# 6

# A MATTER OF POWER

## Relationships between professionals and disabled service users

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### Introduction

In this chapter, I want to examine ways in which power distorts relationships between professionals and service users. I will specifically be discussing relationships between professionals and disabled service users. I will draw on observations made by disabled service user representatives interviewed by Shaping Our Lives (2017) and by Joanne Molloy-Graham and Maggie Cameron, two other disabled people with whom I have talked during the process of writing this chapter. My arguments will hopefully be applicable to the situations of other service user groups as well, though. My focus will mainly be on relations between professionals and disabled people in contexts of service user involvement in the evaluation, planning and co-production of health, education and social care services, though more incidental interactions will also be considered. While I shall be coming at this from a social model perspective – identifying disability as an oppressive social construction or social relationship rather than as an embodied individual condition or problem (UPIAS, 1976; Oliver and Barnes, 2012; Cameron, 2014a) – I shall also be using symbolic interactionist (SI) and structural symbolic interactionist (SSI) (Stryker, 2002, 2008) perspectives to inform my argument. As Forte (2004) points out, core concepts within symbolic interactionism include, for example, symbols (words, looks, gestures), interactions, attitudes, socialisation, role-taking, reference groups, roles and definitions of situations. Structural symbolic interactionism, Stryker (2008) states, places emphasis on the impact of social structures on social interactions.

Rather than reify the idea of power as a 'thing', as a personal attribute belonging to an individual or group, I shall characterise power as a property of social relations (Emerson, 1962). As Mast (2010, p. 26) puts it:

> Power does not exist in a vacuum, it is interpersonal by nature and unfolds in interpersonal behaviour among two or more social interaction partners. Power is affected by both interaction partners' behaviour and their mutual perception thereof.

In other words, in this context, even in situations where a formal commitment to equalising relationships has been made – where it has been stated that service users are recognised as 'experts by experience' and that their understanding and knowledge is regarded as valid – power is at work within assumptions being made about what is going on and in terms of meanings and interpretations made of experience. Central to this, in terms of this chapter, is the understanding of the meaning of disability. While service providers' views remain rooted in an individual model perspective (whether this is identified in medical model or biopsychosocial terms), it is my contention that service user consultation will remain of limited value, often proving an unsatisfactory experience for disabled participants.

I will structure my discussion in four parts. In the first, I will consider the nature of professionalism in health, education and social care. I will argue that power inequalities between service providers and service users persist not because service providers are 'lovers of power' or are unwilling to relinquish power, but because they are inherent in the professional role. Reflecting on ways in which service providers and service users interact, I shall secondly focus on generic processes in the reproduction of inequality (Schwalbe et al., 2000) – means through which inequality is reproduced within interactions, whether intentionally or unintentionally. Schwalbe et al. (2000, p. 422) identify these processes as including:

- Othering
- subordinate adaptation
- boundary maintenance
- emotion management

Thirdly, I shall illustrate ways in which these processes are experienced, both in contexts where service users have been actively involved as service user representatives and in everyday life situations. Finally, I shall conclude by suggesting that progress in terms of establishing genuinely respectful interactions, in which unequal power relations are minimised between service providers and service users, depends upon a shift in thinking about disability from an individual and personal tragedy model view to a social and affirmation model view. I shall outline what this means, why I think it is necessary and why – given the disappearance over the past few years of so many disabled people's organisations due to public funding cuts (Shaping Our Lives/National Survivor User Network, 2019) – this seems at times an aspiration with little chance of fulfilment.

I think it is important to state here that I am writing this as a disabled academic. I have experience as a professional who has worked in various roles in social care, in community development and in higher education, as well as many years' experience of being a disabled health services user. I have worked in and with services organised by local authorities and voluntary sector organisations *for* disabled people with physical impairments and with learning difficulties. These have largely been services organised by non-disabled professionals and have been based on such service philosophies as normalisation, social role valorisation (Wolfensberger, 1972, 2000) and, later on, 'empowerment'. In other words, they have involved plans and strategies about what to do about disability that have been constructed by non-disabled people. Within these, disability has largely been regarded as an unfortunate personal condition requiring professional help to be overcome, adjusted to or made the best of. I have also worked in and with voluntary sector organisations *of* disabled people, established and run by disabled people. The visions, aims and day-to-day practice within these have been based upon social model principles, regarding disability as being about physical, social and cultural barriers which prevent people with impairments from accessing and participating fully in mainstream community life. The ideas underpinning these organisations have been developed by disabled people and have involved addressing these barriers. I make no secret of my commitment, as a disabled person, to the social model. Like good disability research, developing disability theory involves 'the surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation' (Priestley, 1997, p. 91). If it appears that I am arguing that the main obstacle to successful partnership working lies with non-disabled professionals, there is a reason for this. As Schwalbe et al. (2000, p. 443) have pointed out,

> it remains true that far more research focuses on action by subordinates than on action by elites. While this has given us a detailed view of how subordinates adapt to inequality, it has left us with a relatively sketchy view of how elites act strategically to perpetuate it. To understand inequality we need to understand how it is maintained by those with the power to do so, not to continually focus on victims of the process.

I suggest that by taking a look at what is problematic about the way professionals relate to disabled people, a better understanding may be gained of how unequal power relations may be addressed in order to enhance the effectiveness of user involvement and service user representation within health, education and social care services.

## Professionals in context

Young (2011) has asserted that oppression is experienced by many as part and parcel of everyday life. Oppression is something so routine and ordinary that it often passes unnoticed and uncommented upon by others while being felt intensely by those who have to deal with it. Young states that oppression does not necessarily have to involve ill intent or ill will upon anybody's part but makes itself felt in the details of everyday life, in the 'often unconscious assumptions and reactions of well-meaning people in ordinary interactions' (2011, p. 41). Sexism, racism and ageism work in this way, and it can also be found in disabling practices and encounters. Professionals know that for a person to be disabled means that they have something 'wrong' with them. This, after all, is stated in the definition of disability given in the 2010 UK Equality Act (GOV.UK, 2019), for example, in which a person is disabled if they 'have a physical or mental impairment that has a substantial and long-term *negative* effect on [their] ability to do normal daily activities' (my italics). Disability is clearly identified here in negative terms, as a flaw or a failing that is the result of an impairment or condition. It is identified in terms of aberration from a normal ideal. Within this definition, there is implied a need of something to be fixed or of a problem to be resolved. This task is assigned to professionals.

What makes the discussion of relations between health, education and social care professionals and disabled people complicated is that, behind the lexicon of 'care', 'special needs' and 'anti-oppressive practice' prevalent within professional discourse, there is a long history of coercion, containment and control. Both professionals' and clients' identities and role perceptions are formed within ideological contexts. Oppression is evident in the words, deeds, thoughts and gestures of everyday professional life, but so routine are these, so ubiquitous, that they are rarely considered problematic.

> The conscious actions of many individuals daily contribute to maintaining and reproducing oppression, but these people are usually simply doing their jobs or living their lives and do not understand themselves as agents of oppression.
>
> *(Young, 2011, p. 42)*

This is, perhaps, hard to accept. No professional wants to consider themselves as personally responsible for oppression or as being part of a system that perpetuates oppression. This would be considered an affront. Yet a brief examination of disabled people's history provides illumination.

People with impairments have been part of every human society since history first started being recorded (Barnes, 1997). While life for impaired people would never have been particularly easy, this was the experience of most other people, too (Wrightson, 2002). Prior to the Industrial Revolution of the 18th and 19th centuries, however – during which time economy was based on the principle of subsistence rather than profit and most labour was either agricultural or cottage-based – disabled people were part of an undifferentiated mass poor: 'clustered at the lower reaches of society, but not excluded from it' (Borsay, 2002, p. 103). Gleeson (1999) has remarked on evidence that people with physical impairments were regarded as part of the everyday pre-modern social order. Impairment was commonplace, regarded as inevitable rather than as something separate from ordinary life.

Industrialisation changed everything. The mass movement of the population to the rapidly expanding towns and cities meant that greater numbers than ever before lived in close proximity. Coupled with a shift to a factory-based system of production, this created a need for new forms of self-consciousness, discipline and a greater attention to individual bodily comportment and behaviour than had ever existed previously (Elias, 2001). Davis (2013) describes the way in which the word 'normal', in terms of its current usage as an expectation of physical and behavioural conformity, first started being used around 1840. The requirement which emerged for a standard-sized, standard-shaped worker of standard ability to work machines in the factories resulted in the simultaneous appearance of a population regarded as surplus to production requirements. Disabled people found themselves removed from ordinary life and incarcerated within new systems of asylums, long-stay hospitals and other isolated spaces where they came under the surveillance of the increasingly powerful medical profession (Barnes, 1997; Cameron, 2018). It is here that disability first became regarded as a medical issue (Oliver, 1990), where the bodies of impaired people began to be treated as markers of disorder and disruption, of unruly nature threatening to hold back and destroy the achievements of modern society (Davis, 2013). With the growth of Eugenics (Barnes and Mercer, 2010) and the rise of Victorian charities (Borsay, 2002), a discourse was established which viewed impairment as a mark of moral inferiority or a trial to be pitied and overcome. Impairment was no longer considered an unexceptional part of social life, but had become a metaphor harnessed in the business of establishing the boundaries of acceptability in the new social order (Cameron, 2014b).

Once disabled people's disorderly bodies had been removed from the social mainstream, there was considered no need to plan for their inclusion in the design of public architecture, workplaces, public transport systems, homes, schools, places of recreation, worship and so on. The social environment developed within industrialised society was built with a view that there was no need to take the needs of people with impairments into account, for it was presumed they had no role in society.

Throughout the 20th century, the supervision of disabled people's lives became an increasingly sophisticated business, resulting in the emergence of what Albrecht (1992) has described as a *disability and rehabilitation industry*. Oliver (1996, p. 37) has added:

> The medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image; physiotherapy, occupational therapy, speech therapy, clinical psychology . . . each one geared to the same aim – the restoration of normality.

The 'scientific' knowledge and skill sets developed within these and related professions have given legitimacy to the power that professionals hold in relation to service users. In terms of Abbott and Meerabeau's (1998) trait model, the acquisition of theoretical knowledge as a qualification for the practice of highly skilled work is identified as the primary requirement for entry to the 'caring' professions. Each of these professions has carved out its own specialist area of 'interventions and intrusions into disabled people's lives' (Oliver, 1996, p. 37) and developed its own knowledge base and set of skills to practice this. The movement of training for professionals such as teachers, nurses and music therapists, for example, from colleges to universities has been about adding authority to these roles (Swain et al., 2003; Cameron, 2015a). In Abbott and Meerabeau's (1998, p. 13) words:

> The caring professions are powerful because they not only aim to change and control behaviour but also help structure the context of social and cultural life in a more general sense – through their power to command definitions of reality by which the lives of their clients are shaped.

Professionals' knowledge has been regarded as having objectivity and validity, while service users' knowledge has been looked upon as subjective and invalid. This understanding has been expressed by McKnight (2005, pp. 82–83), who states that, in defining need as personal deficiency, 'caring' professionals have communicated a number of propositions to service users:

> *You* are deficient.
> *You* are the problem.
> *I*, the professionalised servicer, am the answer.
> *You* are not the answer.
> *Your peers* are not the answer.
> *The political, social and economic environment* is not the answer.

The requirement for professionals to consult with service users has come about as a result of collective advocacy by service user movements rather than as a result of professional initiatives. The disabled people's movement, for example, has been raising concerns about professional assumptions for many years now. At the time of writing, it is 30 years since Richard Wood (1989, p. 201), then Chair of the British Council of Organisations of Disabled People, stated that

> the truth is that this view of disabled people as 'sick people' or people in need of 'care and protection' is the view most often held by governments and the professionals, and it is the view that dominates services, policies and strategies which other people have imposed on us.

Making the point that care seems to many disabled people 'a tool through which others are able to dominate and manage our lives' (1989, p. 201), Wood lays the blame for disabling professional practices firmly within individual model thinking:

> So strong is this medical model of disability that many disabled people have also come to believe that they must let others manage their lives since they are not competent to do so themselves. Thus, disabled people's lives are often dominated by professionals and services which de-skill us and turn us into passive recipients of care.
>
> *(Wood, 1989, p. 201)*

Wood's comments were made as part of the Disabled People's Movement's Campaign for Independent Living, established during the 1980s. Established in a social model understanding, this placed an emphasis on

> breaking down the barriers which prevent disabled people from living as equal citizens in the community. We believe that these social barriers are the true cause of disability

> and that the solution to the independence of disabled people lies in using their direct experience to inform social policy which would be designed to remove these barriers.
>
> *(Wood, 1989, p. 202)*

From a perspective 30 years further on, we can look back at the ways in which the Campaign for Independent Living was hijacked during the first years of the present century by the personalisation agenda (Garabedian, 2014); at the closure by the Department of Work and Pensions of the Independent Living Fund in 2015; and at the transference of responsibilities to fund independent living to cash-strapped local authorities which have had to deal with a decade of cuts to social care budgets as a result of austerity policies. While disabled people's vision of independent living had been about transforming 'the whole of disabled people's interactions with society; its organisations, facilities and structures' (Elder-Woodward, 2012), Beresford (2014, p. 25) identifies personalisation as part of a market-centred cost-cutting exercise involving the privatisation of services and reliance on unpaid caring: 'In some authorities, personal budgets have been used to mean little more than a re-branding of existing and traditional arrangements'. Far from receiving support to live independently, increasing numbers of disabled people are receiving what Inclusion London (Pring, 2019, n.p.) has termed an extremely basic *clean and feed* model of care:

> The most basic choices such as when to get up, go to bed or use the toilet, when and what to eat, and the choice to leave the house are no longer in the hands of disabled people but subject to local authority budget allocations which are becoming ever more restricted.

At the same time, disabled people identify professional practice within social care as persistently paternalistic: 'making unhelpful assumptions about what service users can and can't do' (Beresford, 2014, p. 23).

I stated in the introduction my intention to argue that change-preventing power inequalities between service providers and service users persist not because service providers are 'lovers of power' or are deliberately unwilling to relinquish power. Many professionals are very lovely people with the best interests of their 'clients' at heart. The problem lies in professionals' inability to see their own practices in terms of the wider picture. While, as McKnight recognises, most social human service professionals have a theoretical understanding of the structural causes of individual problems, their everyday practice isolates the individual service user from this structural context. Because the professional's 'tools and techniques are usually limited to individualised interaction, the interpretation of the need becomes individualised' (McKnight, 2005, p. 79).

What has been apparent to disabled people for decades – that the real causes of disability are to be found in the way that contemporary society is organised rather than within their own individual bodies – still seems to baffle professionals. In spite of professionals' professed commitments to listen to service users' voices, it is the unwillingness of professionals to take on board the implications of the social model for health, education and social care practice which perpetuates disrespect and oppressive power.

## Power, social structure and role

In terms of Stryker's structural symbolic interactionism, society is:

> a never-ending process of routinisation of solutions to repetitive problems. Both persons (humans with minds and selves) and society are created through social process: each is constitutive of the other.
>
> *(Stryker, 2008, p. 16)*

Who we are able to be as individual people depends on when, where and how we find ourselves thrown into the world. This is not to say that we are completely conditioned by the social organisation and structures we find around us, for we exercise considerable individual autonomy in how we respond to our situations (in turn shaping the ongoing emergence of these). It is, however, to say that we are all creatures of our own times and places and that 'behind cognitive organisation lies social organisation' (Stryker, 2008, p. 17).

As self and identity are produced by our life experiences, these are bounded and given meaning within social structures, understood as pre-existing patterned interactions and relationships, characterised by durability, resistance to change and the capacity to reproduce themselves (Stryker, 2008). Society is made up of 'organised systems of interactions and role relationships and . . . complex mosaics of differentiated groups, communities and institutions' (Stryker, 2008, p. 19), intersected by a variety of marked categories based on class, age, gender, ethnicity, religion, disability and so on. These large-scale structures operate through structures more immediate to individual experience, such as professional or human service settings, to impact on interpersonal social relationships: shaping roles, expectations and the contents of interactions. As Schwalbe et al. (2000, p. 420) state:

> the reproduction of inequality, even when it appears thoroughly institutionalised, ultimately depends on face-to-face interaction, which therefore must be studied as part of understanding the reproduction of inequality.

Experiences are not distributed randomly through society. Rather, the content of and the meanings derived from experiences are shaped by where people are located within structures of class, ethnicity, gender, age, religion, disability etc. (Stryker, 2008). Large-scale structures (like disability) channel people into smaller-scale social structures (like local human services), which in turn channel them into interpersonal relationships with people they encounter (like professionals). The interactions people experience within these will importantly impact upon their self-concepts, attitudes and behaviours (Stryker, 2008, p. 23). Society is in a constant process of change and new approaches to problems emerge as, individually and collectively, people adapt existing meanings and behaviours to deal with new contingencies. Processes of service user involvement, user representation, co-production and joint planning represent attempts to bring about change to the way human services are conceived, planned and delivered. These activities are, however, complicated by professional assumptions and role expectations involved.

Disabled people are not just disabled people. Service users are not just service users. Instead, they are people with multi-faceted personalities who may have many different roles. They may be professionals, too. They may be activists. They may be seasoned and experienced campaigners. They may be self-advocates or spouses or parents or lovers or students or artists. Perhaps something like this is what is meant by many professionals who self-righteously emphasise the importance of using the term 'people with disabilities', preferring to see people in terms of their individuality first (although this misses the point in that it often involves an assumption that overlooking impairment is a kindness and, besides, reflects an individual model perspective which regards disability as something people 'have'). In terms of identity salience, though, self-identification as a disabled person (or as a Disabled person) involves taking on a political identity, regarding oneself as among the disenfranchised who have decided to do something to change things (Cameron, 2014d). Participation in service user involvement activities, though, made a frustrating experience (Shaping Our Lives, 2017; Cameron et al., 2019a; Cameron et al., 2019b) when human service professionals cannot get beyond the idea that disability signifies something wrong with a person.

From a symbolic interactionist perspective, social order is a negotiated process and not something that 'just happens' (Sandstrom et al., 2010). Structural realities such as inequality are understood as embedded ultimately in terms of the countless ongoing everyday negotiations that occur in individual interactions and negotiations:

> A social system depends on individuals acting towards other individuals in particular ways. However, it is not simply the behaviours themselves that create the social structure, but rather their sedimentation into a system that individuals understand as normatively appropriate.
>
> *(Sandstrom et al., 2010, p. 164)*

I have already stated that I am not suggesting that professionals intend their words, thoughts and actions to be oppressive, but that unequal power relationships between professionals and disabled service users are often reproduced in interactions that professionals consider normal and unproblematic. Schwalbe et al. (2000, p. 422) have identified four processes (and numerous subprocesses) central to the reproduction of inequality which I contend can be related to common practices of professionals in relation to disabled service users.

## Othering

In Fine's (1994) terms, Othering refers to the process whereby a dominant group defines into existence an inferior group. As discussed earlier in this chapter, during the industrialisation of society in the 18th and 19th century, people with impairments were physically removed from the social mainstream and placed within isolated settings. This was the first time 'the disabled' were identified as a group separate from society. It involved the establishment of abnormalcy in order that normalcy could recognise itself (Cameron, 2014d).

Oppressive Othering occurs, for example,

> when one group seeks advantage by defining another group as morally and/or intellectually inferior. . . . It is a process which entails the invention of categories and of ideas about what marks people as belonging to these categories.
>
> *(Schwalbe et al., 2000, p. 423)*

Eugenic terms such as *incurable degenerates*, *mental defectives*, *feeble-minded* and *idiots* (Quarmby, 2011), along with offensive medical terms such as *cripple, spastic* and *handicapped*, are echoed in professional judgements about service users' *challenging behaviours* or *inappropriate behaviour*s, as well as in descriptions of people as *moderately*, *severely* and *profoundly* disabled. The latter may sound less harsh, but they have the same purpose of negatively marking out, of establishing difference as deficit. Descriptions such as *the most vulnerable* are used to justify professional interventions into disabled people's lives, for example in providing segregated 'special' education. Labelling disabled people as vulnerable identifies disability as *their* problem and directs focus away from physical and social barriers which close off opportunities to gain life experiences (Cameron, 2014e). Hasler (2004, p. 229) has explained that the word vulnerable first started to appear in social care jargon in the late 1990s, stating that this is 'a concept that owes nothing to disabled people and everything to professional concerns'. It is now, however, a word used widely and uncritically in professional practice.

Stereotyping is another form of Othering. Stereotypes are 'vivid but simple representations that reduce persons to a set of exaggerated, usually negative characteristics' (Barker, 2004, p. 263). The practice of stereotyping is found overtly in professional practices where a disabled person's impairment is regarded as their most important characteristic. It is also found more subtly in workplace participation in and endorsement of scripted cultural events such as BBC television's annual charity event *Children in Need* or the Paralympics. Events such as these are key locations for the public recycling of old disabling stereotypes such as *the poor pathetic victim* or *the tragic but brave, plucky struggler against adversity* (Cameron, 2014f). Such activities create and reinforce meanings that shape perceptions and interactions in ways that reproduce inequality. The message is transmitted again that to be disabled is to be a victim of personal tragedy. As 'people who care', the moral identity of professionals is re-established.

## Subordinate adaptation

Schwalbe et al. (2000, p. 426) clarify what they mean by subordinate adaptation by describing this as 'trading power for patronage':

> One way to adapt to subordinate status is to accept it, while seeking to derive compensatory benefits from relationships with members of the dominant group.

The individual model of disability – the view that for a person to be disabled is to have something *wrong* with them, something they need professional help to deal with – is so pervasive and so dominant that it is little surprise that many disabled people accept this view of themselves (Oliver, 1996). When the discourses of dominant culture relentlessly present disability as involving personal tragedy, dependence and incapacity, then it is to be expected that many disabled people come to accept poverty, unemployment, restricted life chances and social exclusion as a consequence of their own characteristics as not-quite-good-enough human beings (Cameron, 2007). Given the unequal power relationships between professionals and disabled service users, approval from professionals in service user consultation contexts is likely to be something which can sometimes enhance self-worth. There is status to be gained for telling professionals what they want to hear. Discussing involvement as a service user representative, one participant in Shaping Our Lives' research (2017, p. 14) said they felt the experience was:

> Pointless as they have their regular service users who get listened to more than others.

The suggestion that professionals sometimes prefer to have passive and compliant service user representatives who can be relied upon to agree with them and will be unlikely to challenge the way things happen seems, perhaps, outrageous. It is, however, supported by the following statement taken from Shaping Our Lives' research report:

> My experience is that the professionals prefer to have victims. I experience an attempt to disempower me. They prefer to make decisions about me without me.
>
> *(Shaping Our Lives, 2017, p. 15)*

The following service user's statement underlines this point. As long as service users' voices assent to those of professionals, then things go well. When service users begin to express dissent, though, their views are dismissed as invalid and naïve. So long as the process of consultation can be shown to have occurred, then this seems to be what is regarded as important:

> It is diminishing to realise how the service providers see service users. It is frustrating in the meetings to sense how little credence most of them actually give to service user

> viewpoints. If our view chimes with theirs they are positive and pleased with how things are going. If the service user perspectives challenge their views then they tend to offer platitudes and try to swiftly move the discussion on.
>
> *(Shaping Our Lives, 2017, p. 15)*

It should really be unsurprising that many disabled people get involved as service user representatives out of a need to feel valued and important or that they should take pride in their involvement. To gain approval from people who seem important will have its rewards, especially if there seems little else to feel good about, but this does not necessarily signify greater respect or equality.

## Boundary maintenance

Schwalbe et al. (2000, p. 435) state that:

> Preserving inequality requires maintaining boundaries between dominant and subordinate groups. These boundaries can be symbolic, interactional, spatial or all of these. By preserving these boundaries, dominant groups protect the material and cultural capital they have acquired and upon which they rely to preserve their dominance.

Structures which legitimise professionals' authority – e.g. codes of conduct, performance standards, registered monopolies over areas of work, membership of selecting, safeguarding and controlling professional bodies (Abbott and Meerabeau, 1998) – are used to establish institutional boundaries between professionals and service users. McKnight (2005, p. 83) notes that to be professional is 'to distance – to ensure that the relationship is defined in terms that allow the client to understand who is *really* being serviced'.

Patricia Chambers, a disabled member of Shaping Our Lives' Board of Directors, spoke of the role confusion she experienced as a result of the different ways she was addressed by professionals on the basis of whether she was being regarded as a service user representative or as 'just' a service user. It was Patricia's comments that led to the development of Shaping Our Lives' 2017 research project *Improving Understanding of Service User Involvement and Identity* (discussed more fully in Chapter 2). Patricia talked about the conflict she felt in being treated, on the one hand, with respect – as an 'expert by experience' – when involved as a service user representative, seen as someone who had a potential contribution perceived as of value to service provider organisations wishing to engage her; and, on the other, outside those situations, finding herself relegated to being 'just a service user' by the same professionals who had extracted expertise from her service user representation:

> In the meetings the say 'Hello, Patricia, how are you?' But when they next see me on a corridor they act like they don't know me.
>
> *(Cameron et al., 2019b)*

It seems clear from Patricia's statements that the respect shown to her by professionals in situations of service user involvement was superficial. Once her service user's expertise had been gained, it was her experience that normal disabling, distancing relations resumed. It is little wonder that, as Shaping Our Lives (2017, p. 9) states, service users are often left feeling 'confused over status and concerned about having been used or exploited' (SOL, 2017).

In terms of the core argument of my chapter, I would argue that professionals' primary means of boundary maintenance is through regulating discourse. In Schwalbe et al.'s (2000, p. 435) terms, discourse is

> more than talk and writing; it is a way of talking and writing. To regulate discourse is to impose a set of formal or informal rules about what can be said, how it can be said, and who can say what to whom.

Discourse regulates the conversation that can be held on any matter, creating openings for the circulation and exchange of certain meanings and closing down possibilities for others. Within current health and social care provision, as I have already argued, disability remains predominantly talked about, thought about and acted upon as an individual problem, or in terms of individual model discourse as opposed to social model discourse. While many professionals acknowledge the existence of the social model of disability, it is far from clear that they understand it. In spite of the many campaigns organised by disabled people rooted in social model principles, and in spite of the volumes of academic writing that disabled people have produced about the social model, many professionals have seemed disinclined to comprehend it or take it on board. For this reason, it is important here to make clear what I am talking about.

The social model of disability needs to be regarded as the response of the disabled people's movement to the individual model, and so the individual model must here be explained first. The individual model of disability, also known as the medical model (Oliver, 1996), while having characterised professional thinking about disability for many decades previously, was most succinctly summarised in the World Health Organisation's 1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980, pp. 47, 143). An important distinction is made in ICIDH between the concepts of impairment and disability.

> Impairment: any loss or abnormality of psychological, physiological, or anatomical structure or function
>
> Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being

It can clearly be seen that, within this framework, disability is regarded as the direct outcome of impairment and is measured in terms of deviance from normality. Disability is viewed here as an individual problem rather than a structural issue. WHO's later revision of ICIDH, the International Classification of Functioning, Disability and Health (ICF), redefined disability as:

> an umbrella term, covering impairments, activity limitations, and participation restrictions.
>
> *(WHO, 2019, n.p.)*

While purporting to be rooted in a biopsychosocial model of disability (WCPT.ORG, 2019), the ICF definition continues to conflate disability and impairment, treating these both as the same thing, and thus reproduces individual model thinking.

ICF overlooked Drake's (1999, p. 14) point that 'the medical and social models are two fundamentally opposed ways of understanding disability'. It allowed professionals to retain focus on addressing individual physicality and behaviour as the source of people's problems and to overlook the social contexts in which disabled people live – which they were largely powerless to do anything about anyway.

The social model, originally formulated in 1976 in the UK by the Union of the Physically Impaired Against Segregation (UPIAS), and developed in 1982 by Disabled People's International (DPI), redefined the terms impairment and disability.

> Impairment: lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body
>
> Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities
>
> *(UPIAS, 1976, p. 14)*

The DPI 1982 classification built on the UPIAS definitions by adding what it termed mental and sensory impairments so that, for example, people with learning difficulties, people with mental health issues, Deaf people and blind people were included as disabled people.

> Impairment: the functional limitation with the individual caused by physical, mental or sensory impairment
>
> Disability: the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers
>
> *(DPI, 1982, in Fougeyrollas and Beauregard, 2001, p. 177)*

Both these social model classifications identify impairment as signifying physical or functional lack or limitation. The added difficulty to life caused by impairment is implied within these definitions. Disability, however, is identified in terms of the way society excludes people with impairments from ordinary community life, whether intentionally – through the establishment of segregated environments and institutions, for example, which reinforce perceptions of Otherness – or unintentionally, through lack of thought, in the circulation of disabling stereotypes or the poor design of new public spaces that are still frequently inaccessible (Heaton, 2014). In terms of the social model, people with impairments do not 'have' disabilities, but they are disabled by society and its practices. Identifying as a disabled person involves a shift in thinking from medical model to social model terms. Being disabled becomes a political identity. It involves having to deal with choices and decisions made by other people, often professionals, which have a significant limiting impact on life opportunities.

The endless recurrence of individual model discourse within professional practice closes down opportunities to think differently about ways in which both impairment and disability may be experienced. Unending sequences of interactions where only individual model discourse can be heard establish demoralising contexts in which impairment can only be made sense of negatively. While individual model discourse remains the norm within professional interactions with service users, it involves both a regulation of emotion and a regulation of action (Schwalbe et al., p. 435).

## Conditioning emotional subjectivity

A core principle of SI is that people act towards things on the basis of the meanings they learn to give to things (Chalari, 2017). The sense that disabled service users can make of their experiences as people with impairments in a disabling society depends largely on the meanings and narratives that circulate in the culture they are part of – or are excluded from (Cameron, 2007). As Schwalbe et al. (2000, p. 437) argue, emotional subjectivity can be conditioned in ways that reproduce inequality and may 'also entail conditioning one's self to accept as normal the feelings that are attendant to subordination'.

One disabled service user representative interviewed by Shaping Our Lives (SOL, 2017, p. 20) observed that:

> Many professionals mean well but can be tokenistic and patronising, especially in the health sector. It is a huge mind set for health to realise that disabled people want choice and control over their own lives although many disabled people who have not had the same experience as some disabled people simply accept this kind of treatment.

What the service user representative describes here is her view of the situation of other disabled service users who have – often because no other options have seemed available – taken on what French (1994) has described as 'the disabled role'. The disabled role is given legitimacy within everyday interactions, practices and contexts in which assumptions equating impairment with tragedy go unchallenged. It is characterised by a number of features. These include being required to aspire above all things to independence; to aspire to appear less disabled and more normal; moving towards acceptance of and adjustment to the tragedy associated with impairment; and taking responsibility for the feelings that non-disabled people have about impairment and disability. It is an oppressive role for a number of reasons.

While unequal relationships of care can create their own problems by developing mutual dependency, pressures placed by professionals on disabled people to carry out time-consuming physical tasks for themselves in order to demonstrate their independence can be regarded as equally oppressive. The thinking underlying such requirements is that 'this is how normal people go about things' and that normality is something disabled people should aspire to. Many disabled people believe that spending hours of indignity, pain and stress in order to complete tasks for themselves for the sake of appearances is a waste of time when they could get a personal assistant to do these things instead. This would free them up to do more interesting things with their lives. In terms of Independent Living philosophy, independence is about being in control of what happens rather than about being physically able to do things (Garabedian, 2014). The expectation that disabled people will aspire to normality leads to situations where disabled people cannot be open about their impairments or access requirements for fear of other people's responses. The requirement to accept and adjust to the 'loss' that 'disability' involves makes it very difficult to think about impairment other than as tragedy or to find anything of value in the experience. Finally, the expectation that disabled people will take responsibility for the feelings non-disabled people have about impairment and disability is wearing:

> People with epilepsy may, for example, be expected to explain constantly their condition and offer reassurance, deaf people may struggle to lip-read, and visually-impaired people may endure boredom rather than 'spoiling other people's fun'. . . . In contrast, non-disabled people are not expected to understand deafness, blindness, epilepsy or paralysis, or to alter their behaviour in any substantial way.
>
> *(French, 1994, p. 56)*

The disabled role, imposed through unequal power relations in countless daily interactions with professionals, often appears the only role available to disabled people and can be very hard to resist. As Jane Kroger (2000, p. 20) has noted, people 'are largely ascribed identities according to their manner of embedding within a discourse – in their own, or in the discourse of others'. The imagination is given little to build on with which to make positive sense of the experience of living with impairment. Disabled people often find themselves caught up in playing a part, and receiving social approval for playing a part, which does nothing to challenge the disabling social relations they experience.

Trying to break out of the disabled role and to assert oneself can be difficult and challenging, particularly when, as one service user representative said, there is a feeling that:

> They are working against me, not with me. They are making decisions in what they think is best for me but not really listening to me.
>
> *(SOL, 2017, p. 19)*

Another service user representative spoke of the emotional impact of having tried to challenge the professionals with whom he was meeting (SOL, 2017, p. 24):

> Just thinking about the impact that can have on you, not just the experience of being humiliated but the experience of trying to explain why that has an impact on you and that being disregarded as well, then that can undermine your confidence and then it becomes more and more difficult then to access services in the future.

The damaging impact upon service user representatives' confidence and self-esteem is not something that is lightly brushed off but can have a deeper demoralising effect. As another service user representative reflected:

> Those negative experiences become part of your private experience, very negative, very harmful.
>
> *(SOL, 2017, p. 24)*

If service providers intend consultation with service users to be meaningful and effective in bringing about real change, there is a requirement to recognise and address the unequal power relations inherent in the nature of their practice. This inequality does not stem from who they are as individual practitioners, but is rather the outcome of wider structural contexts to which perhaps they haven't really given much thought.

Apart from in a minority of cases, the unequal power relations discussed here are not attributable to individual professionals but to the disabling structures of society – to 'the system' or to the flux of a multitude of separate systems to do with disability, gender, race, ethnicity, age and religion. Within symbolic interactionism, structure is recognised as a metaphor for recurrent patterns of action involving large numbers of people (Schwalbe et al., 2000, p. 439), some of whom are human service professionals. There is no superimposing structure to be discovered out there, just the endless activity of other people in other settings doing similar things. What people do in any of these settings depends on the ideas, feelings, procedural rules, tools and habits available to enable their individual and joint action (Schwalbe et al., 2000, p. 440). In these terms, it has to be the responsibility of 'caring' professionals to examine the meanings they adhere to as well as their own values and beliefs about disability if they want to be part of the solution.

## Disabling encounters with professionals

During the time I have been preparing and writing this chapter, I have talked about some of these issues with two other disabled people, Joanne Molloy-Graham and Maggie Cameron.

Joanne is currently a third-year undergraduate student at Northumbria University and Maggie is a freelance Disability Equality Trainer. Both were able to recollect numerous encounters with non-disabled professionals in which they had felt discriminated against by medicalising, individual model judgements and comments, and some of these are included here. These were comparatively small incidents happening in the flow of everyday life. Presumably it would never have occurred to the professionals involved that their words and actions were oppressive. These incidents will have been considered unimportant and have been long forgotten by them. Yet, in contexts in which disability 'is lived in the midst of the meanings given to it' (Titchkosky and Michalko, 2014, p. 101), these encounters have remained with Joanne and Maggie as examples of ongoing unwelcome professional invalidation.

### Joanne Molloy-Graham

I remember arriving at college once to be told by one of my tutors that the lift was out of order and that this meant I could not gain access to the class room. When I asked if the room could be changed, I was told that it could not, and I should either go home or stay in the library. I felt it was assumed that I was the inconvenience. Angry, fed up and tired of having the rug pulled from underneath me, I went home. I was angry and upset and it raised some past issues from other occasions. I remember also attending a lecture at college in my wheelchair and being asked by a lecturer if I should be there. I felt it was assumed that somehow because I was in my chair, I was not capable of the work. It left me feeling annoyed, judged and embarrassed. I felt very self-conscious and stressed.

When I applied for a student representative role, I was asked to attend a chat in which the member of staff suggested that I withdraw my application given my illness. I felt the assumption was being made that I was not good enough or capable of managing myself. I was so angry. It made me fight harder, but my self-esteem and confidence were affected. I am scared to be myself sometimes. Also, she asked me why I was applying to be a disabled representative when I don't look disabled. I felt that the assumption was being made that I was somehow lying and I had to justify myself. I felt judged and it impacted upon my sense of self.

In one of my lectures I was having a seizure. I was asked by the lecturer why I was pulling faces and told to stop doing it or leave. I felt it was assumed that I was somehow trying to be disruptive. I felt embarrassed, stressed and anxious. I didn't go back for two weeks.

I get fed up at the amount of times staff tell me I am an inspiration and that I am so brave. Like I am not a burden or a trouble maker or a complainer but some form of hero that should be a poster for what people with illness or disability can achieve. The truth though is I am not brave or a hero. But just a mother, a wife, a student and a woman who loves her family, who wants to enjoy life. I am from my family's long line of stubborn pig-headed women, not a burden or a hero. Most of these issues need more staff training and awareness. It is lack of understanding. It is those who lack understanding in power that prevent the world from seeing me for who I really am.

### Maggie Cameron

I remember being asked by one of my social work tutors at university if I wanted to go for a coffee while the other members of my group watched a DVD that wasn't

> subtitled. When I questioned this, she offered to let me take the DVD home for the week. Of course, it still wouldn't have been subtitled at home either. She seemed to have this idea that with constant repetition I would somehow be able to hear it. Stuff like this leaves you feeling exasperated and frustrated because you constantly have to validate yourself over trivial incidents. It's not so much the single incident itself so much as that you have to deal with stuff like this over and over again, every day.
>
> Once when I was working in Edinburgh I had gone with a colleague to check out new premises for the disabled people's organisation Self Directed Support Scotland – to check the place in terms of access and room sizes. I had already explained to the receptionist that I was deaf, but when I asked her to repeat her directions to the meeting room she turned to my colleague and told her instead. You just say to yourself 'What the . . .?' It's always disbelief that someone you're talking to responds in such a dismissive way. You always think well, what happened there? Have I missed something?
>
> I had explained to the minister of our parish church, who was also a speech therapist, why I had a positive regard towards my deafness. He responded by saying simply 'No, I can't accept that'. I was struck by his disbelief, at the fact that he could simply negate my opinion of myself. I don't know how he had the arrogance to just say what he did. I was gobsmacked and couldn't think of how to respond.
>
> I was refused a telephone call to a professional at social services. The person on the receiving end of the call just kept putting the phone down while the person from Type/Talk tried to explain. You just feel a sense of annoyance and resignation. It happens again and again. It's the ignorance among professionals who haven't got the wit to understand. Surely access and communication with disabled people should be a key part of their training?

Thomas (1999, p. 47) has argued that as well as social barriers, recognised by social modellists as externally imposed restrictions of activity,

> there are also social barriers which erect 'restrictions' within ourselves, and thus place limits on our psycho-emotional well-being: for example, feeling 'hurt' by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, unattractive, hopeless, stressed or insecure.
>
> *(Thomas, 1999, p. 47)*

Both Joanne's and Maggie's accounts of disabling encounters with professionals vindicate Thomas's assertion here. Professionals' complacent imposition of individual model values and judgements in the ongoing interactions of everyday life have a cumulative wearing effect. 'I am scared to be myself sometimes,' says Joanne. 'You constantly have to validate yourself over trivial incidents . . .' 'It happens again and again,' says Maggie. The problem is to do with the nature of the individual model as dominant discourse in that, on the basis of disabled people's statements considered in this chapter, it prevents professionals from seeing, relating and interacting with respect towards disabled people. The identification of disability with personal deficit allows professionals to presume an asymmetrical relationship between themselves and disabled people. In Sandstrom et al.'s terms:

> A relationship is asymmetrical when one of its participants establishes control or dominance, disproportionately imposing his or her will on the other participants and setting

> conditions, making decisions, and engaging in actions that determine the form and course of the relationship.
>
> *(2010, p. 158)*

Joanne and Maggie describe feelings of anger, tiredness, upset, self-consciousness, stress, exasperation, annoyance and frustration at professionals' presumed rights to impose their own understandings on what is going on in their encounters with disabled people. Yet this is not all they express. The passage by Sandstrom et al. continues. In spite of power inequalities that exist within interactions:

> We include the term 'disproportionately' in our definition because we recognise that subordinates, or less powerful people, are not without power or resources; indeed, they often have ways to initiate action and evade the control of superordinates, or more powerful people.
>
> *(2010, p. 58)*

In spite of their experiences of inequality, neither Joanne nor Maggie are victims. Both identify a requirement for professionals to receive training on disability equality issues. They identify the deficit in the interactions they have talked about as being in terms of professionals' understanding. The stress and frustration they feel is not the outcome of their experiences of impairment but of having to deal with professional condescension. Joanne rejects the roles professionals try to place her in, either as inconvenience or as hero. She identifies herself as 'just a mother, a wife, a student, and a woman who loves her family'. Maggie observes that professionals 'haven't got the wit to understand'. Like the voices of the disabled people who took part in SOL's research discussed earlier, these are the voices of disabled people who can see what is going on and have developed their own subversive discourse.

## Conclusion

The affirmation model is the theoretical development within Disability Studies of the Disability Arts Movement's concept of *Disability Pride* (Swain and French, 2000; Cameron, 2015b). Expressive of transgression, resistance and self-confirmation, the affirmation model summarises in abstract terms the assertion of non-compliance captured in a line penned by the blues singer and disabled artist Johnny Crescendo:

> I'm in love with my body. It's the only one I've got.
>
> *(Holdsworth, 1989, p. 16)*

There is a self-respectful defiance in Crescendo's words and a refusal of expectations that, as a disabled person, he will only be able to relate negatively to his own embodied experience. His point is that impairment is an important part of his everyday experience but not something he intends to waste his time lamenting. This is expressed in the affirmation model in the following definitions (Cameron, 2015b, p. 118):

> Impairment: physical, sensory, emotional and cognitive difference, divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society.

> Disability: a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal.

The disabled people's words in this chapter – the participants in SOL's research on service user identity, Joanne's and Maggie's, Johnny Crescendo's – articulate a demand to be recognised and valued for who they are as disabled people. While impairment can sometimes be messy, tiring and painful, it is not the end of the world. It is something to be lived with, not to be ashamed of. The real difficulty in life is disability which, as UPIAS (1976, p. 14) stated, is 'something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society'. Impairment is not the cause of incessant regret, but a common part of human experience which has much to teach about the ambiguity and temporality of human existence. Pointing out what should be obvious to most people, Hamilton (2014, p. 1) reminds us that:

> Everyone knows that life contains many adversities: we all experience loss, failure, disappointment, waste and pain in various different forms and ways.

In other words, impairment is simply a variant among the difficulties life throws at all people. Jennie, a disabled woman with various impairments who I interviewed during my PhD research (Cameron, 2010), made this point when she remarked:

> There are all kinds of terrible situations in life that I wouldn't be . . . I mean, for instance, the average person in Scotland now reads six books a year . . . it's hard for me to imagine being in that situation . . . and not being terribly unhappy with myself . . . obviously people are just different like that.

To Jennie, the idea of being someone who only reads six books a year would seem an unthinkable shame, something she would not enjoy. She accepts the fact that some people – the average person in Scotland, she says – may spend most of their time without their nose in a book, but that would not be a life she would choose. She enjoys being who she is, but feels sorry for those with less cerebral lives.

Roshni, a blind woman quoted in Cameron (2014g, p. 5), said:

> I've yet to meet the person who's jumping up and down, celebrating that they've got dodgy eyesight . . . but, having said that, it's certainly not a cause for me to cry and weep and wring my hands and give up on the world . . . there are lots of things I'm not happy about. . . . I'm not happy about the fact that I've got dry rot in the next room and the ceiling needs replacing. . . . I think my visual impairment is on the same scale as that . . . life happens.

Disabled people's knowledge seems to elude most 'caring' professionals. Disabled people know that it is possible to live with impairment and to feel all right about being yourself, or that it would be if it weren't for physical barriers everywhere and for the fact that most people – including professionals – seem unable or unwilling to move beyond or to stop imposing individual model thinking. I have recently discovered two books by the South Korean Buddhist monk Haemin Sunim. The first is entitled *The Things You Can See Only When You Slow Down* and the second *Love for Imperfect Things*. Both are international bestsellers, with millions of copies sold. The wisdom suggested by the titles, though, could be related by any disabled person for nothing.

I conclude by quoting Mast (2010, p. 28) again:

> Power emerges in social interactions and affects social interactions in turn. The expression of power of the interaction partners and their perception of each other's power are interwoven in actual social interactions and determine how each individual feels, thinks, perceives, and acts.

For so long as professionals' understanding of disability remains rooted in individual model terms, their relationships with disabled service users will remain asymmetrically structured. Thinking of, speaking of, regarding and acting towards disability as abnormal deficit closes down possibilities for valuing impairment as a characteristic of human difference to be expected and respected on its own terms. Professionals need to learn to listen to what disabled service users have to say.

## References

Abbott, P. and Meerabeau, L. (1998) 'Professions, Professionalism and the Caring Professions'. In Abbott, P. and Meerabeau, L. (Eds.) *The Sociology of the Caring Professions*. London: Routledge, pp. 1–19.

Albrecht, G. (1992) *The Disability Business: Rehabilitation in America*. London: Sage.

Barker, C. (2004) *Cultural Studies: Theory and Practice*. London: Sage.

Barnes, C. (1997) 'A Legacy of Oppression: A History of Disability in Western Culture'. In Barton, L. and Oliver, M. (Eds.) *Disability Studies: Past, Present and Future*. Leeds: The Disability Press.

Barnes, C. and Mercer, G. (2010) *Exploring Disability*. 2nd ed. Cambridge: Polity Press.

Beresford, P. (2014) 'Personalisation: From Solution to Problem?' In P. Beresford (Ed.) *Personalisation*. Bristol: Policy Press, pp. 1–26.

Borsay, A. (2002) 'History, Power and Identity'. In Barnes, C. Oliver, M. and Barton, L. (Eds.) *Disability Studies Today*. Cambridge: Polity Press.

Cameron, C. (2007) 'Whose problem? Disability narratives and available identities'. *Community Development Journal*, Vol. 42, No. 4 October, pp. 501–511.

Cameron, C. (2010) *Does Anybody Like Being Disabled? A Critical Exploration of Impairment, Identity, Media and Everyday Life in a Disabling Society*. PhD thesis. Queen Margaret University. http://etheses.qmu.ac.uk/258/1/258.pdf

Cameron, C. (2014a) 'The Social Model'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 137–140.

Cameron, C. (2014b) 'The Historical Construction of Disability'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 65–68.

Cameron, C. (2014c) 'Identity'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 72–74.

Cameron, C. (2014d) 'Normalcy'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 107–109.

Cameron, C. (2014e) 'Vulnerability'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 153–156.

Cameron, C. (2014f) 'Stereotypes'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 144–147.

Cameron, C. (2014g) 'The Affirmation Model'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 4–7.

Cameron, C. (2015a) 'Does Disability Studies Have Anything to Say to Music Therapy? And Would Music Therapy Listen if it Did?' *Voices: A World Forum on Music Therapy,* Vol. 16, No. 3.

Cameron, C. (2015b) 'Turning Experience into Theory: The Affirmation Model as a Tool for Critical Praxis'. *Social Work and Social Sciences Review*, Vol. 17, No. 3, pp. 108–121

Cameron, C. (2018) 'Social Policy and Disability'. In Beresford, P. and Carr, S. (Eds.) *Social Policy First Hand: An International Introduction to Participatory Social Welfare*. Bristol: Policy Press.

Cameron, C., Moore, M. and Nutt, A. (2019a) 'User Involvement and Identity: Disabled People Bringing Ourselves out of the Half-Shadows'. *Social Work and Social Sciences Review*, Vol. 19, No. 4

Cameron, C., Moore, M., Nutt, A. and Chambers, C. (2019b) 'Improving Understanding of Service-User Involvement and Identity: Collaborative Research Traversing Disability, Activism and the Academy', *Disability & Society*, DOI: 0.1080/09687599.2019.1632693

Chalari, A. (2017) *The Sociology of the Individual: Relating Self and Society*. London: Sage

Davis, L. (2013) 'Disability, Normality and Power'. In Davis, L. (Ed.) *The Disability Studies Reader*. 4th ed. London: Routledge, pp. 1–16.

Drake, R. (1999) *Understanding Disability Policies*. London: Macmillan.

Elder-Woodward, J. (2012) *Independent Living: The Frontier of Communication Welfare*. Lancaster: ESRC Seminar Series, Lancaster University.

Elias, N. (2001) *The Society of the Individual*. London: Continuum.

Emerson, R.M. (1962) 'Power Dependence Relations'. *American Sociological Review*, Vol. 27, No. 1, pp. 31–41.

Fine, M. (1994) 'Working the Hyphens: Reinventing Self and Other in Qualitative Research'. In Denzin, N. and Lincoln, Y. (Eds.) *Handbook of Qualitative Research*. London: Sage, pp. 70–82.

Forte, J.A. (2004) 'Symbolic Interactionism and Social Work: A Forgotten Legacy, Part 1'. *Families in Society*, Vol. 85, No. 3, pp. 391–400.

Fougeyrollas, P. and Beauregard, L. (2001) 'An Interactive Person Environment Social Creation'. In Albrecht, G.L., Seelman, K.D. and Bury, M. (Eds.) *Handbook of Disability Studies*. London: Sage, pp. 171–194.

French, S. (1994) 'The Disabled Role'. In French, S. (Ed.) *On Equal Terms: Working with Disabled People*. London: Butterworth-Heinemann.

Garabedian, F. (2014) 'Independent Living'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 81–84.

Gleeson, B. (1999) *Geographies of Disability*. London: Routledge.

GOV.UK (2019) *Definition of Disability under the Equality Act 2010* [Online] www.gov.uk/definition-of-disability-under-equality-act-2010 Accessed 05.07.19.

Hamilton, C. (2014) *How to Deal with Adversity*. London: Macmillan.

Hasler, F. (2004) 'Disability, Care and Controlling Services'. In Swain, J., French, S., Barnes, C. and Thomas, C. (Eds.) *Disabling Barriers: Enabling Environments*. London: Sage, pp. 226–232.

Heaton, T. (2014) 'Access'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 1–4.

Holdsworth, A. (1989) *Johnny Crescendo Revealed*. London: Self-Published.

Kroger, J. (2000) *Identity Development: Adolescence Through Adulthood*. London: Sage.

Mast, M.S. (2010) 'Interpersonal Behaviour and Social Perception in a Power Hierarchy: The Interpersonal Power and Behaviour Model'. *European Review of Social Psychology*, Vol. 21, No. 1, pp. 1–33.

McKnight, J. (2005) 'Professionalised Service and Disabling Help'. In Illich, I., Zola, I. K., McKnight, J., Caplan, J. and Shaiken, H. (Eds.) *Disabling Professions*. London: Marion Boyars, pp. 69–91.

Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan.

Oliver, M. (1996) *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan.

Oliver, M. and Barnes, C. (2012) *The New Politics of Disablement*. Basingstoke: Macmillan.

Priestley, M. (1997) 'Whose Research: A Personal Audit'. In Barnes, C. and Mercer, G. (Eds.) *Doing Disability Research*. Leeds: The Disability Press, pp. 88–107.

Pring, J. (2019) 'Breakthrough Lords Report Gives Boost to Campaign for Free Care'. July 4, 2019 [Online] www.disabilitynewsservice.com/breakthrough-lords-report-gives-boost-to-campaign-for-free-care/?fbclid=IwAR1mya0-7KgaQ9KH-MCOJ0q1P19soCnJy1rmHiJtI3cnLmwKnMOfEQvIiUY Accessed 08.07.19.

Quarmby, K. (2011) *Scapegoat: Why We Are Failing Disabled People*. London: Portobello Books.

Sandstrom, K.L., Martin, D.D. and Fine, G.A. (2010) *Symbols, Selves and Social Reality: A Symbolic Interactionist Approach to Social Psychology and Sociology*. New York: Oxford University Press, p. 158.

Schwalbe, M., Godwin, S., Holden, D., Schrock, D., Thompson, S. and Wolkomir, M. (2000) 'Generic Processes in the Reproduction of Inequality: An Interactionist Analysis'. *Social Forces*, Vol. 79, No. 2, December, pp. 419–452.

Shaping Our Lives (2017) *Improving Understanding of Service User Involvement and Identity* [Online] www.shapingourlives.org.uk/resources/our-resources/all-publications/improving-understanding-of-service-user-involvement-and-identity Accessed 28.06.19.

Shaping Our Lives/National Survivor User Network (2019) *The Future of User-Led Organisations* [Online] https://shapingourlives.us10.listmanage.com/track/click?u=d3e11cfe1dce72cdbc9c40bb4&id=06f803ca02&e=eb761b4ad2 Accessed 04.07.19.

Stryker, S. (2002) *Symbolic Interactionism: A Social Structural Version*. Caldwell, NJ: The Blackburn Press.

Stryker, S. (2008) 'From Mead to a Structural Symbolic Interactionism and Beyond'. *Annual Review of Sociology*, Vol. 34, pp. 14–31.

Swain, J. and French, S. (2000) 'Towards an Affirmation Model'. *Disability and Society*, Vol. 15, No. 4, pp. 569–582

Swain, J., French, S. and Cameron, C. (2003) *Controversial Issues in a Disabling Society*. Maidenhead: Open University Press.

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

Titchkosky, T. and Michalko, R. (2014) 'Narrative'. In Cameron, C. (Ed.) *Disability Studies: A Student's Guide*. London: Sage, pp. 101–104.

Union of the Physically Impaired Against Segregation (1976) *Fundamental Principles of Disability*. London: UPIAS.

WCPT.ORG (2019) *The ICF: An Overview* [Online] www.wcpt.org/sites/wcpt.org/files/files/GH-ICF_overview_FINAL_for_WHO.pdf Accessed 12.07.19.

Wolfensberger, W. (1972) *The Principle of Normalisation in Human Services*. Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (2000) 'A Brief Overview of Social Role Valorization'. *Mental Retardation*, Vol. 38, No. 2, April, pp. 105–123.

Wood, R. (1989) *Care of Disabled People* [Online] www.psi.org.uk/publications/archivepdfs/Disability%20and%20social/WOOD.pdf Accessed 07.07.19.

World Health Organisation (1980) *International Classification of Impairments, Disabilities, and Handicaps A Manual of Classification Relating to the Consequences of Disease*. Geneva: World Health Organisation.

World Health Organisation (2019) *Health Topics: Disabilities* [Online] www.who.int/topics/disabilities/en/fAccessed 14.07.19.

Wrightson, K. (2002) *Earthly Necessities: Economic Lives in Early Modern Britain, 1470–1750*. London: Penguin.

Young, I. M. (2011) *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press.