

‘Paying for care in Wales’

Response to consultation from the Foundation for People with Learning Disabilities

Introduction

The Foundation for People with Learning Disabilities is pleased to have the opportunity to contribute to the debate about the future of care and support in Wales. (Information about the Foundation is attached as an appendix). The Foundation believes strongly that discussion about the future funding of adult social care needs to start with agreement on the purpose of ‘social care’, as public awareness of the purposes and range of support covered by this headline is very variable. We hold a broad view of the definition, based on social justice values, and we believe that community or locality interventions, such as community development, are as important as direct support to individuals and families. It is therefore important to set the personalisation agenda, which the Foundation supports, in the context of the ‘place-shaping’ role of local authorities. These policy strands need to be firmly linked and directed to the goal of promoting human rights and equality of opportunity, so that all citizens have the chance to lead rewarding and valued lives.

A comprehensive system of care and support might include:

- information, advice and guidance available to all
- ‘reasonable adjustments’ to the physical environment, services and amenities used by everyone, to ensure that they are accessible to all
- financial support to compensate for the disadvantage experienced by, for example, a disabled person
- specific information, expertise and services available to meet specific needs for support. This will require workforce and service market development to ensure that the right mix of skills and services is available locally to respond to individuals’ choices.

People with learning disabilities and family carers find the current system:

- very complicated, with lots of different sources of benefits, allowances, and support services: these are not always well integrated, the entitlements are hard to understand and the process of applying can be both difficult and time-consuming
- unfair: you can get different levels and types of support according to where you live, how competent your advisers (such as care managers) are, and how pushy you are. Once you have negotiated a package of support in one area, it is hard to move around
- inefficient: as well as the administrative costs entailed in operating all the different current systems, the system of funding for social care specifically still includes perverse incentives that mean effective early interventions are squeezed out by the increased demand for intensive support – thus fuelling the demand for intensive support. Further, poor co-ordination between different Government policies means that disabled people who try to work can find themselves worse off
- inflexible: because the different current systems usually look at an individual’s circumstances, the needs of a family group may be missed. For example, a family with two or more disabled members may find that, assessed individually, each person just fails to meet the eligibility criteria for different allowances or services. However, looked at as a whole, the complexity of the family’s circumstances might well lead one to conclude that support is essential in a civilised society.

The term ‘independent living’ still causes concern to some people, who take it to mean ‘living on your own with minimal support’. The Foundation subscribes to the definition

promoted in the Independent Living Strategy, but it is clear that the Government has more to do to explain this vision.

Successive reports have shown that we still have a long way to go to achieve the vision of independence, choice and control. We believe the success of any new approach to care and support will depend on properly co-ordinated action across Government that joins up policies on work, housing, equality and human rights, carers, benefits and wellbeing, as well as health and social care.

The Foundation is supportive of the aims set out in Government strategies such as the Statement of Policy and Practice. However, experience in England with implementation of the White Paper 'Valuing People' reinforces the key importance of ensuring real delivery. Many of the delivery support arrangements for 'Valuing People' were good, but key weaknesses were:

- lack of real cross-Government commitment to delivery
- lack of 'embedding' in the mainstream of local authority and partner activities
- lack of robust performance management.

The delivery support aided those who wanted to make change and the 'critical friend' function challenged those who needed some impetus, but there was little that had any impact on 'resisters'.

Question 1: Sharing the responsibility for paying for care between the family, the individual and everyone in society

Many individuals who need support have family and friends who wish to provide some of this, and such provision is acceptable to the individual. However, this is not always the case. Some people do not have such a supportive network. Families of disabled people are more likely than other families to meet the definitions of living in poverty. Some people are unwilling to accept support from family and friends for a variety of reasons. In most other aspects of life, British society assumes that somebody aged 18 or over is autonomous. Funding for care and support should not be based on assumptions about support from family and friends.

The overwhelming view from those we consulted is that care and support should be funded from taxation and that the focus should be on entitlement to support so all citizens have the chance to lead rewarding and valued lives. This would mean addressing the complex interrelationship between the current welfare, social care, health care and taxation systems. It could include taxing the benefits to which disabled people are entitled, if their income exceeds the tax threshold. This was viewed as simpler and clearer than means-testing benefits or means-testing to determine liability for service charges. One family carer described the aim as being 'an allowance with dignity, not gratitude'. There was also a view that individuals who receive benefits awarded for specific care and support purposes should use those to pay towards their care and support.

Question 2: Setting fair rules for financial support in the future

- **Local flexibility or national consistency?**
- **One system for everyone or different systems?**
- **Target those least able to pay or support those who plan and save?**

Local or national?

The overwhelming preference of those we consulted was for a single national system of entitlement, which they saw as simpler, fairer and more transparent than the current mix of

nationally determined benefits and locally determined service eligibility. A number of people thought that the current system of funding for local government is so complex that it is very difficult for local citizens to understand how money is allocated to social care. Further, the current system has the effect of pitting different groups in need of support against each other (for example, as councils try to decide how to divide social care funding between older people, children and disabled people of working age). As one respondent pointed out, disabled people do not have much voting power in local council elections and thus little opportunity to influence the local flexibility that is prized by some commentators. A number of respondents drew comparisons with health care, child benefit and old age pensions as universal entitlements.

A particular source of irritation to some respondents was the difference in approaches to accountability for spending funding from different sources. For example, a person who is awarded Disability Living Allowance can spend it however they like, whereas they have to account for every penny of a Direct Payment for social care.

Respondents were aware, however, of the difficulties with some nationally organised entitlements. For example, the high percentage of successful appeals against Disability Living Allowance decisions was noted. Further, there was concern that any national system should be sensitive to people with very high needs for support: there may need to be some system for 'topping up' for people whose support needs are particularly complex. In addition there is caution about relying entirely on cash-based entitlements and a care market driven by individual purchasing choices. National entitlement, whether to cash or some mix of cash and services, needs to be supported by excellent local delivery that encompasses:

- skilled assessment of eligibility for the national entitlement (including a holistic view of the individual in their family circumstances, to avoid perverse results based on failure to recognise complex situations)
- information, advice, guidance, and assistance to plan and organise support
- market and workforce development to assure the availability of a choice of services
- 'place shaping' that addresses disadvantage more broadly and creates the conditions in which all citizens can thrive.

Some people pointed out the need for support for carers (family or friends) to be addressed at the same time and in a complementary fashion. As one said, '[caring] is a valuable, worthwhile career choice' for some people and such a choice should be supported rather than deterred. The caring role taken on by some disabled people in respect of others should be recognised and supported equally.

Many of those we consulted suggested that whatever body sets entitlements or determines eligibility should be advised by a panel that includes people with different needs for support.

One system for everyone?

Those we consulted took the view that people who are disabled from birth or childhood usually do not currently have the same opportunities as others to earn income through employment, to save for the future or to accumulate the social capital that might contribute to their support when they are older. In addition people with learning disabilities very often need support to exercise their rights to use universal services, as well as support to meet direct care needs. In contrast it can be argued that for most people ageing is a predictable development and, provided the 'contract' between citizen and state is clear, it is not unreasonable to expect people to make provision for predictable needs. The birth of a disabled baby, or the acquisition of a lifelong disability during childhood or normal working

age, is not predictable in this way. Any new approach to funding care and support needs to accommodate this difference. One way of accommodating would be to establish differential systems of funding. Another way might be to establish a universal system, but to couple this with a progressive tax regime.

Target disadvantage or support savers?

A number of those we consulted thought that people should be encouraged to save for predictable needs – but should then spend those savings to meet their needs. One way of achieving this may be to couple universal entitlements with a progressive tax regime that encompasses savings. A minority view was expressed that people who had contributed during their working life through taxation and were then expected to contribute to the costs of their own support from savings should be entitled to some rebate. One person suggested child trust funds as a possible savings model for people who are disabled from early in their life: a tax-free savings account that could receive government funding and individual contributions up to a set limit.

Some people pointed out that a person might accumulate savings with the express purpose of spending them on something that would reduce their need for support or the costs of that support, and they should not be penalised for doing so.

Contact:

Alison Giraud-Saunders
Co-Director
Foundation for People with Learning Disabilities
07721 843290

23.2.09

About the Foundation for People with Learning Disabilities

We promote the rights, quality of life and opportunities of people with learning disabilities and their families.

We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information.

Our objectives are:

- To promote the rights of people with learning disabilities to play a full part in society.
- To help ordinary services and communities to include people with learning disabilities more.
- To empower people with learning disabilities and their families to take control of the planning and delivery of their support.
- To promote person-centred practice, services and systems.
- To help get improvements in people's physical and mental health, so they can lead fuller lives.

Over the last three years we have worked with over 100 public and independent sector organisations across the UK, helping them to improve opportunities and services for people with learning disabilities. We are part of the Mental Health Foundation, a registered charity with offices in Newport, Glasgow and London.