SCOTTISH HEALTH ADVISORY SERVICE

VISIT TO PHYSICAL DISABILITY SERVICES

IN FORTH VALLEY

NOVEMBER 2000

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Executive Summary

The Scottish Health Advisory Service visited community and hospital services for children and adults with a physical disability in November 2000. The visit covered two NHS Trusts and three local authorities.

Many people with physical disabilities are not in touch with services, although when people do receive the appropriate service they are very satisfied. Primary care services and generic community based health services can offer ongoing review and ‘maintenance ‘rehabilitation for this group but they are limited by resource constraints. The Area Rehabilitation Team provides an excellent service to some people aged between 16 and 64, although over the past year the work of the team has been limited because of long waiting times and the absence of a service to younger stroke patients in the community.

There is no specialised inpatient service in Forth Valley and the absence of a consultant in rehabilitation medicine means that people miss out on specialised assessment and rehabilitation. This is particularly the case for people with acquired brain injury.

There are major delays in the provision and repair of wheelchairs with people waiting several months. This is unacceptable. There are also problems with the patient transport service and these areas may benefit from the review at a national level.

A number of children are admitted to hospital for short breaks because of a lack of suitable services in the community. Children and their families experience difficulties with the continuity of service provision as they grow older.

The quality of services provided is good but a number of gaps need to be addressed at a local and national level.

Contents

Introduction

1. This is the first visit by SHAS to services for people with a physical disability in the Forth Valley area and the third such visit in Scotland since November 1999. Forth Valley Health Board covers a population of 274,600. Based on the national Office of Population Census and Surveys[1] it can be expected that about 9% of people between the ages of 16-69 years will have some form of disability. The Health Board estimates that about 8,617 adults under 65 will have a long term moderate to severe disability[2] - many of whom can benefit from appropriate health care services.

2. Services covered in this review are detailed in Appendix 1. The review focused on services provided by the Forth Valley Primary Care and Forth Valley Acute NHS Trusts. As there are no dedicated inpatient services for people with physical disabilities in Forth Valley this review included some aspects of the inpatient services provided by the Acute Trust and the interface with tertiary centres in Glasgow and Edinburgh. There was a limited opportunity to focus on services to children with physical disabilities provided by either Trust.

3. We concentrated on health services available for younger people (under 65) with physical disabilities. There are additional issues for disabled people over the age of 65 that are considered in SHAS reviews for older people.

4. An important focus of this review was the health needs of people with long term complex and chronic disabilities who live in the community. There are three local authorities within the Forth Valley Health Board area – Falkirk, Stirling and Clackmannanshire and we are grateful for the assistance and information provided by the social work departments and independent service providers.

5. Most important of all was the experience of visiting people in their own homes. We learnt from them and their carers about daily life as a disabled person and thank them for agreeing to meet us.

6. The SHAS Physical Disability Quality Indicators are being developed in association with the National Care Standards for Physical and Sensory Impairment. The visit provided a useful opportunity to identify key issues and preferred outcomes for service users and their families in order to inform this work.

[1] Office of Population Census and Surveys (OPCS) 1988
[2] Forth Valley Health Board (1992) Director of Public Health Report

The Views of People who use the Service and their Carers

7. We had meetings with a number of service users and relatives in the Forth Valley area, seeing people in their own homes, day and residential settings, respite care services and inpatient services. We met with several voluntary organisations that have a key role in supporting people with physical disabilities and their families and in representing the views and experiences of service users. The following paragraphs reflect the information that they gave us.

8. In general people spoke highly of the services and support they receive. The input from the whole range of professionals, medical, nursing, therapy and social work, is valued and appreciated. However, as is the case elsewhere, people experience significant problems in getting access to the services because of long waiting times, difficulties with transport, limited or no provision in some areas and limited information about the range of services available. People also highlighted problems with health service accommodation that is not suitable for people with a physical disability.

9. There is inequity in service provision for people depending on their age, their specific condition and where they live. There is, for example, no community based rehabilitation service for people who have suffered a stroke and are aged under 65. Particular problems were identified for children needing communication aids. People who have a long-term disability have limited opportunity for reassessment or review and may not have their significant continuing or changing needs identified and met.

10. A number of people with very complex needs are supported to live in their own home with up to 24-hour care. For others there is limited access to ordinary community living options and people remain unnecessarily in hospitals pending the availability of suitable accommodation and agreement over funding of care between health and social work. This is a major issue. Delays in the provision of equipment and housing adaptations also lead to delayed discharges from hospitals.

11. The long waiting time for the provision and repair of wheelchairs and specialist seating is another major problem for users and their families. This has also been highlighted in recent SHAS reviews.[3,4,5]

12. There is no dedicated independent advocacy service for people with physical disabilities in the Forth Valley area. A very small number of people with physical disabilities use the Forth Valley Advocacy Service but this is generally related to their mental health needs. This is another major gap.

[3] Scottish Health Advisory Service -November 1999 – Services for People with Physical Disabilities in Lothian

[4] Scottish Health Advisory Service – June 2000 – Services to People with Learning Disabilities in Ayrshire and Arran

[5] Scottish Health Advisory Service -August/ September 2000 – Services to People with Physical Disabilities in Glasgow

13. Users and carers receive a lot of support from voluntary organisations who play a very useful role in making information available in an accessible way and in providing practical help and support. Users and carers are worried about the recent closure of the Head Injury Trust for Scotland (HITS) due to a shortfall in funding, because this organisation provided important support to individuals and their families. This is a significant loss and ways must be found of providing similar support.

14. Some opportunities have been made available for users and their families to contribute to the community care planning within the different local authorities and have been involved in customer satisfaction surveys. We were informed of two user surveys, one relating to consumer satisfaction with hospital inpatient and follow-up services for stroke patients and a second one relating to extended personal care service. There are proposals to distribute a questionnaire on the quality of services provided by the Area Rehabilitation Team (ART).

15. These initiatives demonstrate an awareness of the importance of getting feedback from patients and the two completed surveys suggest a high level of satisfaction. However, when we enquired more generally during the visit it was apparent that there is neither a co-ordinated nor consistent approach to gauging user views. Developing a systematic joint method of getting feedback should be the next step for the Health Board and Trusts in association with local authority partners and relevant organisations. The Local Health Council should also be involved.

Overview – the Patients' Journey through the Service

Promoting ability and well-being

16. The Primary Care Trust has made significant progress in the implementation of the good practice guidance[6] issued by the Scottish Executive Health Department and the Trust Director of Nursing chairs a Disability Action Group. A Disability Advisor has recently been appointed and is improving disability awareness in various settings across health and social work. Work is underway to train staff and offer advice and support. Accessibility problems are being resolved through environmental adaptations and the installation of loop systems in health centres and general practice premises. A recent audit of primary care premises in Forth Valley is exemplary and serves as a good practice model for elsewhere in Scotland.

17. There is less emphasis on disability awareness training in services provided by the Acute Trust. The Disability Advisor has some contact with staff working there, but most of the work has been focused on community and primary care services. At the time of the SHAS visit there was no identified person within

[6] Scottish Executive Health Department (1999): Good Practice – Equality for disabled people in the NHS in Scotland.

the Acute Trust with specific responsibility for heading up a disability strategy and access to goods and services, but this is now being taken forward with the involvement of the Disability Advisor from the Primary Care Trust.

18. The ART also provides some disability awareness training and there are a number of initiatives being taken forward by local authority social work departments These are welcomed and should be co-ordinated to develop a coherent strategy for disability awareness training across Forth Valley. The Health Board should ensure that this is in the Health Improvement Programme (HIP) and that appropriate resources are made available to build on the good work carried out to date.

19. Health promotion strategies in Forth Valley do not yet give adequate attention to the needs of everyone who falls within the full, diverse range of physical disabilities, in terms of centrally organised and co-ordinated health promotion. A very good start has been made with health promotion in cardiac rehabilitation, respiratory rehabilitation and the stroke service.

20. Health promotion was identified as one of the remits of the ART when it was first established, but there is a need to develop a more specific health promotion strategy for this team that takes account of work being done by the Health Board, Local Health Care Co operatives (LHCCs), local authorities and voluntary organisations.

21. The LHCCs and primary care teams are actively tackling secondary prevention of ischaemic heart disease and stroke with the relevant screening programmes in place. Health visitors can focus on primary, secondary and tertiary prevention and complement the health promotion remit of the ART. The Health Board and Trusts, in association with local authorities and other organisations, should ensure that the health and well-being of people with physical disabilities is addressed at both the strategic and service delivery levels.

22. We found variable information available for people with physical disabilities although the voluntary organisations play a useful part. At the time of our visit an information exchange day was being planned for December. This is a partnership exercise between the Health Board, Primary Care Trust and Clackmannanshire Council, which appears to be a well conceived approach that will offer users, carers, and voluntary agencies access to a range of information and the opportunity to comment on services.

23. Service users and carers confirmed that they are often unaware of how to get information. There is a need to ensure that appropriate information on services and contact organisations is made available in various places including GP practices, health centres, day centres and libraries as well as higher profile sites such as the Disability Information Centre in the Whinns Centre, Alloa, which is a good example of how to distribute information. GPs and others commented favourably about the Princess Royal Trust for Carers who have sent out an information pack to every GP practice on physical disability services and support organisations.

24. There is no independent advocacy service for people with physical disabilities in Forth Valley. Many staff we met were unaware of the value of such a service and the potential importance for people who receive such support. The Health Board in association with the local authorities should develop a strategy for the provision of independent advocacy for people with physical disabilities in the Forth Valley area. This is in line with the recent guidance issued by the Scottish Executive[7].

25. Good access and transport are essential if people are to maintain good health and normal living. Transport was severely criticised although we acknowledge that this is an urgent national issue that may be hard to resolve locally without creative, lateral thinking that is less centred on ambulances. Patient transport services were criticised by users, GPs, the Local Health Council and health and social work staff for a lack of flexibility and the use of a quota system. This means that some individuals are unable to get the care and services they need. One GP described the services as “absolutely appalling”. We were told of instances where general practitioners have taken patients in their own cars for clinic appointments. Most ambulances are not wheelchair accessible and there are problems for disabled people when transported separately from their wheelchair. When people do travel by ambulance, there are often very lengthy waiting periods before and after appointments.

26. We were told that the Acute Trust is currently looking at the use of ambulance transport and how this can be improved. A specific issue was raised by general practitioners about the management of ventilated patients. Ambulance transport is sometimes used inappropriately thus making it unavailable for people who require this specialist transport. The development of guidelines about the appropriate use of ambulances should increase their use for patients with the greatest need and should be looked at nationally.

27. Users and carers made representation to SHAS about difficulties in getting physical access to some health service premises. There are problems with the availability and usage of disabled parking spaces, lack of good signposting particularly in the hospitals and, as referred to earlier, a general lack of awareness amongst staff about the needs of people with physical disabilities. The work which has been carried out in health centres and GP practices needs to be taken forward in the acute hospitals.

Needs assessment

28. As is the case in other areas SHAS has visited a key issue is the number of disabled people not in contact with services. There is limited information available about the needs of people with physical disabilities and this is compounded by the difficulty in using such a broad term for a widely disparate group of individuals.

[7] Scottish Executive : Advocacy - A Guide for Commissioners. September 2000

29. Forth Valley Health Board conducted a needs assessment in 1992[8] based on national prevalence information and this provided an overall estimate of the number of disabled people in Forth Valley. It was noted at that time that detailed information on the extent of the use of primary care services by physically disabled persons, with which to accurately estimate future need, was not available. This information is still not available. The report stated 'that whilst a general study of local prevalence may not be cost effective, a focus group or qualitative interview approach could provide useful information on consumers' needs and preferences.' This is an approach that the recently convened strategic group might find useful in attempting to improve services for specific client groups and to identify and meet unmet needs.

30. A number of GP practices are in the process of developing morbidity registers. This should provide good local information on the specific needs of people in the different localities. This does not appear to be an area-wide initiative and consideration should be given to standardising the data set and providing financial support to this programme. Until this is done there will be many people with physical disabilities who are missing out on an appropriate assessment and the provision of services that will optimise their health and well being.

Initial contact with services

31. Because of the diversity of problems covered by the term physical disability there are many routes to initial contact with services. Primary care staff and social work staff are aware of services such as the ART although recognise the limitations imposed by waiting lists for this service. While recognising the ART as a valuable resource working to a high standard GPs and others feel that the team is only benefiting a small patient group and that there are many people who are not in contact with services.

32. We found that there can be different referral routes for the same service such as physiotherapy. This can be confusing for users and referring agents. There is a need for clear information about the role and services provided by the different teams and professional groups.

33. Children who are born with a physical disability or who develop a physical disability in the early years are supported by the acute and community paediatric services. It was not in the scope of the review to examine in detail the services provided to young children although there appears to be good early involvement from acute and community services and liaison with social work and education.

34. A particular difficulty was identified for young people aged 14 to 18 in finding appropriate services to meet their needs. The consultant community paediatrician, together with colleagues, has submitted a proposal to the Innovations Fund for the development of a young persons' service to assist with this problem. SHAS supports this approach.

[8] Forth Valley Health Board (1992) 'Physical Disability and Rehabilitation' – Director of Public Health Report

35. Young people and their families experience difficulties in the transition from paediatric to adult services because of discontinuity in service provision. This is a problem elsewhere in the country. Work is underway within learning disability services to develop a transition pathway for children moving to adult services, but a parallel development for those with a physical disability does not yet exist. There are also issues around the hand-over ages from paediatric tertiary services to local adult services and what services are available for young people. These specific issues should be addressed. Appropriate clinical pathways should be developed for young people with physical disabilities and their families so that they can gain access to the skills, support, services and resources that they need.

36. The establishment of the Area Rehabilitation Team (ART) in October 1996 provided a direct route to multidisciplinary assessment and rehabilitation services for adults (16 to 64) with physical impairment living in the community. The team is involved primarily with those who have neurological impairment. However, at the time of our visit we were told of long waiting times and while there is a system of prioritisation many people experience delayed or no access to this service. Since the visit waiting times have reduced to six weeks for routine referrals. This improvement is welcomed.

37. The team is not always able to provide an area wide rapid service for those at risk of hospital admission, nor is it able to become involved routinely in facilitating discharge from hospital. We are aware that work is underway to address the waiting times and some additional therapy staff had been appointed to the team until January 2001. However this will only address the problem in the short term and further work is required to ensure the resources of the team are targeted to provide services in the most effective way.

38. There are long waiting times for a range of paediatric and adult specialist services. Over the past year we heard of some orthopaedic services having a 65 week waiting time, waiting times for neurology up to 25 weeks, with a six month wait for rheumatology - even for those identified as a priority.

39. Children also experience very significant delays in getting certain services. At the time of our visit there were a number of children waiting for two and a half years for a paediatric occupational therapy assessment, with 150 children waiting up to two years. Children requiring physiotherapy can wait up to 12 months although urgent cases will be seen before then. These waiting times are clearly unacceptable and in the context of resource constraints the Health Board needs to prioritise the services available as clinicians are struggling under ever increasing pressures to see more and more people.

40. Many people come into contact with services following an acute admission to hospital. Apart from those who have had strokes where there are clear pathways for rehabilitation there is no over-arching service for people with a physical disability or a co-ordinated source of in-patient advice or support. A wide range of different hospital specialities is involved in both the initial acute and longer term care of physically disabled patients. There are no dedicated

in-patient beds for patients in this category either for those with acute changes in impairment and disability or for ongoing review and reassessment.

41. There are a number of individuals throughout the hospital system with, for example, an acquired brain injury or an exacerbation of their multiple sclerosis who occupy acute hospital beds (surgical, medical or geriatric). These services are not able to provide targeted assessment and rehabilitation. Examples were given of individuals in these categories occupying acute beds for many months and in some cases waiting for a year or more for rehabilitation or placement. In 1992 a survey identified 40 such patients who had been in hospital for a period longer than four months. We recommend that work be taken forward in obtaining accurate numbers of these patients so a clear pathway of care can be identified.

42. We found, as elsewhere, that there is a particular problem for people with acquired brain injury. People with an acutely acquired brain injury are normally seen in accident and emergency (A&E) or admitted to one of the wards. We were aware of people with acquired brain injury in orthopaedic, geriatric and surgical wards with limited access to the full range of therapy services and no specialist psychology input.

43. A small number of people may be transferred to one of the tertiary centres in Glasgow or Edinburgh. Transfer back to local services can be difficult and people may be admitted to wards that are not appropriate to meet their needs, often for very long periods. Continued specialised rehabilitation is generally not available in these local inpatient settings.

Rehabilitation services

Primary care and generic community services

44. We met with representatives from the two LHCCs in Forth Valley. As noted earlier the services offered by the ART are highly valued although there are issues around waiting times and the small number of people who benefit from this service. There needs to be a robust community infrastructure to support the work of the ART and other specialist services. The current problems with waiting times highlight the need for work to be taken forward in this area.

45. Within the generic community health services there is only a very limited rehabilitation service to meet the needs of people with long-term disabilities who live at home. There is good work undertaken by primary care nursing and community based PAMs (Professions Allied to Medicine) although some of this work is limited because of resource issues and the focus tends to be on the more acute aspects of care and treatment. Primary care and generic community services could provide a routine “maintenance role” in relation to ongoing review and rehabilitation and LHCC staff we met with supported this concept. However this is not possible within the resources available.

46. Podiatry services provide locally based clinics and a home visiting service. People are generally not discharged if there is ongoing need identified.

However, there is an ever increasing caseload and people can wait up to six months for return appointments. A recent review of podiatry services has identified a need for further development. This would benefit people with life-long physical disabilities who are likely to require a continuing service.

47. Community physiotherapy is provided by the Acute Trust although staff are well integrated with LHCCs and local primary care services. There is limited scope for community based physiotherapists to provide ongoing rehabilitation and maintenance therapy. There are links with the ART staff but further integration and liaison could benefit both patients and providers. There are no generic health service community occupational therapists for people under 65 and this is identified as a gap.

48. Dietetic services are provided by both trusts. There is 1.7 wte (whole time equivalent) staff providing community services with a waiting list for new referrals. We were told that waiting times can be up to one year for people referred to this service. There is an additional post identified for enteral feeding. There are major nutritional issues for people with physical disabilities. Opportunities for social care and home care staff to receive training in this important area is limited because of the resource constraints. These issues will need to be addressed at a strategic level.

49. There is a limited speech and language therapy service to adults with physical disabilities living in the community. Some specialised treatments are provided by ART staff but there is no community service for younger stroke patients (under 65). This gap was identified in previous SHAS reports on older people's services. There are problems in funding communication aids and in the provision of technical support. This needs to be addressed across the three local authority areas.

50. Nursing plays a critical part in the care of patients with a physical disability and this applies across the acute/primary care interface. The Primary Care Trust has progressed service redesign through the development of integrated nursing teams, which support patients through the full spectrum of care dependency. The partnership has been developed by the integrated teams and the area redesign team working together. We were pleased to hear about these developments and the good joint working across primary and acute services.

51. Many people with physical disabilities will be able to attend general dental services. We were pleased to hear the positive comments about the community dental service which offers check ups and treatment in people's own homes where there are difficulties in attending clinic or dental practitioner services. An oral hygiene service is also provided in this way.

52. There are a number of examples of local joint working initiatives between health, social work and independent sector organisations. There is considerable effort by all agencies to establish common protocols and 'joined up' working. We were particularly impressed by some of the work going into

establishing common understanding and flexible approaches to supporting individuals in returning to the community from hospital.

53. Hospital and community occupational therapists have an agreed protocol for assessment and access to equipment. There is a joint equipment store involving Falkirk and Stirling Social Work Departments. While we heard many positive comments about the joint equipment store there are some issues around the way equipment is ordered and problems with the current computer system. There are difficulties in uplifting equipment that is no longer required and this is currently being looked at. There is a separate equipment store run by Clackmannan Local Authority and this was described as being very responsive to meeting the needs of people with physical disabilities in the local area. Proposals had been made but not taken forward for the development of satellite stores for the rapid delivery of low–tech equipment. This should be reviewed.

54. The availability of and access to a suitable hydrotherapy pool is an issue for a number of users and clinicians. At present there is one hydrotherapy pool based in the Royal Scottish National Hospital (RSNH) although it does not comply with all recommended standards. The hospital is due to close in March 2002. Other than the RSNH patients people are required to pay for this service due to the cost of having qualified lifeguards. The facility is also considered neither appropriate nor practical for the wider needs of the community. Consideration should be given to the provision of an appropriate hydrotherapy pool in Forth Valley.

Area Rehabilitation Team

55. The Area Rehabilitation Team was established in 1996. An attempt to appoint a consultant in rehabilitation medicine was not successful.

56. The team was established to provide rehabilitation for individuals aged 16 to 64 who have developed a physical disability as a result of disease or traumatic injury. The team is centrally based in Stirling Royal Infirmary and provides a service across the Forth Valley area. The team accommodation is not suitable for active treatment and assessment and many people are seen at home. While this may be most appropriate in some cases the provision of suitable treatment facilities should be considered.

57. An internal review of the team was carried out by the Acute Trust in March 2000 and following that an external review was commissioned by the Acute Trust in August 2000. At the time of the SHAS visit this report was not available although subsequently it has been circulated. Because of time constraints there was limited involvement from the Health Board, Primary Care Trust and relevant clinicians in the terms of reference and scope of the review and a number of people we met with were unaware that a review had taken place. These included key clinicians such as the consultant community paediatrician, rheumatologist and some GPs. While SHAS recognises the merit of such a review there needs to be greater involvement from the range of stakeholders in addressing the needs of the service. However the

recommendations of the review are pertinent and need to be considered by the Health Board, Trusts and Local Authorities.

58. The team is multidisciplinary with dedicated input from physiotherapy, occupational therapy, dietetics, clinical psychology, speech and language therapy and nursing. Medical input is provided by a clinical assistant working six sessions. This has reduced from eight sessions. The grades, skill mix and sessions available from the different disciplines is an issue given differential waiting times and workload pressures. The use of a rotational physiotherapy post was considered by staff and some users to be problematic given the nature of the work and liaison with other disciplines. The original plan for a full time clinical psychologist for the team was not implemented, with five sessions currently being available. The role of the rehabilitation assistants on the team is recognised as being very useful in supporting clinicians.

59. At the time of our visit there was a vacancy for the post of Service Manager and one of the nurses in the team was acting-up in this capacity. There are specific issues relating to the leadership and management of the team which are referred to in paragraphs 123 - 129. At the time of our visit there was no input from a consultant in rehabilitation medicine although the clinical assistant is involved in neurology clinics and shares patients with the neurology service. However the lack of clinical and professional support has been an issue.

60. The team operates an open access referral system which is a strength of the service. However the team is struggling to provide a comprehensive service to an ever increasing number of patients.

61. Since the team was established there has been a high demand for services and this is the main reason why long waiting times have developed. Part of the workload pressures relate to the number of longer-term complex cases requiring ongoing input and commitment from the team, particularly in relation to multiple sclerosis (MS). This is an issue elsewhere in Scotland. Indeed the recent Scottish Needs Assessment Programme report (SNAP)[9] relating to multiple sclerosis suggests that continued support of patients with multiple sclerosis, coupled with intermittent rehabilitation every few months, is good practice. By virtue of its current remit, the team has assumed responsibility for MS patients through their phases of increasing impairment. In the absence of parallel services to support patients with significant long term disability within the community, there is no where else for people to go.

62. The team is well regarded by those in receipt of services and by colleagues in other services. There are many examples of good work being taken forward. However, there is a need to review the role of the team to ensure the existing expertise is targeted appropriately and that care pathways are developed. There is a tension in how much the team should focus on active assessment and rehabilitation as opposed to longer term support. This issue is highlighted in the report of the recent external review of the team.

[9] Scottish Needs Assessment programme (SNAP) Multiple Sclerosis – October 2000

63. The team provides high quality generic rehabilitation and some specialist services such as the provision of communication aids and environmental controls. There are other elements of rehabilitation practice which the ART are currently unable to provide and that services elsewhere are moving towards such as, for example, Botulinum Toxin injections. The scope for the team's development in a more specialised and targeted service is recognised in the recent review and underlines the need to clarify what service is being sought from the team for which patient group and for how long.

64. At this time the team's practice is predominantly neuro-rehabilitation and the ability to develop other alliances, work across other interfaces in both health and social care and develop other areas of clinical practice are limited. Areas where an area rehabilitation service has a part to play were identified by rheumatology and orthopaedic colleagues, for example, patients with ankylosing spondylitis, fibromyalgia and low back pain.

65. The team has been a strong advocate in developing outcome measures which are informing practice elsewhere. There are multidisciplinary records and good clinical documentation.

Services to people with brain injury

66. There is no dedicated in-patient provision for people with brain injury in Forth Valley and a number of people will be admitted to local hospital services or tertiary services in Edinburgh or Glasgow. There are particular issues for people with brain injury who require in-patient admission and, as identified earlier in the report, this can be to a number of different wards in either Stirling or Falkirk hospitals. There is no specialised assessment or rehabilitation service available for this group. SIGN[10] (Scottish Intercollegiate Guidelines Network) guidelines have recently been issued on the early management of patients with head injury. A SNAP[11] (Scottish Needs Assessment Programme) report also provides relevant information on service provision.

67. The ART does provide an assessment and rehabilitation service for people with acquired brain injury in the community. However the numbers of people currently being seen would suggest that many individuals are falling through the net and are not getting services that they require. Recent research conducted in Glasgow[12] identifies significant morbidity in those with traumatic head injury one year after the event. Many of these people will not be in touch with services at all. The absence of neuro-psychological and neuro-psychiatric services is a real problem and needs to be addressed.

68. The difficulty of ensuring smooth aftercare for patients returning from one of the three tertiary centres for brain injury in Scotland was also highlighted as a

[10] SIGN – August 2000 (number 46) Early Management of Patients with Head Injury.
[11] SNAP February 2000 – Huntington's Disease, Acquired Brain Injury and Early Onset dementia. Office of Public Health. Scotland.
[12] Thornhill, S et al. (2000). Disability in young people and adults one year after head injury: prospective cohort study. British Medical Journal, 320, 1631-1634

problem. Some people are admitted to a general medical or surgical ward with little or no opportunity for ongoing rehabilitation.

69. We found that clinicians were not always aware of the range of specialist services available, in particular to support people with severe cognitive impairment who have behavioural disturbance. The Robert Fergusson unit in Edinburgh is a national resource for this group and we were made aware of one individual who may have benefited from this service but was not referred. This is partly related to the fact that there are many different medical clinicians involved with people with brain injury with no one medical speciality having a lead role in the co-ordination and management of this patient group such as a consultant in rehabilitation medicine.

Neuro-rehabilitation services

70. There is no specific in-patient neuro-rehabilitation service in Forth Valley. People are admitted to a range of wards under different consultants with no overall co-ordination in relation to specialised assessment and rehabilitation.

71. The current neurological services are provided as an outreach from the Western General Hospital in Edinburgh. Since our visit the Acute Trust has appointed a full-time consultant neurologist and a Multiple Sclerosis Specialist Nurse for Forth Valley. This will lead to an improvement in the waiting times. Clinical links will be with the Western General Hospital in Edinburgh which will provide professional support to the new consultant.

72. There are close working links between the neurological services and the ART. The clinical assistant provides a weekly neurology clinic and there is immediate access to the ART services.

73. Physiotherapists expressed some concerns that the development in neurology services did not take account of the potential impact on services such as physiotherapy and this should be looked at as part of the strategic framework.

74. There is a specialist Parkinson's Disease nurse and at the time of our visit recruitment was underway for specialist nurses in Multiple Sclerosis and Epilepsy. This is a welcome development and there is an opportunity to develop an appropriate interface with the ART.

75. The absence of a clinical neuro-psychologist is a problem that needs to be faced across all aspects of neuro-rehabilitation. There is involvement of the clinical psychologist from the ART but a very limited service to inpatients.

Stroke services

76. There is a dedicated stroke in-patient rehabilitation service in both Falkirk and Stirling, which is not age related. This multidisciplinary service is provided according to SIGN guideline criteria. There are some issues of mixed sex accommodation that need to be improved to comply with national guidance.

77. Two specialist nurses provide support to Falkirk and District Royal Infirmary and Stirling Royal Infirmary. There is evidence of significant participation in audit, use of outcome measures, health promotion, patient information and patient and carer satisfaction questionnaires. This is a well developed and nationally well regarded service.

78. There is good follow-up and outreach support for patients aged over 65 who are discharged from hospital. However a similar service is not available for those aged under 65 who make up about 20% of stroke patients. The consequence for users is that people under 65 do not get access to the range of services that would enable them to continue their rehabilitation. The ART, for historical and resource reasons, do not provide the service to this group. This is a significant shortfall in services that needs attention.

Respiratory rehabilitation

79. There is a consultant led service with specialist nurses and physiotherapy input which aims to support people at home and prevent admission to hospital. Good links have been established with primary care services and voluntary organisations. An additional temporary nursing post was funded to assist in the prevention of winter pressures.

Cardiac rehabilitation

80. A cardiac rehabilitation programme has been running since 1995 with involvement from a cardiac rehabilitation specialist nurse and a physiotherapist. The service is aimed primarily at patients who have suffered a myocardial infarction and those following cardiac surgery. There are good links with patient support groups.

81. The service does not extend to people in the community who have ischaemic heart disease and who are managed by their GP although there is an educational programme aimed at primary care staff. Such patients could benefit from direct access to the programme and consideration should be given to developing the service to meet these needs.

Amputee locomotor disability

82. An increasing number of people requiring lower limb amputations are under 65. There is no specialised rehabilitation for this group. We heard of people having to remain in hospital because of delays in getting prostheses and some being discharged home without a suitable prosthesis. Falkirk District Royal Infirmary moved their contract from Westmarc to Princess Margaret Rose Hospital in Edinburgh and this has resulted in an improved service. The prosthetic provision for people in Stirling should be reviewed and delays minimised as far as possible.

Wheelchair service

83. The majority of people in Forth Valley receive wheelchair services from Westmarc which is based at the Southern General Hospital in Glasgow and is one of five centres in Scotland. A small number of people in Forth Valley will access wheelchair services based in Dundee and Edinburgh due to the geography of Forth Valley.

84. Throughout the visit we heard of significant problems about the provision and repair of wheelchairs related to the Westmarc service. Unfortunately this is a recurring theme in SHAS reviews, which should possibly be addressed at a national level. The Westmarc service is delivered on a consortium basis to six Health Board areas, including Forth Valley. The monitoring of service delivery by the consortium and specifically Forth Valley Health Board has been limited by the absence of monthly activity monitoring. We understand that Westmarc are now committed to the production of monthly figures for consortium and local review, although there have been difficulties to date in producing this information timeously.

85. Forth Valley Health Board has established a local area wheelchair services group to inform the monitoring of the service locally. Complaints concerning the service are addressed directly to Westmarc and Forth Valley Health Board has in the past been advised only on an ad hoc basis. A more structured feedback on complaints has been requested from Westmarc who are currently working on developing a system to achieve this. Progress in this area will be reviewed by SHAS in three months time.

86. A number of proposals had been made for the development of a local wheelchair clinic in Forth Valley for adults. This is identified in community care plans with an expected implementation date of March 2000. This has not happened and clinicians are frustrated by the difficulties this causes for users and their families. Joint discussions with Westmarc are ongoing in relation to this proposal but no agreement has been reached. This is disappointing.

87. There is no systematic way of recording waiting times although we heard varying timescales of between three and four months for the provision of a chair and up to two months for repairs to be carried out. There is also a problem with specialist seating and again long delays are reported. By contrast the RSNH has developed a satellite seating clinic for people with learning disabilities and there are significant benefits in this approach. We are concerned about specific health and safety issues – in particular the delay in repairs which may mean some people are using wheelchairs which are not safe.

88. The Red Cross provides a loan service that is intended for people who require a chair for a few weeks. However we were told that this service is now being used routinely because of the waiting times with the wheelchair service and chairs are now out on loan for up to three or four months at a time. People are not assessed for these chairs and they may not be suitable for them or their

carers. The Health Board should ensure that these issues are brought to the attention of Westmarc.

89. Numerous problems were identified to us around the wheelchair service which include:

- the lack of information to people in how to use chairs on delivery;
- information on use of lap straps;
- the lack of availability of lightweight chairs, which is a national issue;
- long waiting lists for power chairs with many people ending up purchasing their own; and
- awareness of users and carers needs.

90. There are proposals for local authorised prescribers for Forth Valley which would assist with some of the problems. This is already the case with paediatric services and there should be no reason why this cannot also be extended to adult services, as is the case in other parts of Scotland.

91. Forth Valley Health Board's approach to addressing the problems regarding the wheelchair service has been to establish a local multiagency wheelchair services group. The Health Board informed us that representatives from Westmarc have responded to invitations to attend and have participated in robust discussions on problem areas and potential options for solutions. As a result some progress has been made on specific issues although it is recognised that much remains to be done jointly with users to improve the service.

92. There needs to be better dialogue with the social work departments regarding the aspects of wheelchair prescription that affect the environment. The issue of ramps was discussed and the fact that clients need to contact social workers themselves to highlight the need for a ramp which may add further delays into the system.

93. We are aware that Westmarc plan to set up a Professional Advisory Group to inform the Consortium Group on specific clinical local issues. This is welcomed but the drive to see real improvement in quality, standards and waiting times for individuals in the Forth Valley area must be advanced.

Environmental controls

94. The responsibility for the assessment and provision of environmental control equipment currently resides with the ART. At the time of the visit there were 38 people in the Forth Valley area with environmental control equipment compared to 14 patients being supplied in 1999/2000. Although the ART clinical assistant is currently the medical assessor no members of the ART have had formal training with regard to environmental control equipment and there are concerns regarding installation, training and monitoring of the equipment by the contractors.

95. The ART acknowledge that there are new technological advances in communication equipment, wheelchairs, computers and environmental control equipment, which is leading many parts of Scotland to increasing integration of all these systems. There is no one in Forth Valley with the necessary knowledge and training to be able to take this integrated approach forward.

96. The ART continues to identify a significant unmet need in what is an increasingly expensive and complex technological area. There needs to be a rapid formal review with the ART, Trusts and Health Board with clinical input.

Continuing care and ongoing support

97. People with continuing care needs are cared for in a number of settings but mainly at home. There are no in-patient continuing care beds for this group although as noted earlier there are some individuals who have remained in hospital, sometimes for a year or more, in inappropriate ward settings.

98. We were pleased to have the opportunity to visit a number of people with continuing care needs living in their own home. Most of these people are supported by the joint funded community care packages. This service is co-ordinated by a nurse who is employed by the Primary Care Trust. At the time of our visit there were 21 people receiving up to 24 hours support. Staff providing the care are employed by the Primary Care Trust although the funding is joint between health and social work across the three local authorities. Staff carry out a range of procedures including ventilator management, tracheotomy care, peg feeding and other 'health' care related tasks.

99. There is an increase in the numbers of people living in Forth Valley with joint health and social funded packages of care and support. This increase is predicted to grow over the foreseeable future[13]. While a number of people receive services provided through the joint community care packages there are no clear criteria for health care provision across Forth Valley. The health care and social support provision and the funding of such joint packages is not consistent and there is a need for a clear policy, procedures and pathway. As is the case elsewhere there are difficulties in agreeing the share of funding and responsibility across health and social work services. A multi-agency working group, chaired by the Health Board has been in existence for some time in an attempt to address these issues. This work needs to be progressed.

100. In addition to those individuals on complex care joint funding packages there are people being supported in their own home with input from primary care services, social work care staff and voluntary sector providers.

[13] Forth Valley Health Board (2000) The organisation of management of individuals with jointly funded packages of health care and social support within the community of Forth Valley – The issues: John McGhee and Carol Morrison

101. There is a small number of people with continuing care needs who are resident in nursing homes. We had the opportunity of visiting one nursing home which has a five bedded dedicated unit for young physical disabled. One bed is identified for respite care. The quality of accommodation is good and there is comprehensive patient documentation which clearly addresses the assessment of needs, the development of a care plan and reassessment and evaluation of care. Individuals have access to a range of health services to meet their needs including input from the ART.

102. We did not formally review systems and procedures for monitoring patients' funds in hospital. However there are major implications for staff in relation to the Adults with Incapacity Act[14] which will be implemented from April 2001. The Trusts should ensure that appropriate training for staff and procedures are in place. Assessment of capacity should be part of initial and ongoing assessment and care planning across all services.

103. While the ART provide some ongoing review for a limited number of people with long-term chronic disabilities there is generally little involvement from PAMs and other specialist staff with the majority of people.

104. Functional maintenance issues for those with long-term impairments and disabilities, together with access to regular focused rehabilitation, is a national problem and locally requires a partnership approach between users, carers, primary care and community services, the ART and the hospital services. Re-focusing in isolation the role of the Area Rehabilitation Team will not be enough.

105. An important area, which is often neglected, is that of relationships and sexuality. There can be difficulties for users and carers in gaining advice, support and information. The Health Board should ensure that this area is acknowledged and that appropriate information and advisory services are available to users and their families.

106. Palliative care services identify that about 10% of their patients have non-cancer related disabilities including people with motor neurone disease, multiple sclerosis and other neurological disorders. They are accommodated within palliative care wards and day facilities. There is no specific service for younger non-cancer patients and the interface between palliative care and rehabilitation services is important.

107. There is a MacMillan neurological domicillary nursing post supporting people with neurological problems. This development has identified unmet need. There is an increase in both patient activity, complexity and dependency and the current resources are now unable to meet the demand.

[14] Adults with Incapacity Act (Scotland) 2000

Day services

108. Day services are provided in the main by the local authority social work departments and we had the opportunity of visiting two centres. There is involvement from the ART although as referred to earlier younger people with strokes are unable to access this service.

109. The Dundas Centre in Grangemouth in collaboration with a local GP has been successful in attracting money from the primary care development fund to employ a physiotherapist for two sessions a week to provide a service to people attending the centre and other people living in the community. This will enable people to have easier and early access. As referred to already, a proposal to have a local wheelchair clinic at the Dundas Centre has not been responded to by Westmarc. This is disappointing given the very positive user support for this initiative.

110. There are some innovative and interesting activities being taken forward by the Whinns Day Centre in Alloa and the Dundas Centre. Individual users however did express some concern about the lack of social and recreational opportunities, particularly for those with more complex needs. Further education was also identified as a gap area with some specific difficulties about physical access for people in Falkirk and Stirling Colleges. There are limited employment opportunities although there is an employment project run by Capability Scotland which is aiming to promote employment and support people with work opportunities.

Respite care

111. There is little in the way of dedicated respite care or short breaks available for this group and this is recognised as necessary by all agencies. Some people currently receive respite care in nursing homes and occasionally in acute wards. The planning partners will need to find additional solutions and opportunities for people to remain in their own home with temporary substitute carers.

112. Falkirk Social Work Department had developed proposals for a short breaks bureau. These and other respite initiatives for individuals with a physical disability are being considered by the Forth Valley Multi-agency Strategic Planning Group.

Voluntary organisations

113. We had the opportunity to meet with the representatives from eight voluntary organisations as well as visiting a range of services. There are some very good examples of joint working with health services particularly in relation to organisations such as the Parkinson and MS Societies. There are concerns over the availability of good quality general disability information in relation to non-specified disabilities. The closure of Disability Scotland makes it harder to get information.

114. Some voluntary organisations were involved in joint planning forums and of the consultation process although there was some cynicism over consultations that did not lead to change to services.

Services for Children and Young People

115. There is one consultant community paediatrician for the Forth Valley area who is supported by a number of staff grade paediatricians. The community paediatric service is located within the Primary Care Trust and acute paediatric services are part of the Acute Trust. However the consultant community paediatrician is on the on-call rota for the Acute Trust and there are good working relationships with efforts to provide an integrated child health service. There is a specialist register attachment to the community paediatric service and this is a welcome development.

116. There is evidence of good joint working between health, social work and education with early involvement from the range of disciplines with children who have physical disabilities and their families. Joint clinics are established. As referred to earlier there are major problems with the waiting times for paediatric therapy services in particular occupational therapy and physiotherapy. These waiting times are unacceptable and the Health Board requires to address this and to examine how resources should be deployed.

117. There is minimal specialised clinical psychology and psychiatry services for this group of young people. There are two sessions of clinical neuro-psychology mainly in the Stirling area, although children from Falkirk will be seen. Children require to wait quite a long period to get seen and there is limited involvement because of resource constraints after initial assessment. There is no liaison paediatric psychology service for children with chronic ill health or disability. This has been highlighted in a number of service development plans but there has been no outcome to this work.

118. There is a major problem once again with respite care provision for children with disabilities. The National Children's Home (NCH) runs a respite care service in Falkirk but this has a long waiting list and has difficulty in accepting crisis admissions. There is no input from PAMs and this is recognised as a need in relation to supporting individual programmes and also in the area of staff training.

119. Of concern is the number of children receiving respite care in Falkirk Royal Infirmary. We heard of at least 18 children who are regularly admitted to the paediatric wards for respite care. This is not an appropriate setting to provide respite care and is contrary to national policy. The Health Board and Social Work Departments need to develop plans at an early date. In the absence of other provision we recognise the efforts made by staff to meet the needs of children with disabilities and their families although the accommodation and environment is not suited to their needs.

120. No decision had been made about the location of the in-patient paediatric service in Forth Valley. As a consequence staff in the paediatric ward in Falkirk are unable to timetable children for respite care over the next year. This is causing a lot of anxieties for families who have come to rely on the respite care provision which, while not appropriate, is still the only service available for these young people. This needs an immediate resolution.

121. As is the case elsewhere there are problems in the transition from children to adult services. Work has been taken forward for children with learning disabilities that could inform practice for children with physical disabilities. The ART is not routinely involved in future needs assessment meetings and does not routinely see young people for assessment or review once they leave the paediatric service.

122. We were also told of some difficulties in transition of care from tertiary centres to local centres. We heard of some examples where there were specific gaps in service provision during these handover times. The introduction of a Diana Nurse gives the potential to co-ordinate and improve liaison between different parts of the service.

123. There is no paediatric palliative care service in Forth Valley. The number of patients requiring palliative care is small and some people will go to Edinburgh and Glasgow for specialist support. This issue should be considered in the appropriate planning forum and any unmet need identified.

Leadership and Management

124. The Acute Trust has recently implemented new management arrangements across all services, including the Area Rehabilitation Team and physical disability services. The ART, while located in the Acute Trust has had limited links with the management structure and since its inception has had no appropriate clinical leadership.

125. The ART is now located with the Intermediate Care and Rehabilitation Unit of the Acute Trust along with PAM services, surgical rehabilitation, stroke services, neurology services, day hospitals and geriatric services (inpatient assessment and rehabilitation and outreach services). The ART links with the 'Outreach' subgroup involving day hospitals and geriatric outreach. We recognise the efforts made by the clinical chair of the Intermediate Care and Rehabilitation Unit to assist in the integration of the ART services within the wider rehabilitation context. The service had been isolated with an absence of good clinical support.

126. At the time of our visit the ART was sharing representation on the clinical board of the Intermediate Care and Rehabilitation Unit with outreach geriatric and day hospital services. This means that there is only direct involvement on the clinical board for six months over an 18 month period although there is ongoing involvement on the outreach subgroup. We understand that the

membership of the clinical board is due to be reviewed and there is an opportunity to consider ongoing representation from the service.

127. There has been a lack of focus on the wider context of service provision for younger people with physical disabilities. The absence of a consultant in rehabilitation medicine leaves the service somewhat vulnerable and lacking in dedicated clinical leadership. There is a concern that the services for younger physically disabled are the poor relation of the geriatric services and in the absence of a consultant-led speciality there is a risk that the service is somehow downgraded. This is partly reflected in the current management structure where there is no identified speciality of rehabilitation medicine. We share the concern identified in the external review report that the failure to recruit a consultant has had a major effect on the balance of priorities and the use of available resources.

128. We were aware of mixed views about the merits of continuing with the original plan to appoint a consultant in rehabilitation medicine. However there was significant support from general practitioners and a number of other consultants we spoke to about such a development. During our visit a number of issues that we picked up would lend support for this approach.

129. The intermediate care and rehabilitation unit management team is considering models for longer-term consultant input including a stand alone consultant within Forth Valley or the possibility of sharing a consultant with an adjacent area. Since our visit formal medical links have been established with Lothian Rehabilitation Services at both an operational and strategic level. This will help to bring an appropriate expert perspective on the key issues and proposals for the service.

130. The ART has also been without a dedicated manager since March of this year and this has been difficult. The good work being done by the team needs to be recognised and staff should be involved in the plans for the service as far as possible. Since our visit a service manger has been appointed pending a decision being taken about the appointment of a consultant. The wider management issues will then need to be addressed.

131. There are differing management arrangements for the Professions Allied to Medicine. In general we found that the respective heads of services work well and there is appropriate interface between those services managed by the Primary Care Trust and the Acute Trust. The physiotherapists had put forward a proposal for an integrated management structure for physiotherapy across primary and acute services and this merits consideration.

132. The two LHCCs in Forth Valley cover the entire population. The Primary Care Trust has devolved a number of area-wide services to one or other LHCC and these arrangements appear to work well.

133. The lack of good information management systems impacts on services in a number of ways. There are some difficulties in collecting and sharing information with different approaches being adopted by different services. The

ART has not had a database, with all information available in paper format only. Both Trusts are working towards an integrated information technology strategy.

Clinical governance

134. There is a general support for clinical governance throughout both Trusts and good work is going on in relation to specific projects. Clinicians had an awareness of the clinical governance arrangements and the part they play.

135. The Acute Trust is seeking to unify clinical policies and a system of update and review is in place. There is recognition of the good practice developed in each District General Hospital and the necessity to share such practice trust-wide.

136. There is some good audit work going on, especially in relation to stroke services. Within the ART and across boundaries of practice there requires to be sustained support for audit and for developing the database within the ART to allow audit to take place.

137. The medical responsibility of the ART is operationally with the clinical assistant who is a competent individual but clinically isolated. Since our visit we are aware that the Acute Trust has established formal links with the Clinical Director of Rehabilitation Services in Lothian to provide clinical supervision and support. The Chair of the Intermediate Care and Rehabilitation Unit is providing direct clinical support to help review cases and set priorities in the short term.

138. There is variable work being taken forward in relation to individual appraisal and personal development plans for staff within the ART. More recently the different clinical groups have been linking with their appropriate professional head. This work needs to be consolidated.

139. Complaints procedures are being operated as per national guidance. We are only aware of two complaints relating to the rehabilitation service. There are particular problems with regard to complaints about wheelchairs with no local information available on numbers of complaints and how these are responded to. This was referred to in paragraph 84.

Staff training and appraisal

140. Statutory health and safety training is ongoing. There is a range of training provided by both Trusts and developing opportunities for shared training with social work and other organisations.

141. Staff appraisal and personal development plans are currently being taken forward by the Director of Human Resources in both Trusts as part of the Learning Together Strategy. The strategy will include a Trust-wide approach to Educational Needs and Assessment.

Planning Services

142. Forth Valley Health Board developed a robust plan for rehabilitation services in 1993[15] with a primary focus on services for people with physical disabilities aged between 16 and 64. A three tier model of service provision was envisaged covering community based rehabilitation, short stay assessment and rehabilitation and long term care for those requiring on-going medical and nursing care.

143. The community based ART was set up in 1996. There remain serious problems about ongoing care and support that need to be considered in a strategic context. The lack of progress made against a clear plan is very disappointing.

144. A multi-agency strategic planning group was set up last year to take forward an integrated plan for physical disability services in Forth Valley. The Group is chaired by the Director of Nursing from the Primary Care Trust and involves representatives from the Health Board, Trusts, Clackmannan, Falkirk and Stirling Councils, Forth Valley Local Health Council and service user representation. This is a welcomed development and provides an opportunity for the development of a co-ordinated integrated plan for this group.

145. It was intended to have a draft strategy by March 2001. There has been some slippage with the work of the Planning Group and it is likely to be summer 2001 before the report is available for consideration. The recently published Our National Health plan[16] encourages a focus on services for people with a physical disability and in Forth Valley physical disability is maintained as a local priority.

146. There is a need to ensure appropriate representation and involvement from the range of stakeholders both within and without the health services. In relation to health there is a need for an interface with paediatric services, older people services, mental health services and other areas related to physical disability, for example orthopaedics and rheumatology services. There should also be a link with the good work being taken forward in the areas of cardiac and respiratory rehabilitation. The planning group recognises the need to co-opt representatives from voluntary sector agencies, primary care services, education, housing etc. This work should be taken forward at an early date with the local authority a key partner.

147. Given the uncertainty about the appointment of a consultant in rehabilitation medicine it is essential that there is appropriate consultant input to the planning process. This will involve a range of consultant interests in Forth Valley but should also include a consultant with expertise in rehabilitation medicine with experience of setting up and developing a similar service elsewhere in Scotland. We are pleased to note that since the visit such input has been identified.

[15] Forth Valley Health Board (1993) Purchasing Plan for Rehabilitation Services

[16] Scottish Executive- December 2000: Our National Health – A plan for action, a plan for change.

148. A redesign team has been established to review the role and remit of the ART and as with the wider planning agenda there requires to be appropriate expertise and consultant input in taking forward new service models. This needs to be considered in the wider context of services for people with a physical disability.

149. A number of issues have been identified throughout the report that require to be considered in a strategic context. These include:

- agreement around the funding for complex care packages;
- lack of availability of suitable housing;
- respite care/short breaks;
- lack of specific provision for head injury services;
- rehabilitation services within the community with a specific emphasis on the role of specialist and generic services;
- provision of mental health services;
- services for children with physical disabilities in transition; and
- wheelchair services, patient transport and environmental control.

150. The HIP identifies two main objectives for services for people with physical disabilities:

- to improve the overall health and well being of people with physical disability by ensuring an integrated approach in association with prevention, treatment and rehabilitation, and
- to address health and equalities in terms of lifestyles, life circumstances and access to services.

151. Forth Valley Health Board has funding available for the further development of the rehabilitation services. The immediate gaps in services require to be resolved alongside the medium to long-term objectives.

152. The strategic direction for services needs to be made explicit and ad hoc developments should be incorporated into the wider picture. While progress has been made in a number of areas in Forth Valley with the development of the area rehabilitation team it is recognised that physical disability has been a low national priority and as such is always competing for resources.

153. This review identified a number of major strategic issues, some of which need to be considered at a national as well as a local level. These include wheelchair services, environmental control services, patient transport, services to people with acquired brain injury and access to information.

Examples of Good Practice

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

1. The work being taken forward by the Primary Care Trust in disability awareness and the role of the disability advisor in training staff and developing good practice across both health and social work services.

2. The range of health promotion activities in stroke, cardiac and respiratory rehabilitation.

3. The role played by voluntary organisations in supporting people with physical disabilities and their families and in providing information.

4. The development of integrated primary care nursing teams and the joint work being undertaken across primary and secondary care services.

5. The development of a local physiotherapy service at the Dundas Centre.

6. The proposal by the community paediatric service to develop a specific service for young people aged between 14 and 18 years because of difficulties encountered by this group in accessing appropriate services.

7. The provision of domiciliary services by the community dental service for people with complex disabilities.

8. The work of the Area Rehabilitation Team in developing a multidisciplinary community based model of service provision to help meet the diverse needs of people with physical disabilities in Forth Valley.

9. The developing role for specialist nurses in the areas of cardiac, stroke and respiratory rehabilitation and support for people with Parkinsons Disease, Multiple Sclerosis and Epilepsy.

10. The approach to joint working, for example the provision of complex joint packages of care to enable to remain at home, the joint equipment store and joint work across health and social work occupational therapy services.

11. The provision of a specialist seating clinic at RSNH to meet the needs of people with learning disabilities and local authorised wheelchair prescribers for children.

12. The multi- agency planning group for physical disability services.

13. The good work being taken forward together across the different disciplines.

Main Recommendations

Several suggestions for improving the service are made throughout the text. The main recommendations are that the Health Board, Trusts, local authorities and other agencies where relevant should improve services in the following ways.

1. Ensure an appropriate range of services for children and young people to meet their physical and mental health needs and assist with a smooth transition to adult services. Community based respite provision should be developed to meet the needs of the children currently receiving respite care in hospital.

2. Improve the provision and repair of wheelchairs and specialist seating. Appropriate quality monitoring systems need to be put in place.

3. Improve ambulance and other forms of transport.

4. Provide adequate, accessible and equitable generic and specialist health care for all people with physical disabilities and reduce inequity. In particular services need to be developed for people with acquired brain injury, including stroke.

5. Ensure appropriate consultant-led rehabilitation services and resolve issues about the management, organisation and function of the Area Rehabilitation Team.

6. Promote disability awareness training for all staff and ensure that information is readily available for service users, staff and the general public.

7. Develop a strategic framework for physical disability services that is informed by a comphrensive needs assessment.

This review identified a number of major strategic issues that would benefit from consideration at a national level.

Dr Margaret Whoriskey
Advisor (Disability Services)

Dr Sandra M Grant OBE
Chief Executive

March 2001

Appendix 1

Services reviewed

User/ Carer Groups, Voluntary Organisations and Social Care Providers who met with SHAS

Beechwood Park Nursing Home

Crossroads

Dundas Centre

Forth Valley Advocacy Services

Margaret Blackwood Housing

Multiple Sclerosis Society

National Children's Home – Tayavalla

Parkinson's Disease Society

Red Cross

Strathcarron Hospice

Whinns Centre

Individual Service users and families

Community services

Area Rehabilitation Team

Clackmannan Local Authority Social Work Deprtment

Clinical Psychology

Community Nursing

Community Paediatric Services

Dietetic Services

Falkirk Local Authority Social Work Department

Forth Valley Local Health Council

Joint Equipment Store

Local Health Care Co operative – South

Local Health Care Co operative – North

Occupational Therapy Services

Physiotherapy Services

Podiatry Services

Sensory Impairment Service

Speech and Language Therapy Services

Stirling Local Authority Social Work Department

Palliative Care Services

Departments

Cardiac Rehabilitation Services

Consultants – Falkirk and District Royal Infirmary and Stirling Royal Infirmary

Forth Valley Primary Care NHS Trust Executive Team

Forth Valley Acute NHS Trust Executive Team

Forth Valley Health Board

Intermediate Care and Rehabilitation Unit

Nursing Staff – Falkirk and District Royal Infirmary and Stirling Royal Infirmary

Neurology Services

Respiratory Rehabilitation Services

Rheumatology Services

Specialist Nurses

Inpatient Services

Ward 4 and PITU – Falkirk and District Royal Infirmary

Ward 9c -	Falkirk and District Royal Infirmary
Children's Ward	Falkirk and District Royal Infirmary
Ward 9	Stirling Royal Infirmary
Ward 7	Stirling Royal Infirmary
Ward 28	Stirling Royal Infirmary

Appendix 2

TEAM MEMBERS

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GLOSSARY

Acute services	Care and treatment generally associated with that provided by clinicians in hospital.
Advocacy	A support system for helping people to say what they need, to make choices and to make their own decisions.
Advocate	Someone who is independent of the service a person is receiving. The advocate represents the needs of the person and supports them to make sure they get the rights to which they are entitled.
Acute Trust	Established on 1 April 1999 as part of the *Designed to Care* arrangements. Responsible for a defined set of acute hospital services within the geographical boundary of individual Health Boards. Usually no more than one in each Health Board area.
Ankylosing Spondylitis	An arthritis involving the spine.
Assessment	The work that staff do to understand how to support someone.
Augmentative communication	Electronic or other aid to communication.
Bioengineering	Provision of specially designed equipment, e.g. seating to assist with posture and movement.
Botulinum Toxin Injection	Medication for some neurological conditions.
Bridging Finance	Money that the Scottish Executive gives to Health Boards to help them to set up new services in the community while they are still paying for the upkeep of hospitals.
Charter Mark	The Charter Mark is awarded to the public for excellence in serving the public.
Clinical governance	Clinical governance is defined as corporate accountability for clinical performance. It is an initiative to assure and improve clinical standards at a local level and throughout the NHS.
Commissioning	Making the decision on what services are needed and then contracting with a statutory or voluntary organisation to provide them.

Community care	Care, particularly for older people, people with learning and/ or physical disabilities or mental illness, which is provided outside a hospital setting. This is increasingly being understood as care provided in patients' own homes, but may also include care delivered in a nursing or residential care home.
Continuing care	Ongoing nursing and/or medical help.
Coterminous	Having the same geographical boundaries.
Delayed discharge	A delayed discharge is experienced by an inpatient occupying a bed in hospital who is clinically ready to move to the next stage of care but is prevented from doing so by one or more reasons.
Diana Nurse	Nursing service providing care and support to children with life-threatening or life-limiting illnesses and to their families in their own homes.
Fibromyalgia	A disorder characterised by muscle pain, stiffness and tiredness.
HIP	Health Improvement Programmes are rolling 5-year programmes developed by Health Boards in conjunction with NHS Trusts, general practitioners and the voluntary sector setting out proposals to protect and promote public health, analyse and tackle health inequalities, and track service changes and developments.
Hydrotherapy	A form of physiotherapy which takes place in a warm pool.
Incapax	The term used for the system to manage the affairs of people who are unable to manage own financial affairs
LHCC	Local Health Care Co-operatives are voluntary groupings of GPs and other local health care professionals intended to strengthen and support the primary health care team in delivering local care. LHCCs are part of the management structure of the Primary Care Trust and no legislative provision is required to establish them. There are 70 LHCCs in Scotland, based on natural communities. The exact scope of each LHCC is determined by agreement among member practices and the PCT management.

Local Health Council	An independent body representing patients' interests in the NHS. As such it is able to provide help and advice about local health services, including assistance when making a complaint.
Neurorehabilitation	Specialist support in assisting the recovery of people after damage to the central nervous system.
Neurosciences	Medical and other health services related to the effects of disease or damage to the central nervous system.
Neurosurgery	The surgery or operative treatment of diseases of the brain and spinal cord.
Outreach	A service provided in the community by hospital based staff.
Palliative care	Managing care for someone who is not going to get better.
PAMs	Professions allied to medicine – physiotherapy, occupational therapy, chiropody, radiography, dietetics, orthoptics, art, music and drama therapies.
Primary Care Trust	In Scotland, established from 1 April 1999 as part of the *Designed to Care* arrangements, with responsibility for the provision of the full range of primary care, community and mental health services. There is usually one PCT within the geographical boundary of each Health Board.
Primary care	Family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.
Prosthetics	A service concerned with the design, construction and fitting of artificial devices to replace a missing part of the body.
Rehabilitation	The process a patient undergoes while recovering from an illness to enable them to function within the limitations of the illness.
Resource transfer	The transfer of money from the health service to the local authority for the funding of alternatives to hospital care.
Respite care	The care that is available in health and social care settings and at home so that either the patient or the carer can have a break.

SHAS	Scottish Health Advisory Service - an independent body, originally set up in 1970, and reporting to the First Minister, SHAS exists to help to improve the quality of health service care and the quality of life for people with a mental illness; people with a learning disability or physical disability; and frail older people.
SIGN	Scottish Intercollegiate Guideline Network – Established in 1993 and funded by the Clinical Resource and Audit Group as a collaborative venture undertaken by the Scottish Royal Colleges and other health professionals to sponsor and support the development of national clinical guidelines on a multi-professional basis.
SNAP	Scottish Needs Assessment programme which was established in 1992. SNAP assists Health Boards to carry out their required task of health needs assessment and also aims to raise awareness oh health needs.
Tertiary care	Care of a highly specialised nature that is typically provided in regional centres.
TIP	Trust Implementation Plan – 1 year plan outlining how Trusts will put their Health Board's Health Improvement Programme (HIP) into effect.