



# Disability Concern Glasgow

*Promoting Service Improvements for Disabled  
People in the West of Scotland*

*Helping people to help themselves:  
Self-Management and Self-Assessment*

*Establishing Environmental and Health  
Initiatives in Malawi*

Thursday, 01 November 2007

## **BETTER HEALTH, BETTER CARE: A DISCUSSION DOCUMENT** **Comments on Sections 4 (Inequalities) and 5 (Long Term Conditions)**

### **1. Development of the Approach: suggested additions**

- a) Ensure that the *recommendations made in reports* by national bodies (see References at end for examples) are implemented by Health Boards. Also take more active steps to use existing *models of good practice and other evidence* (eg from the voluntary sector and from the Long Term Conditions Alliance in England) to inform service development.
- b) Establish more effective mechanisms for learning from patient experience – including the needs of *those who have ‘slipped through the net’* and are receiving little or no service.
- c) *Promote self-assessment* as an essential component of self-management – in order to more sensitively identify the needs and aspirations (including employment opportunities) of people with long-term conditions and to reduce the input required by social work and other professionals.
- d) Take steps to convince NHS managers that a key responsibility is to *re-deploy resources* to ensure the best possible use of resources and to keep up with changing circumstances and demands; also that *the best ideas for improving services generally come front-line staff*.

### **2. Suggested priorities**

- a) Ensure that every patient and/or carer is provided with information about access to ‘signposting’ services and opportunities for self-management training at the time of diagnosis and at each visit to hospital.
- b) Recognise the particular needs of people severely disabled by long-term neurological and neuro-muscular conditions and by visual impairment. These groups are excluded from most (possibly all) NHS ‘chronic disease management’ programmes.
- c) Establish much more effective processes for ‘case management’ – so that individuals are provided with the interventions and services they need without delay when they

transfer between organisations/agencies (eg between hospital and community or care home; between child and adult services), and do not 'fall through the net'.

- d) Create a better understanding amongst doctors, nurses, AHPs and managers of the benefits to both patients and professionals of training and promoting opportunities for self-management and self-assessment.

### **3. Suggested specific actions for the NHS**

- a) Take steps to promote a culture of enquiry, creative thought and change amongst health professionals and managers. Encourage 'front-line' staff to put forward ideas and facilitate adoption of those that are promising.
- b) Provide training and other opportunities for health service professionals to learn about the benefits of self-management, and to eradicate misconceptions that it is in any way a threat. Also emphasise the need for doctors, nurses and managers to ensure that patients are given contact details of service(s) to 'signpost' them to sources of information and training in self-management.
- c) Extend 'chronic disease management' programmes to include long-term neurological and neuromuscular conditions and visual impairment, although on a more informal basis – for example by employing 'outreach workers' (possibly through condition-specific charities).
- d) Build on the experience of voluntary organisations – for example by further developing neuro-rehabilitation facilities (eg Revive Scotland – for people with multiple sclerosis) and the role of 'outreach' workers (eg Scottish Huntington's Association; Child Brain Injury Trust).
- e) Shift the balance from 'medical interventions' such as screening, health checks and a focus on medication to the provision of physical therapies (particularly physiotherapy and occupational therapy) and essential equipment (eg vision aids, wheelchairs and other mobility aids) that are of direct benefit to health and wellbeing.
- f) Increase the effectiveness and efficiency of rehabilitation services for people with long-term disabling conditions, for example by:
  - Establishing simple patient-centred goal setting and monitoring procedures, including adherence to strict criteria for case acceptance and discharge.
  - Changing the focus of assessment procedures from what the patient cannot do to what (s)he can or could (with help) do and what (s)he aspires to.
  - Involvement of junior therapists, care workers and family carers in rehabilitation programmes.
  - Ensuring effective interfaces and communications between providers, in order to minimise delays and duplicative activity.

### **4. Collaboration between NHS and partners**

- a) Encourage agencies to develop care plans for individuals disabled by a long-term condition that embrace health and social services, other sources of support, and

opportunities for a fulfilling life. These should be drawn up with full involvement of the patient/carer(s) and should be an essential instrument for ensuring effective care and preventing individuals from ‘falling through the net’ – to be used by patients and professionals alike. The quality and effectiveness of these plans should be monitored, and they should be updated regularly to take account of changes in the patient’s condition and circumstances.

- b) Much improved provision of supported/specialised housing options to meet the needs of severely disabled people who are unable to live satisfactorily in ‘normal’ housing.
- c) Joint working to a philosophy that particularly younger people with a long-term disabling condition have their own aspirations and want to live as good a quality of life as possible to their full potential. Partner agencies should therefore help and encourage patients/clients to express their needs and desires: by providing information, promoting self-assessment processes, exploring (and creating) opportunities for employment and focusing on what individuals could achieve rather than on their level of disability.

## **5. Recent experiences**

### ***‘Outreach workers for severely disabled people living at home***

Some voluntary organisations such as Scottish Huntington’s Association and the Child Brain Injury Trust employ ‘outreach’ workers to meet the particular needs of their client groups and family carers. Outreach workers have also been employed with short-term funding by organisations such as Revive Scotland (for people with multiple sclerosis), Disability Information Greater Glasgow (for acquired brain injury in young adults) and by the Royal Hospital for Sick Children, Glasgow (for young adults with neuromuscular conditions such as muscular dystrophy and congenital ataxias). By working with clients and their families for as long as their input is needed these ‘outreach’ workers gain first hand experience of their problems. Clients may be referred by health service or social work staff, may refer themselves (having seen an advertisement), or are contacted directly (for example young adults who have left school recently or people who have stopped attending hospital or a voluntary organisation for treatment). Their duties include:

- Appraisal of the client’s situation: family, housing, environment support.
- Listening (together and separately) to the perceptions of clients and families of their needs and aspirations; also providing them with the information they need to help them make choices.
- Working out what needs to be done, and how. Discussing with the client and family how best to take things forward.
- Making necessary referrals and acting as an advocate for the client and family. Also keeping track of the situation, and intervening as necessary until goals have been achieved, as far as is possible.
- Re-establishing hospital appointments that have lapsed if this is judged likely to be necessary.
- Recognising that the medical condition and social circumstances are likely to change over time – making it important to maintain occasional proactive contact with the client/family.

'Outreach' workers require to have considerable 'life experience', common sense, the ability to think creatively and be flexible – not working to a checklist. They are extremely effective in pulling together services, financial support, practical help and opportunities to enable clients to live life to as near as possible their full physical and psychosocial potential. *There are now many examples of individuals whose lives have been transformed by an outreach worker from being virtually housebound or even bed-bound to being able to live a reasonably active and rewarding life both in and outside the home.*

### ***Physiotherapy and occupational therapy in care homes***

Involvement in a Big Lottery programme (Non-Cancer Palliative Care) provided first hand experience of life in a number of 'more challenging' care homes. Two major problems identified were little or no access to physiotherapy, occupational therapy and speech and language therapy, and very restricted access to specialist health services – such as nurse specialists, acquired brain injury (including alcohol-related) and rehabilitation medicine. A great deal was achieved by appointing a very part time (4 hours per week) physiotherapist and occupational therapist each working in a single home (but not in the same home) on an ongoing basis. Working with managers, care assistants and with some valuable input from a newly qualified therapist, they were able to considerably improve the physical health and psychosocial wellbeing of most residents, and to change the ethos of the home from the passive provision of 'care' to one of developing the potential of each resident and creating a stimulating learning environment.

The key to the success of the model is having one designated Allied Health Professional (AHP) visit the home, just for one half day each week but on a regular (weekly) basis. Problems and queries can therefore be dealt with speedily and case conferences and reviews can be conducted at times when the AHP is present (or can adjust her schedule so as to be able to attend). Unfortunately considerable efforts to interest health service managers in this model of service provision have so far been unsuccessful.

### **6. Suggested performance targets**

- Success in implementing recommendations from national reports
- Ensuring that all patients with long-term conditions (and/or their carers) are provided with details of (a) a 'signposting' service and (b) opportunities for self-management.
- Employment of 'outreach' workers to help people with long-term conditions that generally do not respond well to medical treatment (eg neurological and visual impairment) to access the services, support and opportunities they need to live to their full potential.
- Much increased provision of supported housing for younger physically disabled adults, and provision of specialist and adequately resourced care homes for those who need residential care and support.

### **References: examples of national reports, many of the recommendations of which have yet to be implemented**

Care in the balance: The Quality and Cost of Residential and Nursing Home Care for Older people. *Accounts Commission/Audit Scotland, 1999.*

Services for Young Physically Disabled Adults in Glasgow. *Scottish Health Advisory Service, 2000.*

**Disability Concern: Scottish Charity SCO23333**

Rockmount, The Stell, Kirkcudbright, DG6 4TH. Tel: 01557 330 326

Website: in preparation

Email: [john.womersley@virgin.net](mailto:john.womersley@virgin.net)

Malawi website: [www.shim.org.uk](http://www.shim.org.uk)

The Influence of the Pharmaceutical Industry. *House of Commons Health Committee, Fourth Report of Session 2004-5, vol 1.*

Improving the Life Chances of Disabled People. *Prime Ministers Strategy Unit, 2005.*

National Service Framework for Long-Term Conditions. *Department of Health, March 2005.*

National Guidelines on Self-Directed Support. *Scottish Executive, July 2007 (publication 04093127).*

Managing long-term conditions. *Audit Scotland, August 2007.*

John Womersley

*Responding on behalf of Disability Concern (details at foot of page)*

*We are content for the response to be made available to the public*

*We are also content for the Scottish Executive to contact us about any matter relating to this response.*