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SOCIAL POLICY TENSIONS – EMPOWERMENT AND VULNERABILITY

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How does recent social policy invite support staff in health and social care settings to understand the implications of having a learning disability?

INTRODUCTION

The twentieth century represented a time of shifting attitudes to disability in general and to people with learning disabilities in particular. This chapter briefly reviews these twentieth century attitude and policy shifts and then looks in more detail at relevant twenty-first century policies which affect the lives of people labelled as having learning disabilities and the practice of those who work with them. New and ostensibly contradictory policies have emerged which simultaneously describe people with learning disabilities as wanting and needing to be empowered, to have more of a say in decision making and in shaping their own lives and services while also being seen as vulnerable to abuse and exploitation and therefore in need of protection. The latter stages will detail examples of good, empowering, safe practice within these policies and will discuss the importance of staff in health and social care settings understanding both the potential vulnerability and the pressing need for empowerment of service users who have learning disabilities.

THE TWENTIETH CENTURY – FROM CONTROL TO CARE

You weren't allowed out of the hospital. You had to write up and ask could you leave the grounds. You had to ask the medical or write to the doctor and ask them. You couldn't just go across the road and look at the shops; it wasn't allowed unless you wrote up and asked. I didn't go out because I got so used to not going out. You'd get lost if you're not used to it. (Cooper, 1997: 27)

The twentieth century commenced with parliamentary lobbying by powerful eugenicists, demanding that the government tackle the 'problem' of mental deficiency. Eugenicists such as Tredgold believed that many social problems such as prostitution, petty crime and alcoholism were inevitably associated with the 'feeble minded': 'the danger lies in the fact that these degenerates mate with healthy members of the community and thereby constantly drag fresh blood into the vortex of disease and lower the general vigour of the nation.' (Tredgold, 1909: 97).

These negative attitudes to people with learning disabilities, purportedly based in science, were further supported by economics. The Industrial Revolution had brought with it the apparent need to classify people in terms of their ability to contribute to emerging technological and commercial processes and therefore the economic competition between industrialised nations (Race, 1995). People with learning disabilities were considered to be a financial burden because of their lack of skill and intelligence. The Mental Deficiency Act of 1913 gave local authority Mental Deficiency Committees the responsibility to certify and detain the idiots, the imbeciles, the feeble minded and the moral defectives (the newly created official classifications of mental defectives) if care and supervision at home were not thought to be adequate. Over the following twenty years many thousands of people with learning disabilities were compulsorily detained in institutions. These actions were driven by the perceived need to protect society from people with learning disabilities by controlling them (and their ability to procreate). As Goffman (1961) noted, the use of punishment to support conformity was a common feature of institutions.

Wolf Wolfensberger (1972) identified a number of negative socio-historical roles which have been thrust upon people with learning disabilities:

- sub-human organism
- menace
- unspeakable object of dread
- object of pity

- holy innocent
- diseased organism
- object of ridicule
- eternal child.

He states that while these role perceptions reflect prejudice rather than reality, they have nevertheless contributed to the shaping of both our understanding and our social policy in relation to people with learning disabilities.

Reflection Point 1

We have grown up in a society that has negative ideas about people with learning disabilities. How might the terms listed above have influenced how you feel about people with learning disabilities? Do you feel sorry for people, or see them as difficult, or are you inclined to treat them as children? How might your own views of people with learning disabilities influence how you act towards them?

The second half of the twentieth century brought increasingly liberal attitudes towards people with learning disabilities and a shift in the intention and nature of social policy from merely control to concern for their human rights. *The Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency* (Royal Commission, 1957) recommended the expansion of residential, rather than institutional, care and paved the way for the new Mental Health Act (1959), and the discharge of many people with learning disabilities from long-stay institutions – which became hospitals with the advent of the National Health Service – into community settings. The 1960s heralded a number of reports into institutional care in Great Britain which described appalling living conditions and ‘custodial attitudes’ among staff. *The Report of the Committee of Inquiry into Ely Hospital* (Howe, 1969) was the most significant of these inquiries.

Attitudes towards people with learning disabilities changed rapidly in the final quarter of the twentieth century. With these changes came different social policies and service design principles. In 1971 the White Paper *Better Services for the Mentally Handicapped* (Department of Health and Social Security [DHSS], 1971) recommended a 50 per cent reduction in hospital places by 1991 with increasing local authority residential and day care. It also recommended the re-training of hospital staff. In 1979, The Jay Committee Report advocated the adoption of service philosophies based

on the principles of normalisation, defined as the utilisation 'of means which are as culturally normative as possible in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible' (Wolfensberger, 1972: 28).

Normalisation played a significant role in shaping the development of residential and other support services for people with learning disabilities in the UK. In 1991 Wolfensberger renamed and adapted normalisation as 'social role valorisation' (SRV) (Wolfensberger, 1992). SRV had more of a human rights approach and advocated the need to create or support socially valued roles for devalued people on the premise that holding valued social roles leads to the good things which society can offer.

These trends, both in terms of progressive service design principles and community based residential care, were further supported by the National Health Service and Community Care Act (1990).

PROTECTION – A TWENTY-FIRST CENTURY CONCERN

The new millennium brought with it increased governmental concern for the protection of vulnerable adults (including those with learning disabilities). *No Secrets* (DH, 2000) established a national policy for the protection of vulnerable adults. It required local authority social services departments to develop multi-agency codes of practice and offered very clear guidance on the development of local inter-agency policies, procedures and joint protocols. Under this policy, a vulnerable adult is one:

- aged 18 and over
- who may be in need of community care services by reason of mental or other disability, age or illness; and
- who is or may be unable to take care of him or herself, unable to protect him or herself against significant harm or exploitation. (DH, 2000)

Clearly, this policy would cover the majority of people labelled as having learning disabilities, thus establishing both their status as vulnerable and their need for protection from abuse and exploitation. All staff working with people with learning disabilities are required to undergo training in the protection of vulnerable adults which details their responsibility to alert others (social services, health or police) if they have a suspicion or concern that abuse has taken place or might take place if no preventative measures are taken.

In 2005 *No Secrets* and adult protection work in general was further strengthened when the Association of Directors of Social Services (ADSS) published *Safeguarding Adults – A National Framework of Standards for Good Practice and Outcomes in Adult Protection Work* (ADSS, 2005). This sought to collect examples of best practice into a set of practice standards intended as both an audit tool and a guide for adult protection work. Despite this endeavour, investigations into the Cornwall Partnership National Health Service Trust (Healthcare Commission, 2006) and the Sutton and Merton Primary Care Trust (Healthcare Commission, 2007) revealed wide-scale dehumanising treatment of service users with learning disabilities, including incidents of physical and sexual violence and abuse.

While concern for people's safety when they use learning disability services remains high, the increasing number of people with learning disabilities moving into independent living or supported living situations raises additional concerns about bullying and exploitation within the community.

A hostile reception awaits some, while others are seen as easy pickings for exploitation by people who 'befriend' them and then go on to use their homes, eat their food, steal their money. Although many people need support to live in the community safely and comfortably, there are growing fears that they are not getting it because over-stretched adult services budgets are being used for those with high needs. (Gillen, 2007)

Indeed, the 2006/07 Learning Disabilities Task Force annual report states:

Evidence shows that people with learning disabilities are often the victims of hate crime. When this happens, they are often not taken seriously by care staff and people working in the Criminal Justice System. This stops people with learning disabilities from reporting hate crime. (Learning Disabilities Task Force, 2007)

These concerns have been validated in the last few years by various incidents of serious bullying against people with learning disabilities which have hit the headlines. In 2009 Fiona Pilkington killed herself and her daughter Francesca, who had learning disabilities, after months of being hounded by local youths. And again:

In 2007, Christine Lakinski, a woman in her 50s with learning and physical disabilities, was taunted, urinated upon and sprayed with shaving foam as she lay dying in the street. Her brother told me that because of disabilities, she had been picked on for most of her life. (BBC News, 2009)

Also in 2007 a young man with learning disabilities, Brent Martin, was beaten to death by a gang on the estate where he lived in north-east England. The year before this Kevin Davies was imprisoned in a garden shed and tortured horrifically until he died. These horrifying murders are coupled with very high levels of less sensational taunting experienced by people with learning disabilities, 'A *Community Care* survey, published in May, found 16 per cent of almost 2,000 people said they had been bullied on the street in the last year.' (Gillen, 2007). Further research conducted in 2007 involving people with learning disabilities living in supported housing schemes concluded that many tenants had curtailed their participation in social activities because of harassment and they felt unsafe on leaving their homes, especially in the evenings (Fyson et al., 2007). It is quite clear that the need for vigilance and the protection of people with learning disabilities from hate crime and bullying remains.

The new 'personalisation agenda', kick-started by *Putting People First* (Ministers et al., 2007) enables the use of self-directed support and individual budgets, allowing some people with learning disabilities to make better use of existing support networks – friends, family and neighbours – as well as individuals who they recruit and employ to offer particular types of support. Couple this with the steady drift away from residential care into supported living and the picture emerges of a positive new emphasis on personal choice and empowerment. However, Fyson (2009) argues that when increased independence is linked to reduced levels of regulated support, people become more vulnerable because:

- supervision of family, friends and neighbours is problematic
- it can be harder for someone with learning disabilities to complain about family, friends and neighbours
- direct payments and individualised budgets are more open to financial abuse
- protection of vulnerable adults regulations do not apply to those employed via direct payments or individualised budgets
- loneliness can make people vulnerable to being inappropriately befriended.

More recently, *Valuing People Now – A New Three Year Strategy for People with Learning Disabilities* outlines the continuing need to tackle both abuse and hate crime against people with learning disabilities: '...the lives of too many people with learning disabilities are constrained by experience of abuse and neglect and many people have been victims of hate crime.' (DoH, 2009: 108). This re-establishes the need for staff to view people with learning disabilities as vulnerable and accept their own role as protectors.

EMPOWERMENT – THE POLICY BACKGROUND

Self-advocacy groups (of people with learning disabilities) have called for improved services and more involvement and control for people with learning disabilities since People First groups began to form in UK cities. While the precise history of the self-advocacy movement in the UK is difficult to trace,

UK based self-advocacy is said to have started in 1984 when People First London Boroughs was founded, following the attendance of a small number of people with learning difficulties at the International Conference held in the USA. (Buchanan and Walmesley, 2006: 134)

While local branches of People First determine their own missions and activities, the common agenda is one of empowerment. The information about Bristol and South Gloucestershire People First, available from the South Gloucestershire Council website, starts with the following statement:

Bristol and South Gloucestershire People First [BSGPF] started as a small group of people with learning difficulties at the Whole Baked Café in Bristol.

We wanted:

- To be in control of our lives
- Equal rights
- Proper choices

(BSGPF, no date)

The following is taken from the front page of the national People First website:

People First promotes the social model of disability. This is a way of thinking about disability that says it is society that needs to change to include disabled people. We should not have to change to fit in with society. We are against the medical model of disability, which is the view that being disabled means there is 'something wrong' with you.

Self-advocacy is people with learning difficulties speaking up for ourselves. Self-advocacy is important because many people with learning difficulties spend their lives being told what to do. If you are always told what to do and never listened to you can get to the point where you don't even know how to make a decision for yourself. (People First, no date)

People First's struggle for more involvement in the shaping of relevant policy was achieved one year after *No Secrets*, when the first White Paper on learning disabilities for thirty years, *Valuing People – A New Strategy for Learning Disabilities for the 21st Century* (DH, 2001) came into force. The White Paper was developed with the involvement of people with learning disabilities and carries a very different message, conveying a progressive view of people with learning disabilities as seeking control over their own lives – empowerment.

There are four 'key principles' at the heart of this policy:

- **Legal and Civil Rights:** The Government is committed to enforceable civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary ... All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. ...
- **Independence:** Promoting independence is a key aim for the Government's modernisation agenda. ... While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.
- **Choice:** Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. ... This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives.
- **Inclusion:** Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things ... be fully included in the local community. (DH, 2001: 23–4).

Beyond this the White Paper includes a chapter, 'More Choice and Control for People with Learning Disabilities', which calls for the development of advocacy services including both citizen advocacy and self-advocacy, increased involvement in decision making, improving information and communication with people with learning disabilities and the development of person centred approaches to the planning of services.

A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences

of a person with a learning disability and covers such issues as housing, education, employment and leisure. (DH, 2001: 49)

It also calls for the involvement of service users in both the selection and training of staff who support them.

‘I want staff who treat you well, who know how to treat you properly’

The best way to achieve this is to promote the involvement of people with learning disabilities and their family carers in training and development activities. Staff and managers at all levels in organisations need to have an opportunity to hear directly from people with learning disabilities about their expectations. (DH, 2001: 99)

The White Paper also established Learning Disability Partnership Boards in all local authorities with responsibility for overseeing the development of local services for adults with learning disabilities and required to include people with learning disabilities as members.

These principles of choice, involvement and increasing service-user empowerment and control which are advanced within learning disability services by *Valuing People* are also at the heart of recent transformation of adult care policy including *Our Health, Our Care, Our Say* (DH, 2006) and the *Putting People First* agenda (Ministers et al., 2007).

This new social policy concern for the empowerment of people with learning disabilities was given significant support by the Mental Capacity Act (MCA) (2005). The Act sets out fundamental legal rules that apply to everyone working with and/or caring for adults who may lack capacity – including family members, professionals and other carers. The rules also apply to people appointed in a formal capacity to act as an attorney or deputy for a person lacking capacity. It seeks to ensure that all adults are enabled to make any decisions for which they have the capacity to do so. Its underlying philosophy is to ensure that individuals who may lack capacity are the focus of any decisions made, or actions taken, on their behalf. The interests of the person who lacks capacity should prevail, not the views or convenience of those caring for that person.

Reflection Point 2

Do you understand your responsibilities if you believe a person lacks the capacity to make decisions? When you are next at work read your organisational policy on what staff must do if they feel a person lacks capacity to consent.

Many of the provisions in MCA are based upon existing common law principles (i.e. principles that have been established through decisions made by courts in individual cases). MCA 2005 seeks to clarify existing law as well as introduce some new legal safeguards, including new ways in which people can plan ahead for a time when they might lack capacity and the statutory introduction of Independent Mental Capacity Advocates who must be engaged to support people who lack the capacity to make serious decisions about medical treatment or changes of accommodation and who are unbefriended. The Act represents the legal framework and is accompanied by a Code of Practice (Department for Constitutional Affairs [DCA], 2007), which provides guidance and information to those acting under the terms of the legislation. The Code of Practice sets out five statutory principles which are intended to support good practice:

- 1 A person must be assumed to have capacity unless it is established that they lack capacity.
- 2 A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- 3 A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- 4 An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- 5 Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action. (DCA, 2007: 19)

The Code of Practice also sets out a simple assessment process which must be employed before anyone concludes that an adult lacks capacity to make a particular decision and subsequently acts in their best interests.

A person is unable to make a decision if they cannot:

- 1 understand information about the decision to be made (the Act calls this 'relevant information')
- 2 retain that information in their mind
- 3 use or weigh that information as part of the decision-making process, or
- 4 communicate their decision (by talking, using sign language or any other means). (DCA, 2007: 45)

Clearly, decision making lies at the heart of any notions of personal empowerment and if properly enacted this policy brings new power and control to people with learning disabilities. For example, the Code of Practice offers the following scenario to illustrate how someone should be supported as much as possible to make a significant decision for herself:

Scenario

Getting help from other people. Jane has a learning disability. She expresses herself using some words, facial expressions and body language. She has lived in her current community home all her life, but now needs to move to a new group home. She finds it difficult to discuss abstract ideas or things she hasn't experienced. Staff conclude that she lacks the capacity to decide for herself which new group home she should move to. The staff involve an advocate to help Jane express her views. Jane's advocate spends time with her in different environments. The advocate uses pictures, symbols and Makaton to find out the things that are important to Jane, and speaks to people who know Jane to find out what they think she likes. She then supports Jane to show their work to her care manager, and checks that the new homes suggested for her are able to meet Jane's needs and preferences. When the care manager has found some suitable places, Jane's advocate visits the homes with Jane. They take photos of the houses to help her distinguish between them. The advocate then uses the photos to help Jane work out which home she prefers. Jane's own feelings can now play an important part in deciding what is in her best interests – and so in the final decision about where she will live. (DCA, 2007: 38)

And again:

Scenario

Providing relevant information in an appropriate format. Mr Leslie has learning disabilities and has developed an irregular heartbeat. He has been prescribed medication for this, but is anxious about having regular blood tests to check his medication levels. His doctor gives him a leaflet to explain:

the reason for the tests,
 what a blood test involves,
 the risks in having or not having the tests, and
 that he has the right to decide whether or not to have the test.

The leaflet uses simple language and photographs to explain these things. Mr Leslie's carer helps him read the leaflet over the next few days and checks that he understands it. Mr Leslie goes back to tell the doctor that, even though he is scared of needles, he will agree to the blood tests so that he can get the right medication. He is able to pick out the equipment needed to do the blood test. So the doctor concludes that Mr Leslie can understand, retain and use the relevant information and therefore has the capacity to make the decision to have the test. (DCA, 2007: 47)

Despite this focus on decision making and support for empowerment, the MCA also concerns itself with the issue of protection and the Code of Practice includes a chapter, 'What means of protection exist for people who lack capacity to make decisions for themselves?' This describes the different agencies that exist to ensure that adults who lack capacity to make decisions for themselves are protected from abuse and sets out what somebody should do if they suspect that somebody is abusing a vulnerable adult who lacks capacity. It also introduces two new criminal offences: ill treatment and wilful neglect of a person who lacks capacity to make relevant decisions. It offers the following scenario to illustrate who should become involved in ascertaining whether someone with a learning disability is making a capacitated decision, or else perhaps being exploited, assaulted or abused:

Scenario

Involving professional opinion. Ms Ledger is a young woman with learning disabilities and some autistic spectrum disorders. Recently she began a sexual relationship with a much older man, who is trying to persuade her to move in with him and come off the pill. There are rumours that he has been violent towards her and has taken her bankbook. Ms Ledger boasts about the relationship to her friends. But she has admitted to her key worker that she is sometimes afraid of the man. Staff at her sheltered accommodation decide to make a referral under the local adult protection procedures. They arrange for a clinical psychologist to assess Ms Ledger's understanding of the relationship and her capacity to consent to it. (DCA, 2007: 60)

Clearly, staff could have responded differently here. If they had prioritised Ms Ledger's autonomy and empowerment this could have obscured the possibility that she is being abused. What matters here is the question of her capacity to consent to sexual activity. If this is established, she has the legal right to determine this for herself; if not, she has the right to protection.

Reflection Point 3

You are a practice nurse and are doing an annual health check and health action plan for an individual with learning disabilities.

Paul is a 52 year old man who has Down's syndrome and has lived in this home for 12 years after spending most of his early life in a long-stay institution. One of Paul's favourite activities is going to the pub, which he does three times

each week (with support to get there and back, but no support while he is there), usually drinking 3 or 4 pints of strong beer. While Paul has no contact with family, 3 years ago he was left a substantial amount of money by an auntie. He manages a weekly budget of 'spending money' by himself - £95, covering outings, holidays, magazines, beer, clothes etc.

Paul communicates effectively with people who know him well using some spoken language, photographs (arranged into sections in a folder - food, people, activities, feelings, etc).

Recently staff at the home have been concerned about Paul. His short-term memory seems to be weakening and his concentration span reducing. He is less communicative generally and occasionally acts out of character. You arrange a visit to the GP which has resulted in tests indicating that Paul is in the early stages of vascular dementia - possibly connected, in part, with alcohol consumption. The GP has strongly recommended that Paul should give up alcohol. Paul is keen to continue his trips to the pub and his consumption of beer.

What are your concerns at this stage?

How might you help the home to establish whether Paul has the capacity to make this decision for himself?

If he does not have capacity to make this decision for himself, how would you try to establish Paul's best interests?

CONCLUSION

Modern social policy offers two lenses through which staff in health and social care settings might view people with learning disabilities. One lens prioritises empowerment, autonomy and self-determination; the other highlights the potential vulnerability of adults with learning disabilities to abuse - within specialist services and in society in general. Sensitive, empowering practice requires staff to hold both of these perspectives in focus, without prioritising one over the other. A lack of sensitivity and vigilance can allow exploitation, neglect and abuse to become part of the everyday, taken-for-granted life experience of people with learning disabilities. As with risk averse risk management practice, an over-protective attitude will disempower and diminish people's lives. Service providers need to have a clear understanding of individual rights, rigorous capacity assessment, opportunities for both staff and service users to learn and develop, and staff who understand their roles as supporting people with learning disabilities to take control of their own lives wherever possible, while staying alert to the reality of vulnerability.

Social care can and should be provided in such a way as to enable adults with learning disabilities to be as independent as they are able, and to have real choices in their lives. However, independence should not be promoted dogmatically. There must also be a recognition that people who receive adult social care services because they have a learning disability are more vulnerable to abuse than other citizens. (Fyson, 2009: 23)

Changing patterns of adult social care, and particularly the increasing numbers of people with learning disabilities who live with greater freedoms and independence and less support from paid staff, place an even greater significance on getting this balance right.

Key Learning Points

- During the twentieth century many people with learning disabilities experienced oppression
- Towards the end of the twentieth century things began to improve with the move from institutional care to residential care and 'ordinary living' principles
- The twenty-first century commenced with increasing governmental concern for the involvement and empowerment of people with learning disabilities
- Recent policies and research highlight the need for the protection of people with learning disabilities from crime, abuse and exploitation as their freedoms and community presence increase.

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