been established to look at the cardiac rehabilitation services across Lothian. This group is chaired by a consultant in rehabilitation from the Primary Care Trust and has representation from Lothian Health, Lothian University Hospitals and West Lothian Healthcare NHS Trusts.
20. The Health Improvement Programme describes medium and long-term aims for physical disability services. Key areas are access to services, information, day

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<sup>1</sup> Lothian Health (2000): Health Improvement Programme 2000-2004 – Draft, March 2000

services, transport and primary and community health services. SHAS was pleased to note the reference made to the role of primary care and community health services in supporting people in the community, particularly those with complex needs. There has been little evidence to date of progress being made with these objectives.

21. Lothian Health has developed eligibility criteria for the provision of health services to meet continuing healthcare needs <sup>2</sup>, in association with the NHS trusts and local authority colleagues. During the visit, a number of questions arose about the number of people who require significant health and social care input and how to fund such 'care packages'. A recent audit examined the social and healthcare components, with costings for 50 people with complex needs. This is an important step.
22. Lothian Health provides additional funding to enable a small number of people with complex disabilities, including people with Huntington's Disease, to be cared for in nursing homes or in their own home. This is currently being provided on a case-by-case basis and there is a need for a more formally agreed strategy for this group to ensure equity of access. There are plans to transfer the responsibility for funding this to Lothian Primary Care NHS Trust and West Lothian Healthcare NHS Trust. However, concerns were expressed by both trusts about the lack of information on assessed need and the potential resource implications that have not yet been identified.
23. The needs of people with Huntington's Disease are very complex, requiring expertise from specialists in genetics, psychiatry, neurology and general medicine as well as practical and psychological support. There is a need to consider the needs of such people within a strategic context that addresses such multi-speciality issues, not just in Lothian but across Scotland as a whole.
24. The SHAS team found particular gaps in planning and service delivery for people with long-term complex disabilities. While considerable attention and resources are focused on the acute assessment and rehabilitation period, little attention appears to be paid to long-term needs and the provision of appropriate services in the community.
25. Two community rehabilitation teams were established as part of Lothian Health's acute, community and older people's services strategies. The teams primarily provide a service to older people to assist with early discharge from the Royal Infirmary of Edinburgh. The service is available up to a maximum of five weeks post-discharge. Recent discussions have taken place with the rehabilitation services at the Astley Ainslie to identify specific roles and responsibilities in relation to younger people with physical disabilities.
26. There are major planning gaps in transitional arrangements for young people with physical disabilities, i.e. moving from children's to adult services, and

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<sup>2</sup> NHS in Lothian – April 1999 – Policy and eligibility criteria for the provision of health services to meet continuing health care needs. Lothian Health and General Practitioners, City of Edinburgh council, East Lothian Council, Midlothian Council and West Lothian Council.

SHAS notes that this is referred to in the Children's Service Strategy.<sup>3</sup> There is a need for clear procedures and systems to be put in place to ensure health needs continue to be properly addressed after 18 years' of age.

## Needs assessment

27. Lothian Health commissioned a comprehensive study in the early 1980s, which looked at prevalence rates for children and adults with physical disabilities. It is disappointing that so little use has been made of this information. While the work is somewhat out-of-date, it nevertheless could provide a useful reference and support the work being taken forward in this area. Information is available from the national Office of Population Census and Surveys (OPCS)<sup>4</sup> to estimate a prevalence of physical disability by local authority area and diagnostic group. In Lothian about 9% of people between 16 and 69 will have some form of physical disability.
28. The SHAS team found an absence of any comprehensive up-to-date needs assessment information on people with chronic disabilities living in the community, although some reference is made to specific needs in the Stroke, Cardiac and Children's Strategies. It is recommended that the health board undertakes a comprehensive health needs assessment across Lothian.
29. There is considerable information available in the paediatric services and this should be considered as part of the overall needs assessment approach. A joint approach with social work colleagues will provide a holistic approach to the identification of need for this client group.

## Service user involvement in planning

30. Service user representatives are involved in the Edinburgh City and West Lothian strategy groups on physical disability. In West Lothian, service users have been actively involved in plans for the development of the Ability Centre, and Disability (West Lothian) was involved in organising a conference to take forward planning in this area. This is a good example of pro-active service user involvement and should serve as an example of good practice to other areas.
31. The SHAS team, however, found little evidence of active service user involvement in planning services in East Lothian and Midlothian. At the time of the SHAS visit, there were no specific groups focusing on services for people with a physical disability.
32. Lothian Primary Care NHS Trust involves service users in an *ad hoc* way with some examples of good service user involvement in services at the Lanfine Unit and Charles Bell Pavilion. However, user involvement and work with user groups within communities is not a priority and there is no specific plans to

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<sup>3</sup> Lothian Health (1997): Children's and Young People's Health Strategy

<sup>4</sup> Office of Population Census and Surveys (OPCS) (1988)

address this. There is an opportunity for the developing LHCCs to engage service users in the development and delivery of these services.

## **Evaluation**

33. Lothian Health is involved in some limited evaluation of specific service initiatives such as specialist nurses and the pain management programme. In association with local authorities it will evaluate the pilot Edinburgh community rehabilitation teams that focus mainly on services for older people following discharge from the Royal Infirmary and also the West Lothian community rehabilitation team. There is a need for ongoing evaluation to inform future service provision.

## **Leadership and management**

### **Lothian Primary Care NHS Trust**

34. The establishment of new trusts led to changes at Executive Director level. The Primary Care Trust inpatient rehabilitation services at the Astley Ainslie Hospital and the Lanfine Unit are managed as part of the Clinical Directorate for Rehabilitation Services along with the Wheelchair Service and Disabled Living Centre. A hospital manager who has day-to-day operational management of the hospital-based services supports the Clinical Director. People working in the Professions Allied to Medicine (PAMs) are managerially responsible to the hospital general manager and report on clinical issues to the Clinical Director. Outpatient services, and other services such as clinical psychology (health and neuro-psychology) report to the Clinical Director. Since the reconfiguration of trusts, the Prosthetics and Bio-engineering services are now part of the Primary Care Trust.
35. The development of LHCCs has led to the appointment of general manager posts in each of the seven areas covering Edinburgh City, East Lothian and Midlothian. Each LHCC has a practising GP as a Clinical Director who is supported by a general manager. Most community-based clinical staff who provide a service to a specific LHCC link in to this local management structure, although physiotherapy and chiropody have a lead LHCC that provides management and professional advice.
36. Community-based speech and language therapy services to adults are managed separately from the LHCC structure and SHAS was unclear how this service linked to the management structure and to the speech and language therapy rehabilitation services.
37. SHAS found a degree of uncertainty and confusion about the new management structures within the Lothian Primary Care NHS Trust. While managers in the rehabilitation directorate are accessible and supportive to staff, SHAS found many staff still uncertain about the line management arrangements.

Professional advisers have recently been appointed, but staff seemed unsure about the role of the advisers and, in some cases, did not know who the person was.

38. Senior management is aware of these issues and is addressing them so that by the time of publication of this report they should be resolved, and SHAS will confirm this.
39. There are policies covering most activities within the service but because of the change in trust structure most policies are currently under review. SHAS recommends that an early decision is taken on the status of policies in the service to ensure there is less uncertainty for staff.
40. The Department of Health has issued recent guidance <sup>5</sup> on access to services for all disabled people and the need for a designated manager to head up a disability strategy on access to goods and services. This should identify the requirements for staff training and access to information in a wide range of formats. There is an overall requirement that premises will be physically accessible by 2004. There is a need for the Primary Care Trust to take forward this guidance.

## **Clinical governance**

41. The Clinical Governance Committee is chaired by the Medical Director and covers clinical effectiveness (including audit), research and development, patient and carer involvement, risk management, complaints management and personal appraisal and development. At the time of the SHAS visit, work was in progress to consider how staff are to be involved in this agenda, which is essential given that the majority of staff SHAS met during the visit were unclear about their role. There is a need to inform staff about the implications of clinical governance and to engage them in the process.
42. Several audit projects are being undertaken on a unidisciplinary or multidisciplinary basis. Of particular note for this review is the Stroke Audit Project.
43. Clinical psychologists are evaluating the Angina Management Programme and the Pain Management Programme. There has already been considerable research on the Heart Manual, which is referred to later. The neuro-rehabilitation service has made a long-standing contribution to research with an impressive number of academic publications.
44. There is a well-established staff appraisal system for nurses in the Astley Ainslie Hospital and the Lanfine Unit. The staff appraisal system works through initial self-assessment and then appraisal of performance through the line management structure. Clinical supervision is evident and appears to work well.

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<sup>5</sup> Scottish Executive Health Department (1999): Good Practice – Equality for disabled people in the NHS in Scotland

## **Staff training**

45. Education and training for all staff has a high profile within the Primary Care Trust. There are good opportunities for professional and multi-professional in-service training. An annual nursing conference took place in September about innovations in clinical practice and effectiveness. There is an acknowledgement of the training needs of unqualified staff.
46. A training needs assessment was completed in January and will form the basis of a multi-professional trust-wide training programme. A clinical development nurse is linked to the Rehabilitation Medicine Directorate and the Care of the Elderly services and is much appreciated.
47. The Clinical Director has developed a training initiative with Queen Margaret College to train staff who work in the area of brain injury. While this is in an early stage of development, SHAS is pleased with the approach being adopted and recommends that consideration is given to extending this opportunity to other staff (including those working in West Lothian).
48. The Rehabilitation Stroke Unit of the University of Edinburgh is located at the Astley Ainslie Hospital, with office and research accommodation in the Charles Bell Pavilion and the administration building. The trust is involved in a programme of disability awareness training for staff and this needs to be accessible to all staff across the different services in both hospital and community settings. There is a library with a good range of books and journals, which is used by all professions for training and research.

## **West Lothian Healthcare NHS Trust**

49. The services in West Lothian are organised to integrate hospital and community services. The Directorate of Primary Care and Community Services has responsibility not only for the range of community-based services but also some inpatient services such as mental health. Liaison between the hospital and primary care services is well established.
50. The trust has identified a manager to take forward the Department of Health guidance on access to services and this area is identified in the Trust Implementation Plan.

## **Quality of care and services**

### **Assessing and meeting individual needs**

51. There are some excellent examples of high quality assessment work being carried out by the range of disciplines providing services to inpatients. The brain injury service has developed a comprehensive assessment of outcomes, this being carried out at the time of admission and at regular intervals throughout the inpatient stay. Clinicians are aware of the need to develop a similar instrument for assessing longer-term outcomes for people in the community.
52. For individuals resident in the community, the SHAS team found less attention being paid to assessment and ongoing review, especially for people with long-term disabling conditions. There is very limited specialist input, with the outreach assessment and rehabilitation services at the Astley Ainslie Hospital restricted to a few specific diagnostic groups. For people accessing the Lanfine Unit, there was evidence of good multidisciplinary assessment and review with some involvement of people attending social care day centres but this service is not available to the majority of people with disabilities in the community.
53. The development of a community rehabilitation team in West Lothian will allow more co-ordinated services for people with physical disabilities, which is a positive step forward.

### **Information for people using services**

54. The SHAS team was impressed with the range and availability of information for inpatients. Efforts have been made to customise information appropriate to the needs of different patient groups and additional support and information is readily available from a number of the voluntary organisations such as Headway and the Pain Society. The situation appears, once again, to be very different for people with disabilities living in the community. Voluntary organisations have a major role in providing information to service users, but this seemed to be less available in community health settings. There is a need for the LHCCs to work with voluntary organisations to ensure that helpful information is readily available to service users and their families.

### **Environment**

55. The accommodation on the Astley Ainslie Hospital site requires major upgrading and redesign in some areas. The design and layout of the Charles Bell Pavilion is not appropriate for the patient groups, although difficulties with access were already being addressed at the time of the SHAS visit.
56. Some wards in the Primary Care Trust have mixed sex accommodation, failing to comply with the Patients' Charter in terms of bathing, toileting facilities and

privacy. Some of these problems will be solved when the West Pavilion moves to a neighbouring area that will provide better accommodation and the East Pavilion is reorganised into two single sex wards in April 2000. There is a need for the Lothian Primary Care NHS Trust to make certain that appropriate action is taken to ensure accommodation is of an acceptable standard across the whole service, with due attention to dignity and privacy. The future plans for the service configuration at the Astley Ainslie site are under consideration but SHAS urges that the trust considers ways to improve the physical environment in the short-term pending these developments.

57. The trust should ensure that all relevant staff are familiar with The Scottish Executive Good Practice Guide referred to earlier. Services should comply with the access requirements identified in the Disability Discrimination Act, Section 3.<sup>6</sup>
58. The accommodation in St. John's Hospital is generally of a good standard with appropriate access for disabled users.

### **Daytime activities**

59. There is a range of therapy services for people in the Astley Ainslie Hospital, St. John's Hospital and the Lanfine Unit, although these are not always available at the week-end and this should be reviewed. Recreational opportunities over the week-end are also sparse for the patients who are in hospital for protracted periods of time. Some people go home for the week-end as part of their rehabilitation programme, but for those unable to do so some hospital social activity should be provided, paying due attention to needs and choice.
60. Volunteers can contribute a lot to such projects and the recent appointment of a volunteer co-ordinator for Liberton Hospital will provide support to the Lanfine Unit. In addition, a volunteer co-ordinator appointed to the Royal Edinburgh Hospital may have the capacity to develop volunteering across different services including the Astley Ainslie Hospital.

### **Multidisciplinary working**

61. The visiting team was impressed by the range of high quality multidisciplinary working within the hospitals, despite some gaps and recruitment problems in clinical psychology, physiotherapy and dietetics. There are major gaps in providing such services in the community.

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<sup>6</sup> Disability Discrimination Act. Section 3 (October 1999)

## **Advocacy**

62. There is no advocacy service specifically for people with physical disabilities either in hospital or living in the community. This has been identified as a priority in the Edinburgh and West Lothian community care plans. Voluntary organisations sometimes perform this role although often on an informal basis. SHAS recommends that the health board and local authority colleagues develop appropriate advocacy services for this client group.

## **Patient Transport**

63. Significant problems were reported about patient transport across Lothian. SHAS was concerned to hear that the ambulance service applies a 'quota' system that can result in some people having extreme difficulties in accessing services. The Trusts are currently monitoring the situation and SHAS urges an early resolution
64. In April 1999 ambulance services were reorganised into a special health board to provide services on a national basis. It is recognised that there are problems with the service, especially patient transport, and a full review is underway. It will not report until next year and SHAS stresses the importance of improving the service meanwhile on an interim basis wherever possible.

## **Clinical services**

65. The inpatient and outpatient services are detailed in the following sections:

Scottish Brain Injury / Neuro-Rehabilitation Service  
Stroke Services  
Cardiac Rehabilitation Services  
Limb Amputation and Locomotor Disability Service  
Lanfine Unit, Liberton Hospital  
Prosthetics and Bio-engineering Services  
Wheelchair Service  
Disabled Living Centre  
Chronic Pain Service

### **Scottish Brain Injury/Neuro-Rehabilitation Service**

66. The Scottish Brain Injury Rehabilitation Service (SBIRS) is based in the Charles Bell Pavilion at Astley Ainslie and this is one of three tertiary referral centres in Scotland. The majority of patients are admitted from the Royal Infirmary or the Western General Hospital in Edinburgh, with 60 per cent coming from the Lothian area. There are 20 beds for brain injury rehabilitation with 100-150 new cases each year. The brain injury service is sited next to the neuro-rehabilitation service, with a separate male and female ward.

67. People are mainly admitted with brain injury following trauma to the head or sub-arachnoid or intracerebral haemorrhage. There are also a small number of people with post-encephalitis, meningitis, hypoxic and hypoglycaemic brain damage. The median length of stay for patients is 30 days although at the time of the SHAS visit, two patients had been in the unit for over a year. Both these patients are from other health board areas and are waiting for discharge to local services.
68. Inpatient neurological rehabilitation takes place in 20 beds in the same accommodation. This is for the post-acute management of neurosurgical cases and for rehabilitation of some people with neurological disorders such as multiple sclerosis, Parkinson's disease and polyneuropathy. About 75 per cent of admissions come from Lothian and there is an average length of stay of between four and six weeks. There is close liaison with the Department of Clinical Neurosciences at the Western General Hospital and regular weekly consultant liaison visits. Similarly, there is a very close working relationship with the Robert Fergusson Unit in the Royal Edinburgh Hospital, which provides specialist management of behaviourally disturbed brain injured patients.
69. Once again there is good evidence of multidisciplinary working. Physiotherapy staff have a dedicated area to work in and other clinical staff also have access to rooms and clinical accommodation. Some occupational therapy services are based in a separate building.
70. The Charles Bell Pavilion was not designed for such a service and there are a number of deficiencies in the physical environment, some of which are being addressed as already mentioned. The ward areas are large and impersonal. Bathroom and toilet facilities are generally of a poor standard and the two main cubicle toilets in one of the wards are next to a television room with swing doors and little privacy. At the time of the SHAS visit there were plans to develop a sensory stimulation room, financed from endowments.
71. The SHAS team was impressed by the enthusiasm shown by nursing staff and the efforts made at developing a good range of services. There is a relatives support group and a sexuality group. There are plans to develop a recreational therapy post. Good information is available for patients and relatives and there is impressive care planning, with care plans accessible to patients and families and kept by the patient.

### **Stroke services – Lothian Primary Care NHS Trust**

72. Lothian Primary Care NHS Trust provides dedicated stroke rehabilitation for patients under 70 in the Astley Ainslie Hospital. There is also a separate stroke unit for older people, which was transferred from the City Hospital in 1997, but this service was not included in the current review.

73. The Stroke Rehabilitation Service is provided to individuals in the South of Edinburgh with admissions predominantly from the Royal Infirmary, although a small number of younger stroke patients from West Lothian also access the service. Separate stroke rehabilitation services are provided by the Western General Hospital and West Lothian Healthcare NHS Trust. The stroke service provided by the Western General Hospital was not included in this review.
74. The stroke service is based in the East Pavilion and has access to 12 beds in a 20 bedded ward. The other eight beds are used for cardiac rehabilitation. There are about 90 admissions a year with a median length of stay of seven weeks.
75. There is a strong multidisciplinary emphasis with dedicated input from physiotherapists, occupational therapists, speech and language therapists and clinical psychologists.
76. There is good liaison with the Royal Infirmary including shared assessment measures from acute admission through to discharge from rehabilitation. Discharge planning is facilitated by an outpatient co-ordinator and there is some follow-up for outpatient therapy. However, in general, there is no formal outreach resource.
77. The ward provides mixed sex accommodation. There are designated male and female toilet areas although these facilities are generally of a poor standard. This will be solved when two single sex wards for stroke services are created.

### **Stroke services - West Lothian Healthcare NHS Trust**

78. Since 1997, St. John's Hospital has provided 11 beds for people who have had a stroke, irrespective of age. There are about 150 admissions each year to the unit, staying about six weeks. The SHAS team was impressed with the flexibility and liaison with the care of the elderly rehabilitation ward located near the stroke ward. The majority of patients in this service are over 70, although some younger people are admitted.
79. At the time of the SHAS visit there was a vacancy for a consultant in the Care of the Elderly service. The previous incumbent led the stroke service but each consultant had an input. In the 11 bedded unit there are patients under the care of three separate consultants, which could make multidisciplinary co-ordination rather difficult. While there may be preference to have one consultant leading the service, the present consultants appear to work well with the current arrangement. At the time of the SHAS visit, arrangements were in place to recruit a replacement consultant who may have a specific lead role for the stroke service.
80. There is good multidisciplinary working with a dedicated physiotherapist and occupational therapist and input from dietetics and a speech and language therapist. Clinical psychology services are available as required. There are multidisciplinary care plans, with each discipline keeping their own notes in the same folder held on the ward, but this is unfortunately separate from the formal

medical notes. Individual therapists arrange follow-up where possible but resources for comprehensive follow-up and outreach is limited. This will be facilitated to some extent by the development of a community rehabilitation team.

81. Transport problems make outpatient appointments and continuing therapy difficult. It is also hard to gain access to community-based speech and language therapy, with at least a two-month waiting list.

### **Cardiac rehabilitation - Lothian Primary Care NHS Trust**

82. There is a small inpatient unit of ten beds in the East Pavilion of the Astley Ainslie Hospital for cardiac rehabilitation, shared with the stroke service. This is backed up by an extensive outpatient service, although access depends on available transport (in some places a subsidised taxi service is available).

83. There are three main components to the cardiac rehabilitation programme:

- post-bypass surgery;
- angina management; and
- myocardial infarction.

84. The bypass surgery programme involves close liaison with the Royal Infirmary. If there are no complications, patients are transferred to the Astley Ainslie rehabilitation service five days after surgery. Seventy five per cent of cardiac surgical patients are transferred to this unit. Patients stay on average five days, receiving a programme of active physical rehabilitation, information and education. There is a strong psycho-social focus to the rehabilitation programme.

85. The only problem identified by SHAS is the increase in the number of bypass operations carried out. There appears to have been little account taken of the impact on the Cardiac Rehabilitation Service with the increase in the number of patients transferred to the Astley Ainslie Hospital. The Lothian University Hospitals NHS Trust and the Lothian Primary Care NHS Trust need to ensure that effective liaison and communication arrangements are in place and a clinical pathway is developed for cardiac rehabilitation. Clinicians reported that bypass surgery is now including a more elderly population who, in many cases, have additional and different needs for rehabilitation.

86. There is an angina management programme that operates on an outpatient/day-patient basis. The clinical psychology service is primarily responsible for this programme. The consultant recognises that there would be a benefit from earlier involvement with patients in the early stages of angina and also with pre-operative patients. However, very often patients are referred later in the stages of their angina management. Work is currently under way to look at the effects of the angina management programme and it is intended to try and establish earlier contact with appropriate patients. SHAS supports this approach to early intervention and proactive support.

87. There is also a post-myocardial infarction programme that is recognised as best practice nationally. The service at the Astley Ainslie led to the development of the Heart Manual<sup>7</sup>, in collaboration with colleagues in West Lothian. The manual has been well researched and validated and 4-5,000 copies are sold every year. 150 different NHS services including eight health board/authority regions in the United Kingdom use the manual. A cardiac nurse working within the service is funded by the reinvestment of the sale of the manuals. Training is provided in the use of the manual to over 200 nurses a year. The manual is given to patients who are discharged from acute hospitals after a myocardial infarction and the patient is followed up by some of those nurses, who support the individual in the use of the manual. This is excellent.

### **Cardiac rehabilitation - West Lothian Healthcare NHS Trust**

88. The West Lothian Healthcare NHS Trust provides a community-based cardiac rehabilitation programme. The service is nurse-led and has been awarded the Chartermark Award. The aim of the service is to enable individuals to resume as near their normal lifestyle as quickly as possible following a myocardial infarction. Contact is made with patients soon after admission to the acute ward, and support and advice offered on physical and psychological issues.
89. Much of the support is delivered on an outpatient basis with the involvement of local support groups. Two nursing staff are dedicated to the service, with input from physiotherapy. Funding of one of the posts relies upon external sources, which leads to some uncertainty about future funding and provision.
90. Patients waiting for surgery are given advice and programmes to assist in preparation and recovery.
91. The Cardiac Rehabilitation Services in West Lothian are also involved in the Heart Manual programme. There is a need to ensure that there are strong links and the sharing of good practice between the Lothian Primary Care Trust and West Lothian Healthcare Trust. As referred to in para. 19, a review of cardiac rehabilitation services is being carried out across Lothian.

### **Limb amputation and locomotor disability - Lothian Primary Care NHS Trust**

92. Twenty-one beds in the Sutherland Ward in the Astley Ainslie Hospital are used for a rehabilitation service for people with lower limb amputations and locomotor disability due to arthritis, neurological conditions or peripheral vascular disease. A number of people are seen on an outpatient basis in addition to those who require inpatient assessment and rehabilitation.

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<sup>7</sup> The Heart Manual (1994), revised (1996). Edinburgh Healthcare NHS Trust.

93. Most of the 130 people who are admitted each year are transferred one week after amputation and they mainly (85 per cent) come from Lothian. They tend to be older people, with an average age of 68 years.
94. The primary aim is to gain functional independence as early as possible and be discharged home. Patients are assessed for wound healing and if a prosthesis is appropriate then they will be seen by a prosthetist between four to six weeks after amputation. If patients do gain functional independence early and can be discharged home, they will be seen by the prosthetic service on an outpatient basis. Significant delays in discharge were reported for some people due to the need for housing adaptations or new housing. This is leading to some problems with 'bed blocking' and people having to remain in hospital for a considerably longer time than is actually necessary.
95. The ward is a mixed sex ward and bed areas are very small and cramped. There is only one male and one female toilet. It was of some concern to the SHAS team that the toilets used curtains rather than doors, which affords little privacy, in particular in the context of mixed sex accommodation. The ward is being relocated to the neighbouring area to provide improved accommodation.
96. There is good multidisciplinary working with a lot of input from physiotherapy and occupational therapy. The general atmosphere on the ward is very positive with patients at various stages of rehabilitation to act as an incentive and encouragement to new admissions.
97. There needs to be better interface between the acute services and the rehabilitation services, particularly with regard to the preparation of patients for surgery and the potential for preventative rehabilitation. There are good links with the prosthetic service that is currently sited at the Princess Margaret Rose Hospital. Access and transport were identified as problems for people attending as outpatients. There is currently a lack of certainty regarding the future siting of the prosthetic service when the Princess Margaret Rose Hospital closes in two years.

#### **Lanfine Unit, Liberton Hospital - Lothian Primary Care NHS Trust**

98. The Lanfine Unit is based at Liberton Hospital and has accommodation for 33 patients within two wards. Since the last SHAS visit to Liberton Hospital the Lanfine Unit has moved progressively towards short-stay and shared care for younger people with physical disabilities. Of the 33 beds, only three are providing long-stay continuing care for people with severe disability. The remaining beds are used on a respite/rehabilitation basis for people across Lothian.
99. The service has developed since the appointment of a consultant with a specific remit for community rehabilitation. In addition to the core beds within the Lanfine Unit the consultant is involved in an outpatient clinic at the Astley Ainslie Hospital, the chronic pain management service and in developing links

with social care day centres for younger people with physical disabilities in the Edinburgh area.

100. The service has a strong multidisciplinary focus involving physiotherapy, occupational therapy, speech and language therapy along with nursing and medical staff. There is limited dietetic input and at the time of the SHAS visit, no clinical psychology service due to recruitment problems. This was identified as a particular gap by clinicians, users and carers. The Lanfine Unit is in the early stages of the development of multidisciplinary clinical notes and this should be taken further.
101. The team has developed good links with social work colleagues and SHAS was impressed with the approach to integrated working between health and social care services for people with chronic disabilities. Staff have developed a patient satisfaction survey and SHAS supports these efforts to seek views from service users. There is good patient information available that clearly identifies the purpose of the service. SHAS was impressed with the work being done in relation to evaluating user and carer anxiety and depression.
102. The Lanfine Unit has mixed sex accommodation but with adequate bathroom and toilet areas. The use of internal screening in bathroom areas would assist in providing more privacy for patients. While efforts have been made to create a homely domestic environment for patients, it is recognised that a significant upgrade of the accommodation is required.
103. A proposal has been put forward by the occupational therapy department for a dedicated OT department within the unit, although there is a lack of clarity as to how this proposal is being taken forward within the new organisational structures. This issue needs to be clarified.
104. A number of activities are available for patients in the Unit but there is a lack of social and recreational opportunities, particularly over the week-end. There is a need for the service to develop this element of care as a major component in the overall philosophy for this client group.
105. Although the service has a community focus, it is recognised that a considerable number of people with chronic disabilities across Lothian are not receiving services. Within existing resources there is limited opportunity for outreach work, other than the outpatient clinics and links with the day centre. There is a need to develop further the community approach to rehabilitation and build on the existing good work established by the consultant and the multidisciplinary team.
106. There should be a review of the overall allocation of resources to ensure that disabled people living in the community have equitable access to health and social care services.

## **Prosthetics and Bio-engineering Services (artificial limb and appliance services) - Lothian Primary Care NHS Trust**

107. The Prosthetic and Bio-engineering Services are based at Princess Margaret Rose Orthopaedic Hospital in Edinburgh and provide a service to Lothian, Fife, Borders and West of Scotland Consortia. Management has recently transferred to the Lothian Primary Care NHS Trust. A lack of clarity about the future siting of the service was raised by a number of service users, particularly in terms of potential transport and access problems. The orthotic service (not included as part of this review) is managed by Lothian University Hospitals NHS Trust. There is a need for close collaboration about the future of both these services. At present there is considerable space available at Princess Margaret Rose Hospital and staff worry about the likelihood of finding adequate space for the relocated service.
108. Prosthetics and Bio-engineering Services are highly regarded with a national and international reputation for quality and innovation. The SHAS team was impressed with the work that has been taken forward in relation to the paediatric service and the development of a 'pathway' for the Special Needs Design Service. This approach is necessary also for adults, for whom delays are still an inevitable part of the process. Some concerns were expressed by users about the delay in repairs and modifications to prosthetic devices. This issue was also raised in relation to the orthotic service. The Lothian Primary Care NHS Trust and Lothian University Hospitals NHS Trust must solve these problems.
109. A review to seek users' views of the services provided by the Artificial Limb and Appliance Centre was conducted in 1995 and a Prosthetic Local Users Committee now meets on a quarterly basis to inform service planning and get feedback on current provision.
110. The Bio-engineering Service is also responsible for environmental control systems, although the provision and installation of such systems is the responsibility of commercial contractors. Assessment for, and specification of, the system is carried out by the consultant in rehabilitation medicine and the principal bio-engineer who is then responsible for liaison with the commercial supplier and the social work department.
111. The specialist seating service provides wheelchair seating for individuals who are unable to use a standard wheelchair as a result of one or more disabling conditions. The service provided is based on the needs of the individual, taking into account also the views of carers and the clinical staff. Assessments are conducted in association with the Mobility Centre in order to ensure that the most appropriate combination of wheelchair seating is achieved. Seating is then manufactured in the bio-engineering workshop before a trial takes place, when appropriate alterations can be made.
112. Particular concerns were raised with the SHAS team about the delay in assessment for specialist seating. This is a major issue for both inpatients and people living in the community. Waiting times were reported to be several

months. It is recognised that the Primary Care Trust has only recently taken over responsibility for this service and SHAS recommend an early review of the specialised seating service and the development of an action plan to address the issues.

## **Wheelchair service**

113. The wheelchair service, one of five in Scotland, is clinically based and provides NHS wheelchairs to disabled people in Lothian, Fife, and the Borders. All equipment is purchased via a national contract through Scottish Healthcare Supplies (a Division of the Common Services Agency). Several wheelchair clinics are held at the Astley Ainslie.
114. The service is efficiently run and offers a range of choices to clients. Nevertheless concerns were expressed by users of the service about limited access to lightweight wheelchairs and delays in assessment and provision of power-assisted wheelchairs. A user survey was undertaken in 1995 and it is recommended that there is a follow-up survey and audit of the service. This is a service that would benefit from the ongoing monitoring of patient satisfaction.
115. It was reported to the SHAS team that there is a problem across Lothian about access to wheelchairs on a short-term basis. The wheelchair service is only required to provide chairs to people with permanent disabilities or mobility problems. The Disabled Living Centre has set up a wheelchair hire service to cover short-term loan wheelchairs. The effectiveness of this service should be evaluated.
116. As with other aspects of the rehabilitation service, there are some issues about the overall accessibility of the service and the trust should consider a review of possible decentralisation of some aspects of the provision to locally based wheelchair clinics.
117. The service operates with specific standards for assessments and waiting times, that are well monitored. Particular problems have been referred to earlier in areas of specialised seating and the waiting time for assessment and provision.
118. The physical separation of the prosthetic service from the wheelchair service is not ideal and, with the closure of the Princess Margaret Rose Hospital, there is an opportunity to address this.
119. The Scottish Executive should review the national contracts for wheelchair services and consider the implication of the recent report from the Audit Commission in England on provision of equipment.<sup>8</sup>

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<sup>8</sup> Audit Commission (2000): Fully Equipped. The provision of equipment to older or disabled people by the NHS and social services in England and Wales

## **Disabled Living Centre**

120. The Disabled Living Centre is based in the Astley Ainslie Hospital and gives people in Lothian the opportunity to view and try out items designed to help with daily living. This enables people to make an informed decision about equipment and services best suited to meet their needs. The centre is staffed by occupational therapists who are employed by the Primary Care Trust with the role of providing information and advice.
121. Although this service is targeted at people living in Lothian, staff reported receiving a number of requests and visits from people elsewhere. This has increased following the closure of a number of disabled living centres elsewhere in the country.
122. The centre offers a very high quality service to users who are able to receive impartial advice on various aids and equipment products. However, people have to travel to the Astley Ainslie Hospital to receive such advice and it is suggested that the development of a greater community focus could assist in easier access to service users.
123. At the time of the SHAS visit, thought was being given to the siting of the Disabled Living Centre along with the wheelchair service and the prosthetic and bio-engineering services rather than in its current cramped accommodation in a prefabricated building. An early resolution to this would assist in the planning and delivery of services.
124. Staff and users reported a problem with delays in social work department occupational therapy assessments in areas such as bathing, which is not deemed 'a high priority'. People with physical disabilities are waiting for twelve months or more for such assessments and often choose to purchase their own equipment to avoid further delay. This is not acceptable and this issue should be addressed in a strategic context.

## **Chronic pain service**

125. In Lothian there are two main services accepting GP referrals for the treatment or management of chronic pain. The two services have begun to work together, developing protocols for GPs to assist in the identification of the most appropriate service and developing an integrated care pathway for the management of chronic pain. There is an anaesthetic-led pain control clinic at the Western General Hospital (Lothian University Hospitals NHS Trust) and a psychology-led multidisciplinary pain management programme provided within the Medical Rehabilitation Services at the Astley Ainslie Hospital.
126. The Royal Infirmary of Edinburgh provides a tertiary referral service for pain control and a service to inpatients through the anaesthetic department. A small number of outpatients are seen, but no regular clinic is provided. A similar service is available at St. John's Hospital, Livingston. The Royal Hospital for Sick Children manages pain control within general paediatric resources

including a specialist nursing post linked to short-term pain control and palliative care.

127. Lothian Health has recently provided additional funding as part of a waiting list initiative. This has led to additional input from consultants, psychology, physiotherapy and the appointment of a specialist nurse. Good links have been established with voluntary organisations such as The Pain Association for Scotland and Lothian Pain Association.
128. Referrals to the pain management programme at the Astley Ainslie Hospital have increased significantly since it was first established in 1993. Because of the recent additional funding, waiting times have reduced from 6 months for initial assessment to around 3 months.
129. The average age of patients referred to the pain management programme is 45 years, with 70 per cent of patients being under the age of 50. An outcome study on a sample of patients indicates highly significant change on nearly all measures of psychological, functional and physical outcome. The resource constraints have led to little opportunity to follow up people over the medium-to-long term.
130. There is a large training need to develop appropriate skills and give support to primary care and community-based staff. This would assist in providing maintenance and 'top-up interventions' to help with long-term pain management. SHAS recommends that the integrated pain management service identifies how this can best be taken forward in close collaboration with general practitioners and other staff.

## **Community services**

### **Lothian Primary Care NHS Trust**

131. The SHAS team met with representatives from two LHCCs in the Lothian Primary Care NHS Trust and representatives from primary and community services in West Lothian. In addition to general practitioners SHAS met with a range of other disciplines including district nurses and community based physiotherapists and occupational therapists.
132. General practitioners and community-based staff had patchy knowledge about the 'specialist' services. There was a lack of clarity how the needs of people with physical disabilities, particularly those with life-long disabilities, are to be met within the LHCC arrangements. While a number of care programmes have been identified for other care groups, such as mental health and learning disability, the services for people with physical disabilities were subsumed in general primary care services.

133. There is only a limited rehabilitation service to meet the needs of people with long-term disabilities in the community. The service being developed by the consultant at the Lanfine Unit has the potential to offer a more comprehensive community rehabilitation service but this will have resource implications. While individuals have access to the acute assessment and rehabilitation services, as appropriate, the SHAS team found little evidence of systematic monitoring and review of people's needs on an ongoing basis. Very limited outreach is available from the specialist services based at the Astley Ainslie Hospital and the Lanfine Unit.
134. The SHAS team was informed that there are 'specialisms' within community-based services such as neuro-physiotherapy, but this does not appear to be equitable across the area. Also, input tends to be time limited and of short-term duration. Service users identified significant difficulties in accessing appropriate information on such services. SHAS recommends that the health board and Trust, in association with local authority colleagues develops comprehensive community rehabilitation services for all people.
135. As referred to earlier in the report, a relatively small number of people have access to specialist services at the Lanfine Unit. The developing work with two day centres in Edinburgh should be built upon and arrangements must be put in place to ensure that community staff have access to and support from the specialist services.

### **West Lothian Healthcare NHS Trust**

136. In West Lothian the health board, trust and social work department have funded a community rehabilitation and brain injury team, aided by Mental Illness Specific Grant from the government. When SHAS visited, recruitment was taking place for a project leader. The team will also have a full-time occupational therapist, three rehabilitation assistants and sessional commitment from physiotherapy, speech and language therapy and clinical psychology. In addition a GP with a specific interest in community rehabilitation will be involved. This rehabilitation team will be based initially in the Winchburgh Day Centre but will move to the Ability Centre when it opens. This is a very good example of integrated joint working.
137. The team will help rehabilitate people with chronic disability, those who have suffered traumatic brain injury and people being discharged from hospital. Although the main focus is on younger physically disabled people, the team will provide a service to some older people. SHAS welcomes this focused approach on the needs of chronic disability in the community. The trust and social work department understand that there may be a significant demand for this service. SHAS recommends that the health board, trust and social work department ensure that this service is funded beyond the initial pilot period of one year pending evaluation.
138. There is an expectation that the community rehabilitation team will assist in earlier discharge from specialist services at the Astley Ainslie Hospital –

particularly for people with acquired brain injury. To date little discussion has taken place between the West Lothian service and the rehabilitation services at the Astley Ainslie Hospital. There is a need to have closer links to ensure appropriate targeting of resources and the provision of specialised support and advice as required.

139. The new Ability Centre provides the opportunity for the development of more locally based services for people in West Lothian. The health board, Trusts and local authority should consider the decentralisation of some services that could be appropriately provided in that setting, such as the Pain Management Programme and Wheelchair clinic.

### **Social care**

140. The SHAS team visited Firrhill Day Centre in Edinburgh and Winchburgh Day Centre in West Lothian. There are excellent links with the health services and this approach is another example of good joint work between local authorities and the health service. In Edinburgh the consultant in rehabilitation with community responsibility works closely with staff at the day centre along with other members of the multidisciplinary team. This service is an integral part of the disability service and SHAS was impressed by the skills and expertise of the staff. Greater involvement of voluntary organisations and input from specialist nurses will be the next step forward.
141. Winchburgh Day Centre in West Lothian will be moving to the new Ability Centre in Livingston in May 2001. The Ability Centre will provide a 'one-stop-shop' for people with physical disabilities that includes the community rehabilitation service, voluntary sector organisations, for example Disability (West Lothian) and it will have close links to primary care services. This is an exciting and innovative development.

### **Voluntary Groups**

142. There are a number of voluntary organisations supporting younger people with physical disabilities. A range of services for respite and residential care are provided by organisations such as the Leonard Cheshire Services, Thistle Foundation, Sue Ryder and the Multiple Sclerosis Society. While these resources were not visited by SHAS, staff and users spoke positively about the role the voluntary sector plays in meeting the diverse needs of this care group.
143. The SHAS team was pleased to have the opportunity to meet with a number of voluntary groups such as Headway, ECAS, Lothian Coalition for Disability, Disability (West Lothian) and the Lothian Centre for Integrated Living.
144. Headway and ECAS have space at the Astley Ainslie Hospital but there is a lack of certainty about future accommodation as at present, there are no leasing arrangements with the trust, which means there is no security of tenure.

145. Headway offers a wide range of support services and has over 50 volunteers. Links between Headway and the ward staff in the Charles Bell Pavilion are very good and a range of support and counselling services are offered to inpatients. Headway also provides supports carers and service users living in the community and is currently running a befriending project to give respite for carers. Headway receives core funding from Lothian health board and Friends of Headway.
146. ECAS offers support to patients at the Astley Ainslie particularly over the weekends, including access to internet facilities.
147. Both organisations have good links with the managers of the hospital who support their work. The role and function of groups such as Headway and ECAS need to be considered as part of the physical disability strategy. The future accommodation also needs to be addressed at an early stage.
148. Lothian Coalition for Disabled People provides a range of services including information and advice to local groups in Edinburgh, Midlothian and East Lothian. Representatives are actively involved in planning groups and in providing information on services and supports available.
149. Disability (West Lothian) provides an information service to people with physical disabilities living in West Lothian. The group has been actively involved in user consultation on the physical disability strategy for West Lothian and SHAS was pleased to see the role voluntary organisations were playing in the strategic development of the services and in representing user opinion.

## **Services for children and adolescents**

150. Lothian clinicians are involved in the Scottish National Special Needs Database System that holds relevant information on children and young people with special needs. Clinicians report that this information, however, is not used to inform the strategic planning process, especially the identification of the future needs for adult services. The health board and the Lothian Trusts must use this information to assist the strategic planning for children and young people with complex needs.
151. Lothian Health funds healthcare packages for several children and young people living at home. The health board gives £340,000 each year, with additional funding coming from the local authority. This funding does not automatically continue for people over the age of 18 and arrangements have to be reassessed and considered at that time. This causes uncertainty and distress for patients and their families.
152. A range of respite care is available with Cairdean and Douglas House in Edinburgh providing specialist respite for children and young people with complex health needs.

153. There is no expert neuro-psychological service for children and young people in Lothian. An *ad hoc* service is provided by the adult neuro-psychology service. There is a liaison psychiatry service to support children and families with chronic disabilities but this is available only up to the age of 14. These gaps in service provision will need to be addressed.
154. Major problems arise when children move to adult services. There are difficulties in linking with the rehabilitation service and there is an urgent need to develop appropriate protocols to ensure a smooth transition to adult services.

## **Professional staff**

### **Medicine**

155. There are five consultants based at the Astley Ainslie Hospital, each taking a lead on a specific speciality. One of the consultants is the Clinical Director for the Rehabilitation Services at the Astley Ainslie Hospital and the Lanfine Unit.
156. There are four specialist registrars but this number will reduce to three within the next six months. This is because of national reorganisation of specialist training posts. Four senior house officers (SHOs) who work on a rotational basis across the service support the medical establishment. A resident first on-call rota of SHOs and registrars provides an out-of-hours service at the Astley Ainslie, while consultants give senior cover.
157. A visiting GP service gives routine support to the Lanfine Unit and out-of-hours general cover is provided by the on-call GP service. On occasions rapid access to medical staff is required and an informal arrangement has been reached with the elderly care service in Liberton Hospital, with the senior house officer attending in an emergency. Nursing staff reported some difficulties given the informality of the arrangement and the trust should review this on-call arrangement to ensure there is a responsive service that best meets the needs of the patients.
158. There is no dedicated consultant in rehabilitation medicine in West Lothian. Consultant physicians/geriatricians have responsibility for younger physically disabled inpatients. There are close links, however, with the Astley Ainslie services and the rehabilitation consultants are available for advice if required.
159. In West Lothian a GP is employed for three sessions as a community rehabilitation specialist, providing medical input to the community rehabilitation team and providing support and information to primary care services.

## **Nursing**

160. The SHAS team was impressed with the quality and numbers of nursing staff throughout the service. There is a good ratio of registered to unregistered staff and on the whole staff establishments matched the needs of the different clinical areas. This should not lead to complacency and there is a need for continuing reassessment, perhaps especially for the brain injury unit.
161. In the Rehabilitation Directorate, nursing staff are managed by a clinical service development manager with charge nurses participating in an on-call rota. Nursing staff in the main are attached to their specific service areas such as brain injury, cardiac etc. The directorate should consider opportunities for rotation of trained staff across the service as a means of sharing good practice and skills.
162. In the Lothian Primary Care NHS Trust, the SHAS team was made aware of particular difficulties in recruiting trained nursing staff and there is regular use of bank and agency nurses, who are costly and do not provide continuity of care for patients. The use of temporary contracts has been discontinued in the rehabilitation service and this practice is under review elsewhere in the trust.
163. Overall, SHAS considered that the nursing care being provided across the service was of a very high standard, with staff demonstrating skills, enthusiasm and a strong commitment to their work. There is a firm belief in the benefits of multidisciplinary working and this was apparent nearly everywhere. Good nursing practice and the documentation of it where appropriate was witnessed in most of the wards visited. This is not universal and the trust should find ways to facilitate the sharing of good practice.

## **Specialist nurses**

164. Specialist nurses based at the Department of Clinical Neuro-Sciences at the Western General Hospital provide a Lothian-wide advisory service to the rehabilitation directorate and to people living in the community. There are specialist nurses for epilepsy, Parkinson's disease, motor-neurone disease, multiple sclerosis and pain control. These nurses work closely together, although as each specialist post is single-handed there is no service when the a nurse is on leave. The staff are well-supported by nurse management and there are opportunities for personal and professional development. Knowledge of these services is not wide-spread in the community and access is obviously harder for people living in West Lothian.

## **Occupational therapy**

165. There is a well-resourced occupational therapy service based at the Astley Ainslie Hospital. Recent management changes have seen the appointment of a professional adviser and separate heads of service for occupational therapy across the Lothian Primary Care Trust. The occupational therapy service at the

Astley Ainslie Hospital is primarily involved in providing assessment and rehabilitation to the inpatient population. The absence of outreach and domiciliary occupational therapy services was identified as an area of difficulty for the effective management of patients on discharge.

166. The occupational therapy service to people at the Lanfine Unit is provided by the occupational therapy service at Liberton Hospital.
167. Occupational therapists are closely involved in the multidisciplinary working across the service. There are excellent staff development opportunities with evidence of good quality assurance.
168. The occupational therapy service in West Lothian covers both hospital and community services. The development of the community rehabilitation team provides the opportunity for dedicated occupational therapy input to meet the needs of the younger physically disabled in the community.
169. Occupational therapists employed by the social work departments are responsible for the assessment and provision of equipment and aids. The SHAS team was pleased to see the development of joint equipment stores both in the Lothian Primary Care NHS Trust and West Lothian Healthcare NHS Trust. Some questions were raised about the different roles and responsibilities of staff employed by health and staff employed by social work when it came to providing certain items of equipment. While not a major barrier to the delivery of services to individuals, there is inevitably some overlap in roles and potential duplication of assessment. The trusts and social work departments should review this to ensure the most effective use of resources across the different services.

## **Chiropody**

170. The Lothian Primary Care NHS Trust has a well-established chiropody service that has been accredited by Investors in People, ISO 9002 and Chartermark. A service is given to inpatients at the Astley Ainslie Hospital and the Lanfine Unit but most of the work is carried out in the community in clinics and at home. This can lead to a degree of isolation but efforts are made to link in with other professionals for training. The West Lothian chiropodists also have good links with the inpatient services and there is a comprehensive community-based service.
171. Standards for a first appointment continue to be met (urgent within 24 hours, high priority within 14 days) although times between appointments can be in the region of 15 weeks. The staff that SHAS met identified the need to have a greater profile in relation to health promotion initiatives and also closer links with the diabetic clinic.

## **Dietetic and nutrition service**

172. There is a full-time dietician at the Astley Ainslie Hospital for the Rehabilitation Directorate. Because of a vacancy in services to the Care of the Elderly Directorate the post-holder is providing cover, which reduces the overall service available to the rehabilitation services.
173. The dietician gives specialist advice and input to the inpatient services, with limited involvement in outpatient work, primarily with cardiac patients. In addition to working with people who have problems swallowing there is a strong health promotion focus. The dietician has very good links with the catering staff, and the catering service responds positively to suggestions and recommendations.
174. There is no formal post-discharge follow-up, although some links are made with community dietitians. There does not appear to be an established clear pathway for discharge follow-up.
175. Because of the resource constraints, the dietician has difficulty in attending regular multidisciplinary clinical meetings. The Trust should review the provision of dietetic services to the Rehabilitation Directorate and ensure that there are appropriate post-discharge arrangements and links with the community dietetic service.

## **Clinical psychology**

176. The Department of Clinical Psychology at the Astley Ainslie Hospital provides specialist services in neuro-psychology and health psychology for inpatients and outpatients from across Lothian. There are good links with other specialised services based at the Western General Hospital, psychologists in general clinical psychology and psychologists working in West Lothian.

### Neuro-psychology

177. There are 2.5 wte psychologists and 2.5 wte assistant psychologists. The neuro-psychologists work in the Scottish Brain Injury Rehabilitation Service, and have good links with other brain injury services such as the Robert Fergusson Unit at the Royal Edinburgh Hospital. The department is involved in interesting research and the use of virtual reality as part of rehabilitation. A small number of children under the age of 16 are referred for assessment because of the lack of a similar service from the child and adolescent mental health services.

### Health Psychology

178. There is a well-established expert service in cardiac rehabilitation, stroke and chronic pain. The Heart Manual project is based here.

179. The department is working hard to recruit to vacant posts to allow closer links with primary care and community services and to increase the training role. The excellent work being undertaken within the Department of Clinical Psychology at the Astley Ainslie Hospital could usefully be extended to other health care settings.
180. The psychologists are involved in research including the angina management programme, pain management programme, children and brain injury and the effects of exercise and cognitive functioning after brain injury.

## **Physiotherapy**

181. This is a well-staffed service with just under 20 wte trained physiotherapists and 1.85 wte assistants. The physiotherapists at the Astley Ainslie Hospital work in neuro-rehabilitation, cardiac and stroke rehabilitation, locomotor rehabilitation and pain management, mainly with inpatients. Most of the work is concentrated on rehabilitation with a small input into the care of the elderly services. In addition, there is an open access service that is not specifically related to the physical disability rehabilitation services. A hydrotherapy pool is a useful resource for inpatients and people attending from the community.
182. Physiotherapists at the Astley Ainslie Hospital also provide an input to the bio-engineering and ALAC services currently based at the Princes Margaret Rose Hospital. There are good links with other specialised services such as the Robert Fergusson Unit. There is a separate physiotherapy service in the Lanfine Unit.
183. The staff are involved in research and audit in stroke, personal mobility and spastic foot drop and there are links with national audit.
184. A domiciliary physiotherapy service is provided by both trusts and there is a growing need for this because of more complex problems and earlier discharge from acute hospitals. The service in West Lothian is well-established and the new community rehabilitation team will allow closer working relationships with other disciplines in primary care.

## **Speech and language therapy**

185. There are 3 wte posts based in the Astley Ainslie Hospital, with most of the work focused on the brain injury and neurological services and limited input to stroke rehabilitation. The main commitment is to the inpatient population, although there is some follow-up and outpatient work.
186. An additional four posts were developed three years' ago to work with adults in the community. Up until then, there had been no speech and language therapy services available to adults, other than the services linked to inpatient services. The community-based posts are currently not linked managerially with the Speech and Language Therapy Department in the Astley Ainslie Hospital,

although the post-holders have office accommodation there. There is a need to ensure good co-ordination and target limited resources across the speech and language therapy services. The Primary Care Trust should consider developing more formal links between the adult-based community service and the service at the Astley Ainslie

187. A separate service is provided to adults with physical disabilities in West Lothian and the multidisciplinary community rehabilitation team includes speech and language therapists
188. Speech and language therapists are involved in research projects and audit, including a number of multidisciplinary audit projects with physiotherapists and dieticians. This multidisciplinary focus to research and audit is to be commended.

## **Social work**

189. The good joint working in the provision of day centres with health input has already been described in paragraph 139.
190. There is a hospital-based social work team at the Astley Ainslie Hospital and also St. John's Hospital. Both teams have developed good close working relationships with health colleagues and are proactive in the discharge planning process. The team at the Astley Ainslie Hospital are actively involved in all aspects of the rehabilitation directorate, with the Senior Social Worker a member of the Heads of Department meetings, audit structure and team briefing system.
191. Joint health and social work discharge planning standards were established three years ago, although they have not been reviewed. Community care assessments are completed within two working days and packs of care reviewed within four weeks of discharge.
192. The social work team at the Astley Ainslie Hospital should liaise with social work colleagues in the four local authority areas. A number of problems relating to discharge planning were identified, such as:
  - a lack of post-discharge follow-up by local social workers;
  - up to 50 per cent of discharges delayed because of lack of NHS resources being in place;
  - difficulties in meeting specific housing requirements; and
  - insufficient training for local social care workers in the needs of people with chronic physical disabilities.
193. Some of these issues are being taken forward as part of the developing strategy. The trust and local authority colleagues should ensure that every effort is made to facilitate discharge planning and adequate provision of resources.

194. Social work services in the community are part of general community care. There are no dedicated workers specifically for people with physical disabilities. There are good links between the community-based occupational therapists and hospital-based occupational therapy staff.

## Conclusions

1. The Primary Care NHS Trust and the West Lothian Healthcare NHS Trust provide a range of specialist services for people with disabilities that is excellent in the assessment and rehabilitation phase. The multidisciplinary working is particularly impressive. Some of the examples of good practice are listed overleaf. Areas needing to be improved are described below.
2. Services in the longer-term for people who live in the community are not equitable, with patchy development of new initiatives such as the West Lothian community rehabilitation team. This is partly due to the difficulty in undertaking a population based needs assessment of people with a wide range of different conditions, in order to plan services. It also reveals a failure to continually reassess the changing and life-long health needs of people. The voluntary sector is vital in providing support and information and in raising the profile of disabled people.
3. There are major problems for service users in getting suitable transport. This results in people being unable to attend treatment sessions or arriving late, which is not acceptable. It is equally unacceptable that access to social and leisure opportunities are limited in this way. In addition some people have had difficulty getting electronic and lightweight wheelchairs. Mobility became a major theme during the review. This is not directly under the control of the trusts but they should make this a priority in working with other organisations.
4. There is lack of clarity about the reorganisation and relocation of services when the Princess Margaret Rose Hospital closes, the new Infirmary opens and the Astley Ainslie site is rationalised and this is causing anxiety.
5. There are problems with the transitional arrangements for children and young people when they move to adult services. Clinical co-ordination is often difficult and services provided to children and young people are not always available when a young person reaches 18 years.

## **Good practice**

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

- the specialist rehabilitation services and the excellent multidisciplinary working;
- the integrated pain management programme involving the Primary Care Trust and the Lothian University Hospitals NHS Trust;
- the high quality work being taken forward by the prosthetics and bio-engineering services;
- the excellent information available for patients at the Astley Ainslie Hospital.
- the good links with voluntary services and organisations and their role in supporting service users;
- the development of the community rehabilitation service in West Lothian and the close working between health and social work linked to day centres in Edinburgh and West Lothian;
- the excellent range of audit and research being carried out by clinicians;
- the national success of the Heart Manual;
- the developing work with service users; and
- the high standards of professional practice across the different disciplines.

## **Main recommendations**

1. The health board and trusts, in association with the local authority social work departments, should develop equitable community services based on a comprehensive needs assessment.
2. The health board and trusts, in association with the local authority social work departments, should ensure that the current strategic plans for people with physical disabilities are better known to service users and carers. In particular there is a need to clarify:
  - the future of services currently provided at the Lanfine unit;
  - the impact of the planned reconfiguration of services; and
  - the role of community rehabilitation and the links with specialist and primary care.
3. The Lothian Primary Care NHS Trust should improve parts of the service for people in the Astley Ainslie Hospital and the Lanfine Unit:
  - the quality and accessibility of patient accommodation;
  - an appropriate range of day care and recreational opportunities, especially at the week-end;
  - the development of advocacy and volunteer services; and
  - the employment of a clinical psychologist at the Lanfine Unit and increased dietetic support across the service.
4. The health board and trusts, in association with other agencies, need to ensure arrangements are put in place to meet the needs of young people with physical disabilities during the transition to adult services.
5. The Scottish Ambulance Service should improve the transport as a matter of urgency.
6. The health board should work with the wheelchair service and Scottish Healthcare Supplies to ensure speedy provision of optimal wheelchairs.

**DR SANDRA M GRANT**  
**Chief Executive**  
**20 April 2000**

## **APPENDIX**

### **TEAM PROFILE**

**DR MARGARET WHORISKEY**  
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*Qualifications:* BA(Hons), M.Phil., C.Psychol., PhD

*Previous posts:* Director of Clinical Services, Fife Healthcare NHS Trust.  
Head of Psychology Services (Learning Disabilities),  
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**Ms. Irene Souter**  
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*Previous Posts:* Director of Nursing, Acute Services, Fife  
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**Dr. Peter Williamson**  
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**Mr. Bob Benson**  
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