

## Social work support in the community

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### What is a social worker?

The British Association of Social Workers states: 'Social work practice addresses the barriers, inequities and injustices that exist in society. It responds to crises and emergencies as well as to everyday personal and social problems. Social work utilises a variety of skills, techniques, and activities consistent with its holistic focus on persons and their environments. Social work interventions range from primarily person-focused psychosocial processes to involvement in social policy, planning and development. These include counselling, clinical social work, group work, social pedagogical work, and family treatment and therapy as well as efforts to help people obtain services and resources in the community. Interventions also include agency administration, community organisation and engaging in social and political action to impact social policy and economic development. The holistic focus of social work is universal, but the priorities of social work practice will vary from country to country and from time to time depending on cultural, historical, legal and socio-economic conditions.'<sup>1,2</sup>

Within the field of social work with disabled people there are a number of models of theory. These include:

#### *Medical model*

A medical practitioner may view a physical disability as a dysfunction or abnormality located within an individual's body. Within medicine there are different ways of categorising disability: in terms of specific medical diagnosis; the bodily system affected; functional loss. Each of these forms of categorisation provides different kinds of information. What unites all the systems is the focus on pathology. However when looking at the nature and variability of impairments it becomes clear that for some conditions the degree of physical impairment cannot be predicted by the medical diagnosis as the physical consequences vary from person to person. The experience of the impairment also varies within the same person, as impairment is rarely fixed. Historically, disabled people came to be perceived as sick and as in need of a cure.<sup>3,4</sup>

#### *Psychological models*

Many, but not all, psychological approaches to disability share with the medical model a focus on the individual. Traditionally the role has been to assist the disabled person to adjust to their impairment. Therapeutic work based on behavioural or cognitive perspectives may focus on improving coping strategies.

#### *Social model*

In contrast to the medical and some psychological models, in 1983 the disabled academic Mike Oliver coined the phrase 'social model of disability'. Oliver locates disability within society, in the built environment and the values and social practices which discriminate against people with certain differences. The social model of disability is based on a distinction between the terms 'impairment' and 'disability'. Impairment is used to refer to the actual attributes (or lack of attributes), i.e. the abnormality, of a person, whether in terms of limbs, organs or mechanisms, including psychological. Disability is used to refer to the restrictions

caused by society when it does not give equivalent attention and accommodation to the needs of individuals with impairments.<sup>5</sup> Oppression stems from an environment that is hostile towards disability in which physical and social barriers inhibit personal choice. Disabled people can find themselves in a socially devalued and disempowered position. Oliver did not intend the 'social model of disability' to be an all-encompassing theory of disability, rather a starting point in reframing how society views disability. With his theory, if a building has ramps and slopes it would be accessible for wheelchair users. Within the inclusive environment the wheelchair user would, according to the social model, cease to be disabled but continue to have an impairment. The social model of disability focuses on changes required in society.

A holistic approach looks at the whole of the client's life rather than just their body, psyche or social environment to maximise their independence and improve their lifestyle. As with other socially disadvantaged client groups, people with epilepsy may need assistance in understanding their rights, up-to-date disability legislation and social policy. They may need assistance in gaining access to and managing their own benefits and services, including advocacy services. For a social worker with service users who have epilepsy these might be in terms of:

- Attitudes. Promoting to society a more positive attitude toward epilepsy so that others do not underestimate the potential quality of life of those who experience seizures.
- Social support. Provided either by statutory bodies, charities or the provision of an advocate.
- Dealing with barriers in resources, aids or information. For example, a social worker could use other formats, such as Braille for those with a visual impairment or information in simplified language or symbols for persons with cognitive difficulties.
- Physical structures. A referral could be made to an occupational therapist for an assessment of the client's property for adaptations, e.g. a level entry walk-in shower, a text message service to remind a person to take anti-epileptic medication, or equipment such as a one-cup water dispenser to reduce the risk of scalds in the kitchen.
- Flexible work. To start later if a person has a seizure in the night or early morning, or provide a screen for privacy if a person has a seizure at work, and a quiet space to recover.

The medical, psychological and social theories all contain valuable insights. A social worker can learn from the service user the physical consequences relating to their impairment, as well as the emotional and cognitive experiences and the constraints of living in an able-bodied biased society/environment.

### **Social work with disabled client groups**

Disabled people are a recognised group of people who face discrimination and oppression.<sup>6</sup> People with epilepsy can fall within one or more different groups, including physical disability, learning disability, mental health etc. It is important to move away from a medical model where the emphasis can be to focus too much on care and doing things for people and not enough on rights and empowerment. As Oliver comments<sup>3</sup> 'discrimination against disabled people is institutionalised throughout society and...welfare provision has compounded rather than alleviated that discrimination.... The fact remains providing welfare systems on the basis of individual need has aided the process of excluding disabled people from society rather than facilitated their inclusion'.

People with disabilities, including epilepsy, can face 'infantilisation'.<sup>7</sup> Within social work, for example, people with disabilities are not always fully consulted about steps that are being

taken on their behalf, nor are they provided with a choice of service provision. Recognising people's status as 'full citizens' is therefore an important part of social work. The needs-led assessment should address a range of activities geared towards reducing risk, maximising independence and improving quality of life. Support services for people with epilepsy should include the promotion of employment, education and leisure opportunities as part of a programme of developing independence and life skills.

### **Disability and management of risk of harm**

The Report of the Inspection of Scottish Borders Council Social Work Services for People Affected by Learning Disabilities outlines substantial failings in services designed to protect vulnerable adults.<sup>9</sup> The report looked at the prolonged financial, emotional, sexual and physical abuse of a woman with a learning disability over a lengthy period. The woman's case was opened to both health and social work.

There are increased risks of many forms of abuse and exploitation where people have any form of impairment in cases where their disability presents as a barrier against them taking action to protect themselves. The report also implied that disablement factors may discriminate against a person obtaining appropriate services and protection. Unfortunately there are areas of the service provision where the person's need for care, support and protection in the community is not met. It is apparent that this is not due to a lack of legislation in place to protect people however. Practitioners need to be aware of the increased risks posed to people with epilepsy where people can have more than one impairment, and the risk to the person of failing to meet those needs.

### **Sexuality**

A social worker working with service users with epilepsy has to look at all aspects of that person's life. Sexuality is included in psychological measures of quality of life, such as the World Health Organization's Quality of Life Scale. However, sexuality is often omitted from the representations of disabled bodies and therefore excluded from the identities of disabled people. It has been suggested that disabled people are treated in an asexual way by their parents, healthcare and social care workers,<sup>10</sup> and that this is fuelled by the belief that disabled people are incapable of having or being interested in sex.

Berman et al<sup>11</sup> examined sexual knowledge, sexual behaviour and beliefs about sexuality among adolescents with congenital physical impairments. The authors felt that the lack of research in this field was disturbing because sexuality is a central concern of adolescents and their families, and because its absence in the literature reinforces the myth that disabled people are not sexual. They found that adolescents with physical impairments are generally uninformed or misinformed about sex and sexuality and how these relate to their impairment.

A social worker can assist a person with epilepsy and/or a learning disability access specialist dating agencies which help a person find a partner, while providing support and assessing risk. A social worker can also support a person with epilepsy and/or a learning disability during pregnancy and assess any risks to the mother and baby, though this can lead to what is normally a 'private/personal' experience for an able-bodied person becoming a publicly controlled experience for a person with epilepsy.

### **Employment and economic contribution**

The social model of disability also relates to economics in that it proposes that people can be disabled by a lack of resources to meet their needs. The model looks at the underestimation of the potential of disabled people to add economic value to society if they are given equal

rights and equally suitable facilities and opportunities as others. In 2001, the UK Office for National Statistics found that approximately one-fifth of the working-age population were disabled.

The report also found that disabled people were unwilling to enter the labour market because the consequent reduction in their disability benefits would make it not worthwhile to undertake employment. A three-pronged approach was suggested: incentives to work via the tax and benefit system; helping people back into work; and tackling discrimination in the workplace via anti-discrimination policy.

In the United Kingdom, the Disability Discrimination Act defines disability using the medical model – disabled people are defined as having certain conditions or limitations on their ability to carry out ‘normal day-to-day activities’. But the requirement of employers and service providers to make ‘reasonable adjustments’ to their policies or practices and physical aspects of their premises follows the social model. By making adjustments, employers and service providers are removing the barriers that disable.

In 2006, amendments to the act called for local authorities and others to actively promote disability equality. The Equality Act 2010 makes it unlawful for employers to ask questions about a person’s epilepsy at a job interview or for a referee to comment on such in a reference, except where there is a need to make reasonable adjustments for an interview to proceed. Following an offer of a job, an employer can then lawfully ask such questions.

A social worker will be able to support a person with epilepsy in seeking either paid employment or voluntary work, advising them of their rights and signposting them to organisations such as The Shaw Trust (a not-for-profit organisation which helps disabled people find and sustain employment or enjoy more independent living) or the Disability Employment Advisor (within the Job Centre Plus).

### **The Care Act 2014**

In the past, obtaining support from community social services has been a ‘postcode lottery’. The Care Act 2014 modernises and consolidates the law on adult care in England into one statute and has been described as the biggest change to the law in 60 years.

Key changes include the introduction of national eligibility criteria, a right to independent advocacy and, from 2016, a cap on care costs faced by self-funders. At the heart of the act are the principles of wellbeing and prevention and the recognition that an individual and their family, and/or carer must be enabled to make decisions regarding their own care.

The College of Social Work has consistently argued that ‘the wellbeing principle’ is the Care Act’s most radical innovation. The Act outlines that in exercising the promotion of individual wellbeing a local authority must have regard to factors such as the need to protect people from abuse and neglect, based on the assumption that the individual is best placed to judge their own wellbeing, as well as the importance of participation, having regard for all an individual’s circumstances, and achieving balance between the individual’s wellbeing and that of any friends or relatives involved in their care.

The Act’s definition of wellbeing is broad and includes: physical and mental health and emotional well-being; participation in work, education, training or recreation; social and economic wellbeing; domestic, family and personal relationships; and suitability of living accommodation. The definition also includes personal dignity, being treated with respect, and control by the individual over their day-to-day life. The Act requires that attention is given to the individual’s views, wishes, feelings and beliefs.

## **Personalisation**

The Care Act 2014 promotes personalisation and outlines scope for individuals who have eligible needs to receive a personal budget, potentially independently of the local authority and possibly in the form of a direct payment. Personalisation is a social care approach described by the Department of Health as meaning that ‘every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings’.

For people with epilepsy, support from social services is often associated with direct payments and personal budgets, under which they can choose the services that they receive. Personalisation should also mean that those services are tailored to the needs of every individual rather than delivered in a one-size-fits-all fashion. It should also allow better provision of improved information and advice on care and support for the families of people with epilepsy, and investment in preventive services to reduce or delay people’s need for care, as well as the promotion of independence and self-reliance for themselves and improved access to community-based resources.

## **Appendix: Legislation and guidance to be replaced in whole or part**

The following summarises some of the key legal provisions and existing statutory guidance which are to be replaced by the Care Act 2014 and the associated regulations and guidance.

Where existing provisions relate to jurisdictions other than England, the provisions will be disapplied so that they no longer relate to English local authorities. Where provisions relate to children as well as adults they will be disapplied in relation to adults, but will remain in force in relation to children. The repeals and revocations required will be provided for by Orders under the Care Act.

The final detail of which precise provisions are to be replaced is to be confirmed during the consultation process. The areas listed below are not therefore a final position, but are intended to give an indication of the scope of the Act and the key existing provisions which are to be affected.

- National Assistance Act 1948
- Health Services and Public Health Act 1968
- Local Authority Social Services Act 1970
- Chronically Sick and Disabled Persons Act 1970
- Health and Social Services and Social Security Adjudications Act 1983
- Disabled Persons (Services, Consultation and Representation) Act 1986
- National Health Service and Community Care Act 1990
- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- Health and Social Care Act 2001
- Community Care (Delayed Discharges etc.) Act 2003
- Carers (Equal Opportunities) Act 2004
- National Health Service Act 2006.

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