

# Social Care Services and the Social Perspective

Peter Gilbert

If the 'Whig' interpretation of history is to be believed, namely that progress follows an upward linear curve, then the Government's White Paper on learning disability, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001; see also Greig, *PSYCHIATRY* 2003; **2:8**: 2–4), could be seen as the 'base camp' before the final assault on the summit of universal good practice. But of course it is not that simple. There have been major improvements in values, skills and services, but also a marked decline in some areas, notably the management of the transition from childhood to adulthood (see below and Gilbert, 2002) and a reduction in commitment from the NHS (see Greig, 1999). As Rob Greig, now director of the Government's Taskforce on Learning Disability, remarked: 'herein lies a major national policy issue. We understand how to deliver effective person-centred services, and national policy calls for them to be delivered, yet they are largely absent' (Greig, 1999).

The Social Services Inspectorate national report of April 1998 spoke positively about progress, pointing to major changes in services and increases in opportunities, but acknowledged starkly that 'the range and quality of social care resources for people with learning disabilities did not match users' and professionals' aspirations' (Social Services Inspectorate, 1998).

## Towards a social model of learning disability

People with learning disabilities have often been devalued and disadvantaged throughout history (Figure 1). *Valuing People* looks to redress this, on the basis of four key principles:

- rights
- independence
- choice
- inclusion.

The White Paper does not, however, avoid the challenges ahead, which are set out in Figure 2.

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**Peter Gilbert** is a Fellow in Social Care with the National Institute for Mental Health in England (NIMHE)/Social Care Institute for Excellence (SCIE), and an Associate Consultant with the National Development Team (NDT). He is also a visiting research fellow at the University of Sussex and honorary research associate at Staffordshire University. He has worked for many years with people with learning disabilities and their carers, and was formerly Director of Social Services for Worcestershire. His book, *The Value of Everything: Social Work and its Importance in the Field of Mental Health*, was published in June 2003.

## Historical attitudes and responses

Image	Attitude	Response
Subhuman	Lacks the emotional and physical needs of 'normal' people. Primitive and unpredictable behaviour	No rights. People with learning disabilities segregated and controlled
Threat to society	A weak mind in a strong body with potential for unpredictable behaviour and procreation	Control and segregation leading to a denial of freedom and possibly destruction
The eternal child	Catered for as children with no responsibilities and no rights	Stress on care but not development
Scapegoat	Tolerated and cared for until society comes under pressure	Segregated and perhaps killed at times of societal stress
The uneconomic unit	A burden on society	Segregation into units to fit economics of scale and exploitation
Burden on charity	Judgement of weakness from a strong moralistic standpoint	Basic needs are met in return for submission and gratitude
Object of pity	Suffering individuals of whom no demands should be made	Paternalistic. Shelter against risk. Low expectations
Sick person	Seen as sick and the passive recipient of medical care	Hospital model of care with emphasis on diagnosis and prognosis
Developing individual	An optimistic view of the individual with potential for growth	Stress on individuality, dignity and personal responsibility
The unfulfilled hope	Seen as not having met society's expectations after increased expenditure on education and training	Return to antagonistic or paternalistic ideology

(From Gilbert and Scragg, 1992; based on Wolfensberger, 1972. See also Race, 2002; Wolfensberger, 1992)

### 1

The emphasis is now firmly on issues of rights and responsibilities, social care models, and social inclusion and citizenship; but there are potential hazards. The move away from a biomedical model of disability and towards a social model has meant that in some areas the NHS has withdrawn attention and resources from learning disability. This is particularly problematic as the proportion of people with profound, multiple disabilities living into adulthood has greatly increased in the last 20 years, as has the number of those with complex challenges such as autism. The new primary care trusts (PCTs), which could be a major force for good in working with individuals and their families, are under financial pressure and seem to be struggling to cope with a complex commissioning agenda. Organizational divisions in local authorities have led in some areas to a decline in the good practice that was developed in the 1980s. Resource constraints in local authorities and the NHS have resulted in a tightening of eligibility criteria, leaving a number of vulnerable people with inadequate services.

Positive working relationships between primary care, second-

ary care and social care are essential in assisting individuals and their carers to achieve valued lifestyles. One of the ironies of the current situation in the UK is that, in large measure, we know what works, but good practice is still not being developed into standard practice.

### Tracing history

The philosopher George Santayana famously pronounced that 'those who forget the past are condemned to repeat it'. While it is easy to sentimentalize the past, there is little doubt that in the world-view of the pre-enlightenment age, learning disability and mental illness were recognized as having some value in society (see Gilbert and Scragg, 1992; Race, 2002; Atkinson *et al.*, 1997; Ryan and Thomas, 1987). Monasteries throughout medieval Europe provided asylum and care for people with learning disabilities in a system sometimes described as 'the first welfare state'. While this was usually a caring approach, it was paternalistic and lacking in any developmental process,

### Social care services today: problems and challenges

- Poorly coordinated services for families with disabled children, especially for those with severely disabled children
- Poor planning for young disabled people at the point of transition into adulthood
- Insufficient support for carers, particularly for those caring for people with complex needs
- People with learning disabilities often have little choice or control over many aspects of their lives
- Substantial healthcare needs of people with learning disabilities are often unmet
- Housing choice is limited
- Day services are often not tailored to the needs and abilities of the individual
- Limited opportunities for employment
- The needs of people from minority ethnic communities are often overlooked
- Inconsistency in expenditure and service delivery
- Few examples of real partnership between health and social care or involving people with learning disabilities and their carers

(From Department of Health, 2001)

## 2

with those cared for conceptualized as ‘children’ and ‘objects of pity’ (see Wolfensberger, 1992). This changed radically in the 18th and 19th centuries as the ‘Age of Reason’ and the Industrial Revolution brought in a more individualistic and utilitarian approach. Irrational behaviour was perceived as a threat, and lack of economic productivity was seen as a burden on society (see Figure 1). The ideas of Charles Darwin brought to the fore themes of racial fitness, which led to a powerful and pervasive eugenics movement in the 19th and early 20th centuries. This was discredited only when the Nazi regime interned and then annihilated thousands of people with learning disabilities and mental health needs.

In the UK, the local authority ‘colonies’ for disabled people were transferred to the NHS in 1948 but they remained isolated from mainstream developments in healthcare. The exposure of abuses in the long-stay hospital system – e.g. at Ely Hospital, Cardiff, in 1967 – provoked calls for change and led in part to the 1971 White Paper *Better Care for the Mentally Handicapped*. Targets were set for community resources in both residential and day services, but there has always been a shortfall. While some regional health authorities worked collaboratively with local authorities to set up progressive service models, others used the massive increase in availability of social security funds in the 1980s to ‘decant’ residents into often unsuitable and unsupervised private places. Although the NHS and Community Care Act 1990 placed a greater emphasis on social care and a more focused approach, it also led to very tight resource parameters as local government funding failed to meet the increased life expectancy and higher rate of dependency levels of people with learning disabilities.

### The social perspective

The disabilities and experiences of individuals are often much more to do with society’s attitudes than the original impairment. Vital to the whole issue, as the historical perspective shows, is the notion of citizenship and social inclusion. The Government’s Social Exclusion Unit defines the concept as ‘a combination of linked problems ... that lead people or places to be excluded from the mainstream’ (Social Exclusion Unit, 1999).

Recently, the newly formed Social Perspectives Network defined a ‘modern social model’ for the connected area of mental health. Key factors included the need to understand and relate to the complexity of human health and well-being, and how social and biological factors interact in the construction of health (Duggan *et al.*, 2002).

### Social care and social work

Within this overall framework sit both social care – ‘the function of supporting people to lead independent lives’ (Behan, 2002) – and social work, with its emphasis on using the self and personal skills in order to empower individuals and groups to work towards purposeful and positive change (see Thompson, 2000; Gilbert, 2003). As the revised British Association of Social Workers Code of Ethics points out, ‘principles of human rights and social justice are fundamental to social work’ (BASW, 2002).

### Identifying what users and carers want

In a highly competitive and discriminatory society, individuals and their families can become trapped in a negative spiral of low expectations and poor outcomes (see Figure 3). Many individuals experience double or even triple discrimination through gender, race or sexual orientation and/or additional health needs (see Chamba *et al.*, 1999).

From the outset, parents need a speedy and accurate diagnosis, sensitively delivered and followed through with ongoing support (see Gilbert and Hunter (1982) and pages 47–8). As parents do not always need or want continuing follow-up by a social worker or community nurse, contact around predictable life events (see Gilbert, 1985) is one way to ensure that major hurdles, such as the complex transition from childhood to the adult world, are successfully negotiated.

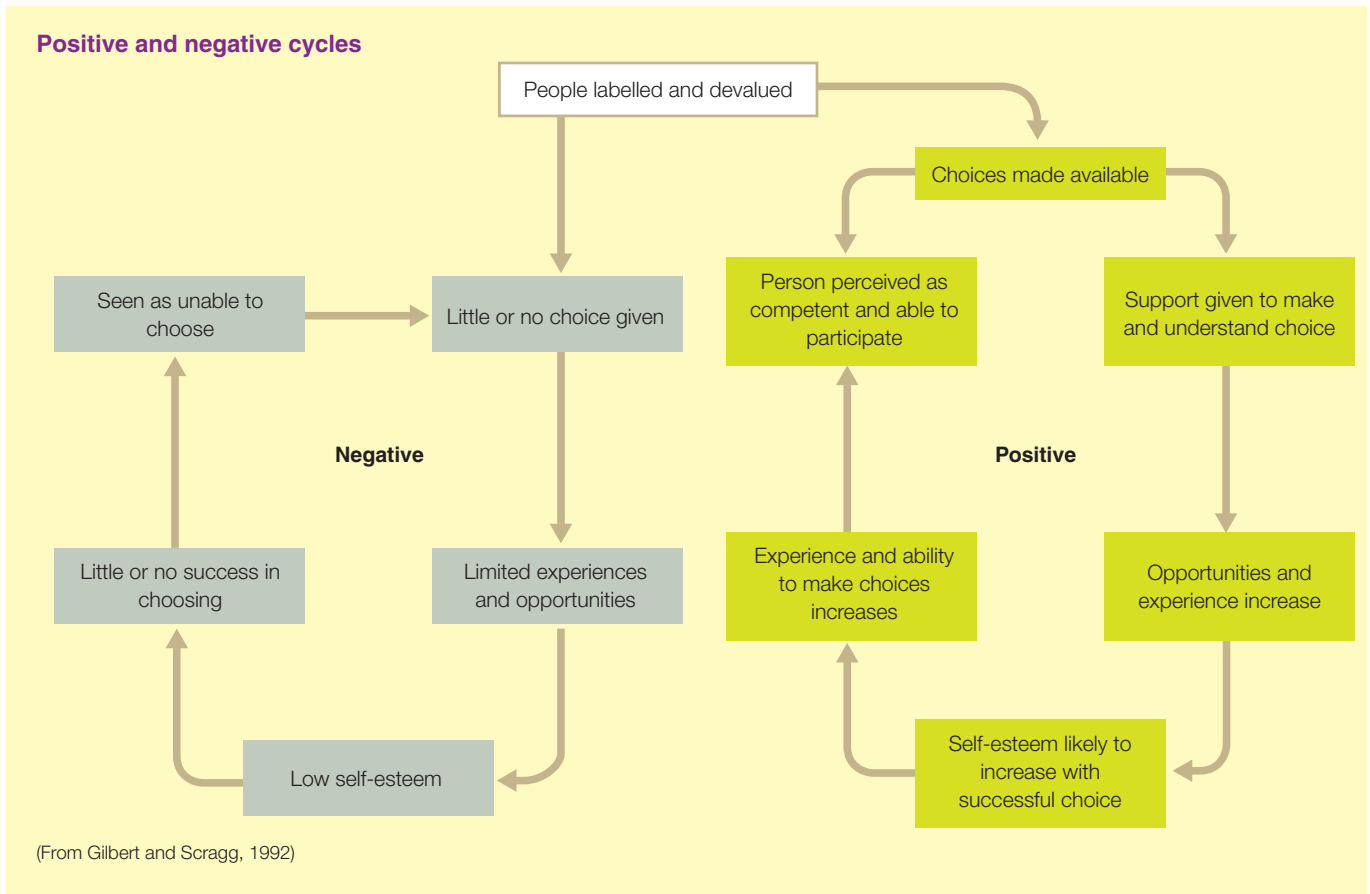
As they get older, people with learning disabilities will inevitably develop different perspectives from those of their parents. While people with learning disabilities will increasingly require assistance to access mainstream services where appropriate, carers need support and sometimes respite from the caring role. The recent Mencap report *No Ordinary Life* (2001) demonstrates vividly how difficult life is for carers.

### Services

#### Assessment

Assessment has always been a primary social work task, undertaken in a holistic way by staff who consider the individual within their familial, community and social context. The ethos is of empowerment and promoting independence – ‘working with’ rather than ‘doing to’.

Both users and carers want the emotional and psychological



3

issues in their lives to be addressed, and practical problems tackled. Since the NHS and Community Care Act 1990 (fully implemented on 1 April 1993), the emphasis has tended to be more on the practical (e.g. procuring packages of care through the process of care management, assessing need, care planning, implementing the care plan, monitoring, reviewing, reassessing), perhaps to the detriment of the interpersonal approach. To some extent, *Valuing People* has redressed the balance with the introduction of person-centred planning (see National Development Team, 2002; Swinton, 2001). This is not a new concept, but one reshaped in the light of the White Paper. Local authorities have specific responsibilities for assessing the needs of carers under the Carers (Representation and Services) Act 1995.

**Advocacy and empowerment**

Citizen advocacy and self-advocacy models have been developing over the last 20 years. Many people with learning disabilities derive strength from being part of a self-advocacy forum, but as many individuals have difficulty communicating their needs and aspirations, citizen advocacy remains an important component of any service. Users and carers should not just be involved in their own service plan but should be brought in to plan overall and to evaluate services for the future (Beresford, 2002).

The Government is encouraging local authorities to increase the number of people with learning disabilities using the Direct Payments Scheme (see Valios and Aspis, 2002), which gives them direct control over the services they purchase to meet the needs they themselves define.

**A place to live**

The last long-stay hospitals in the UK are due to close by April 2004 (see also Hollins, *PSYCHIATRY* 2003: 2:8: 1–2), but this is by no means the end of the story. *Valuing People* describes limited choices in housing; provision across the country ranges from the conventional 24-bed local authority hostel, built in large numbers in the 1970s on the grounds of economy, to supported living schemes in which individuals own their own homes or are tenants of a housing association, with outside support coming in as required. Margaret Flynn (1987) speaks movingly of how precious one’s own front door key is after years of institutionalization.

The place of village communities, which have a more protective ethos and are usually sited in rural areas, is still much debated. Originally formed by parents’ groups, such communities have become more outward-looking in recent years. With the rise in the number of people diagnosed with autism, the National Autistic Society has been working with social services and health authorities on helpful service models for those people with specialist needs. There is, however, a worrying increase in the use of out-of-area placements by local authorities, particularly for people with challenging needs, rather than the development of local capacity to meet complex needs locally in full.

**Day opportunities**

When local authorities were building adult training centres (ATCs) as the main day service in the 1970s, these were seen as a progressive and professional approach to what had been a fragmented problem of inadequate or non-existent care for adults,

delivered in dispersed settings. Like all institutions, however, they have largely become isolated and isolating for users (Gilbert and Scragg, 1992; Rooney, 2002). *Valuing People* requires local authorities to modernize day services by 2006 and has produced recommendations for change in conjunction with the National Development Team (Department of Health/National Development Team, 2002). Many areas have successfully developed, for example:

- employment services
- social firms (cooperative schemes which bring an ambience of enterprise without exploitation)
- sheltered employment
- further education opportunities
- leisure services.

One lesson from the USA is that many more people can get into and retain employment than has previously been thought possible in the UK.

### A valued lifestyle

No single approach is an end in itself. Sarah Rooney (2002) remarks that 'work is not a panacea for loneliness, or a guarantee of companionship'. Similar issues relate to respite care (see Oswin, 1984), in which it is vital that the service attends to the emotional and social needs of the child or adult as well as the respite requirements of the family. One of the main challenges that remains, even when services are successful, is the issue of developing valued friendship networks other than with immediate family and staff, in a society where difference still creates barriers (see Richardson and Ritchie, 1989).

In essence, the innate dignity and value of each individual must be considered at all times. One of the most powerful statements of the past few years has been the drama, art and poetry (see Atkinson and Williams, 1990) that results as people with learning disabilities say 'know me as I am'. ♦

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### Practice points

- There should be productive partnership arrangements between primary care, secondary care and social care
- Good work with parents at the time of diagnosis and early childhood will reap benefits later on
- There should be investment in sound transitional arrangements from childhood to adulthood
- Professionals should ask themselves 'is this service good enough for me and my family?'