

ISSUES RAISED IN REPORT OF SHAS VISIT TO PHYSICAL DISABILITY SERVICES IN GLASGOW, AUGUST/SEPTEMBER 2000

Summary

Main findings

1. Many individuals are not in contact with services
- 2.(a) Some nursing home placements appear to be inappropriate
 - (b) The environment for long-stay young physically disabled adults (in care homes and continuing care in SGH) is unsuitable and “boredom is likely”.
 - (c) There is a need to re-assess the role and the range and quality of services in care homes and in continuing hospital care. There should be regular review of patients/residents in these settings – including the involvement of AHPs.
- 3.(a) The modes of operation of the Community Physical Disability Team , Physical Disability Rehabilitation Unit and AHP Training Team require to be reviewed (eg in relation to referral criteria, outcome measurement, audit and appropriate changes made).
 - (b) There needs to be greater coordination between the CPDT, PDRU, and the AHPTT in order to provide a joined up service for disabled people. The rehabilitation service is ‘very limited’.
 - (c) There is a need for specialist nurses, AHPs and others - based in hospitals and elsewhere - to extend their responsibilities to physically disabled people in other settings, and to establish working relationships with professionals responsible for this group in a generalist capacity.
4. There is a need to focus on audit and clinical effectiveness ; to establish appropriate outcome measures and to standardise these for community and continuing care services.
5. Future need planning should be adopted for children from the age of 14 years onwards, and adult services put in place to meet their needs when the time comes .
6. The Queen Elizabeth Special Injuries Unit provides a good example of what can be achieved in relation to, for example, comprehensiveness of services, range of ‘stimulating and normalising activities’, coordination with outside agencies, reviews, drop-in facilities, sensitivity to the need for relationships and sexuality, focus on audit and clinical effectiveness.

Other important issues

1. Access to information- for example about the range of services available; there is no organised collation or dissemination of information.
2. Difficulty in obtaining therapies, services and equipment, particularly wheelchairs and specialist seating and augmented communication equipment;
3. Difficulty in obtaining housing adaptations.
4. Addressing relationships and sexuality needs – for people at home and in care homes.
5. Respite: in hospital (PDRU), care homes and for people at home.

Suggestions for improving working practices

1. Involvement of staff in putting forward ideas and developing plans
2. Involvement , half time, of the new consultant in rehabilitation medicine
3. Encouraging establishment of a coalition of voluntary organisations with responsibility for people with physical disability.
4. Use of registers to ensure that as few people as possible ‘slip’ through the net.
5. Developing a locality focus (LHCCs, now CHCPs)
6. Exploring the role of district nurses and health visitors.

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Extracts (with refs to paragraph numbers in the Report)

Lack of information about the range of services available (7)

Limited access to services: including transport (7)

Limited therapy services (8)

Limited access to ‘ordinary’ community living options (9)

Problems with housing adaptations and the provision of specialised equipment (9)

Suitable housing for people with disabilities (9)

Long waiting time for the provision and repair of wheelchairs and specialist seating (10)

Very limited independent advocacy (11)

Community Physical Disability Team carry only a small proportion of the overall disability service workload (12)

A need for health visitors to focus on primary, secondary and tertiary prevention (16)

While we saw many examples of information resources and documentation, its collation and dissemination is not co-ordinated (17)

Often disabled people resent being transported in ambulances, feeling it is a stigmatising experience (19)

A key issue is the number of people not in contact with services (20)

SHAS was given the name of 73 relevant voluntary organisations – and there is a need for a degree of coalition if clear guidance is to be given to planners (20)

Until registers of younger physically disabled adults (including their needs) in each area (are available) there will be many who miss out on the provision of services (21)

There should be a robust mechanism in place for referral to specialised services and clear agreement about the role of primary care services and review (22)

There is a problem knowing what services can best meet the health needs of young people as they grow older - particularly for the 14 - 18 year age group (25)

Many people do not get a service from the Community Physical Disability Team (CPDT) because of long waiting times, referral criteria that require involvement of more than one discipline and lack of awareness (26)

There are delays in gaining admission to the Physical Disability Rehabilitation Unit (PDRU) both from the community and from medical neurology wards (30)

Within the generic community health services there is a very limited rehabilitation service to meet the needs of adults with long-term (physical) disabilities. A community nursing strategy should assist in identifying the role of primary care nursing for this group (33)

The CPDT needs to develop a greater locality focus (44)

The (various) providers need to align themselves, to ensure a joined up service for disabled people (46)

Patients miss out on early rehabilitation. There is a need for tracking patients to ensure that they do not fall through the net. (49)

Specialist nurses (eg for motor neuron disease, MS, Parkinson's Disease, epilepsy, palliative care) could enhance access to and act as a resource for CPDT's - (and CHCPs) (51)

Although a database exists on PDRU activity it has not yet been analysed. It is recommended that this be progressed. (57)

There is a limited opportunity for daytime activities in PDRU, particularly at weekends. Boredom is likely to occur. (60)

Day hospitals which are primarily for older people are not an appropriate setting for younger physically disabled adults. (62)

The comprehensive range of services for residents of the Queen Elizabeth Spinal Injury Unit (multiprofessional, patient/carer involvement, close links with many agencies) stands in stark contrast to the resources and services available to young adults with similar levels of disability due to other causes (64)

The 'Options Group' offers (in the QESIU) a range of stimulations and normalising activities and hobbies for people in wheelchairs (65)

Nurse-led review clinics (at QESIU) have been very successful . and a drop-in clinic for patients and their families is much appreciated. Training is also available to carers. (66)

Many users reported long delays in wheelchair provision and delay: even as long as 6 months, which is unacceptable. There are particular problems with specialist seating. There needs to be greater emphasis on information and communication with users and clinicians. (71 and 72).

There are concerns about the appropriateness of placement in nursing homes for some younger people with physical disabilities. The CPDTs have identified this as an issue (76)

There is a team of PAMs (AHPs) which offer advice, training and support to care homes: but the service is mainly for older people. (77)

There is limited involvement from PAMs (AHPs) and other specialist staff for people with long-term disabilities, and no system of regular review for the vast majority of people. These are major issues. (79).

There is a need for specialists to provide support to staff working in more generic areas (80)

Particular difficulties with augmented communication were highlighted for people with severe disabilities in nursing homes. There is a need for urgent

consideration of the recommendations of the report *Alternative and Augmentative Communication*, 1988 (81 and 82)

The Health Board should ensure that the area of relationships and sexuality are addressed (as has been achieved by QESIU) - both for people living at home and in nursing homes (83)

Users and carers identified respite care as a major service gap. Planners will need to address this. A review of respite care should include the services provided in hospital. (84 and 85).

The environment on which severely disabled people live for the rest of their lives should as far as possible be homely and domestic, with access to gardens and open space. It is difficult to see how this can be achieved within an acute hospital site (93)

For most adolescents with physical disabilities there is a discontinuity of service and lack of clarity as to how their needs are to be addressed in future (96)

Community *Learning* Disability Teams are involved in future needs planning for children from the age 14 years. A similar approach should be adopted for younger people with physical disabilities (97)

We found that staff have few opportunities to influence plans and developments for the future delivery of care and services. CPDT members find it difficult to gain information and input to decision making. This should be looked at. (100 and 103)

A recent appointment has meant that there is now a half time consultant involved with the (south) CPDT who is to take the clinical lead. All LHCCs (CHCPs) should have a focus on the needs of people with physical disabilities. (106)

The focus on audit and clinical effectiveness evident in QESIU should be adopted by PDRU. There is also a need to establish appropriate outcome data and to standardise this for community and continuing care services. (107)

The child/young persons special needs database should be used to inform the strategic planning process and to plan resource for adult services. (112)

Voluntary groups feel distanced from planning and steps should be taken to ensure involvement of all stakeholders.

There is a particular need to address the needs of residents in the continuing care unit (SGH) and in nursing homes, and access to community and inpatient services (recommendation 7)

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