

RAD Meeting, 7th December 2007
Big Lottery Programme: Non-cancer palliative care

Key personnel

1. *'Transition' Workers -RHSC :* 0.5 wte physiotherapist (2y)
 0.86 wte 'outreach' worker (2y)
 -Your Choice: 0.6 wte 'outreach' worker (1y)

for young adults with neuromuscular conditions (muscular dystrophy and congenital ataxias) and acquired brain injury.
2. *Nurse Manager (NHS GG&C):* 1.0 wte Clinical Nurse Specialist (2.5y)

developing good practice in palliative care for patients with conditions other than cancer: in hospital, general practice and in care homes.
3. *Development Officer ('Your Choice'):* 0.6 wte (3y)

establishing programmes of activities in care homes and developing self-management programmes and processes.
4. *Hospital-based information and communication (Southern General Hospital, Dr Grossett):* (a) Patient Information in neurology out-patient consulting rooms (b) Clinical Information System for Parkinson's Disease.
5. *Clinical decision making in the physical therapies (Southern General and Yorkhill Hospitals):* Making the most efficient and effective use of physiotherapy, occupational and speech and language therapy resources (cf. process developed at Brain Injury Rehabilitation Centre).
6. *Gaining new evidence and putting new evidence into practice: University Departments of Geriatric Medicine and Centre for Disability Research:* focus on 'physical disability' and on the experience of minority ethnic groups; also *Yorkhill Hospital and Your Choice:* evaluation of the 'outreach' worker role.

EXPERIENCE GAINED FROM THE BIG LOTTERY (Non Cancer Palliative Care) PROGRAMME: NHS GREATER GLASGOW 2003 – 2007

It is very important to ensure that the considerable body of evidence accrued from the various components of the Big Lottery (non-cancer palliative care) programme is used to the greatest possible good effect for patients/clients. The total cost of the Big Lottery programme will be almost £900,000, and the main aim of most of the components was to establish an evidence base and models of good practice to promote service improvements for people with long-term palliative needs.

A considerable number of individuals have benefited from the Big Lottery programme, but by far the greatest benefit will be to those who, it is hoped, will benefit in the future from improved services and opportunities. A great deal of evidence is now available, many of the staff involved - with their specialist knowledge and expertise - are still around, and models of good practice have been established. It is important that these valuable findings and resources are now used to bring about improvements in services for patients. A presentation on the Final Report will be made to the NHSGG&C Disability and Rehabilitation Planning and Implementation Group will make in December. This will help address difficulties for those involved in the Big Lottery work in engaging with those responsible for delivering the relevant services – senior managers across the new joint planning and operational structures in NHSGGC. It is very much hoped that this large investment of public money is put to much more effective use than has been the case with many reports and recommendations in the past (eg Scottish Health Advisory Service, survey of senior AHPs, Health Needs Assessment for Young Physically Disabled people).

Examples of evidence gained from the Big Lottery programme that should be used to inform service development

Experience in (some 12) Care Homes

Experience of working with managers of care homes and of care home companies: progressively increasing understanding of their perspective, difficulties etc.

Development of trusted working relationships with staff at all levels in a variety of care homes: working together to maintain therapeutic interventions, create opportunities for meaningful activity and to improve the quality of life of residents; identifying problems relating to staff status, opportunities for learning and communication with NHS staff.

Exploring access to specialist services (eg nurse specialists in specific medical conditions and palliative care; specialists in brain injury and rehabilitation medicine; physiotherapy, occupational and speech & language therapy): lack of awareness of staff; feeling that it is inappropriate to seek specialist help; unwillingness to provide services to care homes.

Developing the care home as a learning environment: taking every opportunity to teach, encourage questions and suggestions, and provide feedback to staff.

Working with NHS-funded staff to demonstrate what can be achieved in a few hours each week by a physiotherapist working in a care home for younger people and by an occupational therapist working in a care home with residents of all ages: in terms of physical benefit to residents, the attitude of staff (emphasising what residents can or could do for themselves, rather than the negative); the ethos of the home as a whole; reversing long established negative behaviour and attitudes of staff.

Observing what can be achieved by continuing input from an occupational therapist, physiotherapist and activities-promoter in a 'partnership' care home: Greenfield Park.

People with a long-term 'physical' disability living at home

Identifying many individuals isolated in their own homes as a result of inadequate support and helping them to secure the services, equipment and opportunities they need to help live life to their full potential; some receiving no services.

Gaining first hand experience of the stress, frustration and disablement suffered by many moderately/severely disabled people as they attempt to find their way through the complicated processes of gathering the information they need and of obtaining help.

Demonstrating the dramatic benefits to the physical and mental health of physically disabled people that can be achieved by providing meaningful employment opportunities matched to their capabilities, knowledge and experience.

Development of a detailed understanding of the information needs of people with a long-term disability - from pre-diagnosis onwards. Also exploring methods to ensure that patients/clients have access to the information they need as their condition changes.

Gaining a detailed understanding of the problems faced by children (and their families) during the period of transition to adulthood: particularly those with muscular dystrophies, ataxias and acquired brain injury. Identifying problems experienced by children in 'special' and in mainstream schools. Directly intervening to help resolve problems in individual cases; and identifying changes and service improvements needed to prevent these difficulties from recurring.

Similar understanding achieved for adults with specific conditions (eg MS, acquired brain injury, muscular dystrophy, epilepsy, visual impairment).

*Demonstrating the value of 'outreach' support workers: to identify individuals in need of services (including during and after the period of 'transition' to adulthood); to provide direct support; make referrals; assist in obtaining 'benefits' and Direct Payments; guide individuals and families through the complex network of support services and opportunities; and to act as advocates. **This is particularly important for individuals who have conditions not included in NHS chronic disease management programmes.** NHSGG&C mental health division has for many years funded Scottish Huntington's Association to provide such a service for its clients.*

Self-management

Development of a series of self-management programmes: including 'expert patient' programmes; programmes targeted to local populations; condition-specific courses (eg for people with epilepsy, acquired brain injury, visual impairment, MS); and courses for younger people with specific emphasis on employment issues. These courses take account of developments in England (Long Term Condition Alliance, University of Bangor) and in Glasgow (David Reilly, Centre for Integrated Care; Alistair Wilson, Dept of Psychiatry)

Establishing and continuing the development of self-support groups: eg continued meeting of self-management course participants (thereby contributing to their evaluation); condition-specific support groups (e.g. for people with congenital ataxias).

Appraisal, acquisition and presentation of evidence

Department of Geriatric Medicine, Glasgow Royal Infirmary: compilation of an electronic evidence base.

Centre for Disability Research, University of Glasgow: studies of young 'physically' disabled adults in care homes and at home; investigations of access to services and other aspects of the care and support of 'physically' disabled people from minority ethnic groups.

Appraisal of the UK literature relating to young physically disabled adults: including National Service Framework, Prime Ministers Strategy Group, reports on self-management (see above), Scottish Health Advisory Service. Summaries of all of these and of other literature are available, as are summaries and full reports for each of the examples given above.

Suggested Actions

- 1. All patients (in-patients and out-patients) and their families should be made aware of the existence of 'signposting', self-help and self-management services and opportunities. This should take place at all stages of their disability/medical condition.*
- 2. Even some of the most severely 'physically' disabled people have abilities that are either not identified or not valued. Young 'physically' disabled adults need to be encouraged to develop and utilise their strengths and skills - changing the focus from the negative to the positive, to what the person can do (or with help could do) rather than cannot.*
- 3. Many, probably the great majority, of younger 'physically' disabled people are fully capable of assessing their own needs, and of working out how these can best be met. They should be encouraged to undertake their own preliminary assessment of needs (example given in National Guidelines for Self-Directed Support, Scottish Executive, 2007) in preparation for the formal Community Care Assessment process.*
- 4. The process of accessing services from social work requires to be made clearer and more efficient, with fewer delays and progress monitored so that clients do not have to repeatedly 'chase up' requests. The very considerable difficulties in obtaining a Direct Payment also need to be addressed.*

5. *Mechanisms are required to ensure that individuals do not 'slip through the net' and that 'cases' are not closed* by social work (as often happens when a social worker leaves) when there are substantial needs still to be met.
6. *Appointment of 'outreach' support workers:* for young adults with long-term 'physical' disabilities, particularly for conditions - such as acquired brain injury, cerebral palsy, neuromuscular disorders and severe visual impairment - that are not included in NHS chronic disease management programmes (see above). The value of such 'outreach' work has been clearly demonstrated by the longstanding success with patients with Huntington's Disease and cerebral palsy (and their families), and more recently by the brain injury and muscular dystrophy/congenital ataxia components of the Big Lottery programme.
7. The needs of younger people with a 'physical' disability are very different from those of older people. *Young people need help to enable them to live life to their full potential, and this cannot be achieved by a workforce (home care service) or institution (care home) where the primary responsibility is for older people.* Many 'statutory' services encourage dependency by focusing on the provision of care and support. For some conditions such as acquired brain injury, Huntington's Disease and multiple sclerosis special training of care workers (and teachers) is desirable.
8. *There is a need to build the confidence of disabled students and young adults;* lack of confidence is often shaped by the low expectations of teachers, social workers and health service personnel (Report of the Equal Opportunities Committee, Scottish Parliament, 2006)
9. *Young adults in Care Homes require continuity of access to physiotherapy.* Even four hours per week to a Home of 24 residents can make a considerable difference to residents and to the Home itself. The assistance of a newly qualified physiotherapist is a great help, and care workers and residents/families can also contribute.
10. *All Care Homes should have occasional but regular input from an occupational therapist:* to improve social integration of residents, develop previously hidden cognitive abilities, and changing individuals from passivity to being able to exert influence and do at least some things as they wish.
11. *Specialists* (eg the nurse specialists in diabetes, epilepsy and other specific conditions; rehabilitation consultants; speech & language therapists; dieticians) *recognised as having the same responsibilities for Care Home residents as for people living in their own homes.* Also ensuring good communication between them and care home staff, and making specialist input a learning experience.
12. *Changing the focus of health service and Care Commission involvement in care homes from one of regulation and control to one of encouragement and facilitation.* There is a need to "promote a culture of learning and enquiry rather than of judgement and control: emphasising learning over regulation is the linchpin of improving care" (Donald Berwick).
13. *Development of training opportunities in Care Homes:* for nurses, AHPs, doctors and social workers – both as students and after qualification.
14. *Establishing simple goal-setting and monitoring procedure for rehabilitation of people with long-term 'physical' disabilities in all setting:* as for example was achieved with minimum difficulty and delay at Murdostoun Castle.

15. *Promotion of and support for self-management for young people with a long-term disability*: provision of training for front-line health service and social work staff; training opportunities for patients; greatly improving access to information; creating opportunities for meaningful activity and employment.

16. *Promoting the same kind of research, trials and evaluations conducted by pharmaceutical companies to areas such as physiotherapy, occupational therapy and educational /coping strategies* (House of Commons Health Committee: Influence of the Pharmaceutical Industry, 2005).

Conclusion

As a result of the Big Lottery programme and related work we have in Glasgow a body of evidence, expertise and practical experience relating to people with long-term 'physically' disabling conditions that is almost certainly more extensive and impressive than almost anywhere in the UK. It is important that this resource is used to the full – not only in Glasgow but elsewhere in Scotland, and beyond. There has been no process to date to disseminate this. However an undertaking to disseminate to the new planning structures has been made. This will follow from the presentation to be made in December. The problems identified in care homes, and in relation to younger 'physically' disabled adults have already been neglected for far too long, despite a plethora of reports and recommendations for improvements in services. People with learning difficulty and those with addictions have specialist services to meet their particular needs. Physically disabled adults on the other hand, whether in care homes or in their own homes, all too often have to make do with a 'service' which is a reluctant adjunct to a service for older people.

What has been established as a result of the Big Lottery Programme surely cannot be 'shelved' as have so many reports on younger physically disabled people in the past. Much could be achieved by creative redeployment of existing resources. All the evidence needed to inform the necessary changes and developments is already available. This should be translated into action now.