

5. In the future, community services for people with learning disabilities in the UK are likely to:
- a ensure availability of a health professional who will facilitate access to health care services
 - b make training in disability awareness a fundamental part of professional training
 - c make special provision for health care for all
 - d provide Health Care Plans for all
 - e stop providing specialist learning disability health care services.

MCQ answers

1	2	3	4	5
a F	a T	a F	a T	a T
b T	b F	b F	b F	b T
c F	c T	c F	c T	c F
d T	d F	d T	d F	d T
e T	e F	e T	e T	e F

Commentary

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Lindsey's paper (2001, this issue) summarises what is known about the poor health status of people with learning disabilities. Also, it provides an overview of the ways in which the barriers to effective health care, which differ in type and levels of resistance, may be lowered or removed. Pinpointing the alignment of the long-stay hospital care with the discipline of psychiatry as anomalous, the paper helpfully draws attention to the messes that have arisen from this and from putting people with learning disabilities into hospitals that were not really hospitals.

The pervasive practice of segregation in the National Health Service (NHS) has a bitter history, the ripple effects of which are still being felt in respect of, among other things, the long-standing voids in the general medical and nursing curricula in respect of the health of people with learning disabilities; the major differences in their health status when compared to those without learning disabilities; the death rates for adults with learning disabilities, which tend to exceed those for adults without (McGuigan *et al*, 1995); effective exclusion from health screening; inexperienced caregivers with both health and social care backgrounds attributing people's behaviour to their learning disabilities; the

alarming absence of 'health consciousness' in many services for people with learning disabilities; the overreliance on disconnected community learning disability teams, largely comprising social workers and learning disability nurses (Brown *et al*, 1992) to deliver health care to adults with learning disabilities; and tolerance of 'less favoured treatment' such as that evidenced by the following, from the Royal Brompton Hospital (RBH) & Harefield Hospital's (2001) summary report on paediatric cardiac services:

In our view there was an agreed practice throughout the 1980s to recommend medical management rather than surgical intervention for children with Down's Syndrome. (para. 123, p. 39)

Some doctors at the RBH, by taking into account non-cardiac concerns and the possible future demands on the family did not focus sufficiently on what was in the best interests of the child as the patient. As a result the treatment offered was construed by parents as discriminatory. (para. 124, p. 40)

Against such a backdrop, it is perplexing that a population that has always been within the province of the NHS is such a neglected minority. Little wonder that the White Paper for England, *Valuing People* (Department of Health, 2001) states:

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Because mainstream health services have been slow in developing the capacity and skills to meet the needs of people with learning disabilities, some NHS specialist learning disability services have sought to provide all encompassing services on their own. As a result, the wider NHS has failed to consider the needs of people with learning disabilities. This is the most important issue which the NHS needs to address for people with learning disabilities. (para. 6.3, p. 60)

While Lindsey's paper encodes the insights that arise from people with learning disabilities, their relatives and caregivers in learning disability services, it also reflects the collective aversion to confronting the legacies of investing in long-stay hospitals, specialist accommodation and health care. This permits most of us, including 'the mainstream NHS', to believe that people with learning disabilities have to live elsewhere – in places that do not involve us. Yet we cannot cut 2% of the population off from the rest of the body politic and pretend that it never belonged. 'Person-centred approaches' and the mantras of 'rights, independence, choice and inclusion' enshrined in *Valuing People* have a naivety that confirms their elusiveness – especially when the same White Paper asserts as a 'Key Action' that 'All people with a learning disability [are] to be registered with a GP by June 2004' (p. 61).

So, the place in the NHS where many important decisions are made – primary care – is unavailable to some people with learning disabilities. They have just under 3 years to hang on until they have GPs. There is no change for the majority of people who are registered with GPs, who do not access primary care as often as their health needs would require.

Valuing People reminds us that the National Service Frameworks 'apply equally to people with learning disabilities as to other patients and people with learning disabilities should benefit from all of these initiatives' (para. 6.2, p. 66). It offers no clues as to how this ideal is to be realised. There is no change, for example, in the current situation in which child and adolescent mental health services discontinue well before adulthood and 'mainstream' mental health services decline to treat people with learning disabilities and mental health problems. And there's the rub. *Valuing People* is not a National Service Framework with accountable targets and clear standards.

Valuing People presents a compelling analysis of all that is wrong with services offered to people with learning disabilities and their families. It buckles when it proposes solutions. Although it is superficially persuasive to propose that the tasks of health facilitation to be assumed by learning disability

nurses 'will support people with learning disabilities to access the health care they need from primary care and other NHS services' (para. 6.12, p. 13), as complemented by the Patient Advocacy Liaison Service in NHS Trusts, there are 11 000 learning disability nurses and 1.2 million people with learning disabilities. 'Comprehensive healthcare' must acknowledge the constraints surrounding such solutions if health care coverage is to be enacted. Facilitation requires parallel animation from senior clinicians throughout 'the mainstream NHS'. It also requires rethinking of impermeable specialities and resourcing of the kind that would enable all vulnerable adults to have person to person help when they go into hospital for example. Further, it has to demonstrate convincingly that health promotion and health maintenance can be accomplished collaboratively.

Having a learning disability is powerfully determinative of being offered the means to survive beyond infancy, if the stigmata of a syndrome are present, of health status from childhood to adulthood and even of the manner of dying. We must not concede the inevitability of these disadvantages. Achieving comprehensive health care is a long-term project in which we have an obligation to create anxiety in 'the mainstream NHS' about lopsided interpretations of equality and discrimination and our roles in sustaining these. We should also be required to demonstrate local, corporate and unprecedented solutions that foster sound development in which the participation of people with learning disabilities and their relatives is dramatically expressed.

References

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