

Working with disability across the counselling professions

Mel Halacre

Good Practice across the Counselling Professions 007
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Contents

Context	5
Using Good Practice across the Counselling Professions resources	5
1 Introduction	6
2 British view of disability	6
2.1 Models	8
2.2 History, power, oppression and the legacy of non-affirmative practice	9
2.3 Impact on therapist and client	10
2.4 Intersectional understanding	12
3 Common themes	13
3.1 Physical barriers are far-reaching	13
3.2 Isolation	13
3.3 Trauma	14
3.4 Third parties	15
3.5 Bodies, sex, intimacy and relationships	16
3.6 Touch	17
3.7 Futures and death	17
4 Groups with distinctive themes	18
4.1 Congenital and acquired impairments	18
4.2 Health-related chronic conditions	19
4.3 Invisible impairments	19
4.4 Mental health intersectionality	20

5	Affirmative working	20
5.1	Transference and projection	20
5.2	Exploring the individual or collective	21
5.3	Language and communication	21
5.4	Changing and challenging boundaries	22
5.5	Supervision and training	23
6	Summary	24
	About the author	25
	Acknowledgements	25
	References	25
	Further resources	30

Context

This resource is one of a suite commissioned by BACP in liaison with other professionals, to enable members to develop good practice across the counselling professions.

Using Good Practice across the Counselling Professions resources

BACP members have a contractual commitment to work in accordance with the current *Ethical Framework for the Counselling Professions*. The Good Practice across the Counselling Professions resources are not contractually binding but are intended to support practitioners by providing information on specific fields of work including good practice principles and policy applicable at the time of publication. Specific issues in practice will vary depending on clients, particular models of working, the context of the work and the kind of therapeutic intervention provided. As specific issues arising from work with clients are often complex, BACP always recommends discussion of practice dilemmas with a supervisor and/or consulting a suitably qualified and experienced legal or other relevant practitioner. In this resource, the word 'therapist' is used to mean specifically counsellors and psychotherapists and 'therapy' to mean specifically counselling and psychotherapy. The terms 'practitioner' and 'counselling related services' are used generically in a wider sense, to include the practice of counselling, psychotherapy, coaching and pastoral care.

1 Introduction

Disability has a unique feature compared with other diversity groups. Anyone can join any time (White, 2011) making it emotive, evoking complex thoughts, feelings and behaviours, many operating unconsciously, non-verbally and primitively (Livneh, 1982). Informed by society's views of disability, they influence how we interact with a(nother) disabled person. Views of disability are formed at an early age, with studies showing a preference for 'able-bodied' over 'disabled' present in children starting primary school (Huckstadt and Shutts, 2014).

Watermeyer reflects:

'We all have feelings about disability, which tend to be strong, diverse and at least partially hidden. Cultural and political forces leave us extremely uneasy with most of these feelings ... But beneath the surface the simple truth is that we all, disabled and nondisabled alike, struggle with the cultural phenomenon of disability. This shouldn't surprise us and is no cause for shame. As humans, difference is something we find hard' (2013:5).

To understand people, we form an immediate impression using information from our senses and categorise it, increasing our likelihood of survival (Comer and Gould, 2012). Those not fitting the 'normal' category are more likely to be treated differently or marginalised (WHO, 2018).

It can be hard to acknowledge awkward feelings and complex interactions surrounding disability. This resource aims to make this easier from a place of safety, openness, acceptance and empathy. Our focus is on increasing awareness to provide effective therapy. That is, what happens *after* a therapist has met the legal requirements and any reasonable adjustments.

It is impossible to encapsulate this nuanced topic and undoubtedly, we have omitted things or excluded certain groups or individuals, for example multicultural views of disability or intersectionality with other diversities. Likewise, there will be individuals who are part of groups described who do not consider themselves disabled; disability identity and language are complex.

This resource is a starting point for further discussion, reading, CPD and reflection and assumes limited prior knowledge of the complexities of disability. Readers will be in different places with regards to their own experiences of disability and difference, disability awareness and social justice awareness.

Impairments vary widely, impacting in unique ways. It would be impossible to provide a complete guide, nor to sufficiently demonstrate breadth of opinions on appropriate responses for specific impairments. This resource aims to give an overview of common themes and ideas to encourage affirmative practice.

BACP publishes other relevant Good Practice in Action resources such as those on equality, diversity and inclusion (including working with disability, reasonable adjustment and working with interpreters), fitness to practise and supervision www.bacp.co.uk/gpia.

In BACP's *Ethical Framework for the Counselling Professions* (2018) the principles of trustworthiness, autonomy, beneficence, non-maleficence, justice and self-respect are important for all practitioners but particularly so when thinking about disability.

2 British view of disability

Approximately 13.9 million people in the UK have an impairment (Scope, 2020); it is likely that one in five clients has an impairment. Whether we or our client is disabled, aging, a family member or paid/unpaid carer or has professional contact with disabled people, our working knowledge of the cultural landscape of disability informs both our work and its outcomes.

Disability is recognised as a protected characteristic under the Equality Act 2010. However, British culture has been influenced by successive models of disability (see 2.1). This legacy can be seen in the attitudes, systems and interpersonal interactions that significantly impact disabled people today such as the differing views regarding preferred language and descriptors and limitations to the definition of being 'disabled'.

When we use the term 'disability' we mean someone who has an impairment or identifies as disabled, whether due to a physical or mental impairment. Some neurodivergent people (with or without an impairment) may also consider themselves disabled. Neurodiversity acknowledges differences in thinking and learning as normal variation, rather than impairments or deficits and includes neurotypicals and those with, e.g. autism.

Impairments may be visible, invisible, congenital (born with) or acquired; someone may be simultaneously visibly and invisibly disabled. Many people who are classed by others as disabled may not consider themselves so (for example, people who are neurodivergent may identify as disabled or different but without an impairment). Someone with the same diagnosis and mobility device e.g. wheelchair or walking stick may identify differently.

'Impairment' and 'disability' are used interchangeably in everyday language with people preferring one word over the other, or neither. 'Impairment' is a 'medically classified bio physiological condition' (Barnes and Mercer, 2010, p11) and 'disability/disabled' seen as 'the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have ... impairments and thus excludes them from the mainstream of social activities' (UPIAS, 1976:14, cited in Oliver and Barnes, 2012). Realistically, the terms overlap, are socially ascribed and value laden. This resource uses these terms to distinguish between the individual medical condition and the socially engendered disadvantage.

Similarly, some people prefer the people-first language of 'person with a disability' to emphasise they see the person first. However, the term 'disabled person' confers the meaning 'disabled by barriers in society' and more accurately reflects the reality of disabled people's lives and the identity-first approach. It supports the prevailing social model view of disability (see 2.1) implemented in the Equalities Act 2010.

In the same way, many disabled people who need assistance (many don't) dislike the word 'carer', preferring to have a paid Personal Assistant (PA) who 'assists'. Often unpaid family members are called 'carers' by professionals. This resource will use 'PA' to identify those assisting, paid and unpaid.

2.1 Models

The Equality Act views disability mainly from an 'impairment' point of view or medical model. However, disabled people make sense of their lives through various models (Oliver and Barnes, 2012), some of which are:

- *tragedy* – sees the individual as a victim of circumstance, helpless and dependent on care from others (perhaps the hardest to understand because it is masked with kindness for example, charities).
- *medical* – sees the impairment or adjustment to it as problematical, where the solution is to fix/help and make 'normal'.
- *moral* – based on beliefs that impairment is a punishment for bad deeds perpetrated by the individual or their ancestors.
- *social* – focuses on the disadvantages or barriers experienced in the physical and social environment. How society is structured, services organised and delivered; institutions, language, culture and attitudes all have influence (Oliver, 1990). Disability is a barrier preventing full societal participation and is experienced *in addition to*, not *because of*, impairment. Many disabled people state it is society, not their impairment, that disables them (Oliver, 1995).
- *Biopsychosocial* – underpins current welfare reform. Whilst acknowledging the role of barriers created in society, the complex classification system of disabilities makes it difficult to use and it is easier to measure some categories than others.

Though many see the social model as the most empowering, it has received criticism that it does not include enough focus on the psychological impact of disability (Reeve, 2014a). This has led to many disability affirmative therapists basing their work on an *expanded social model* view, one recognising the social constructs in society which disable (structural disablism), but also the physical effect of an impairment (for example pain or mobility issues), emotional impact of impairment and of structural and psycho-emotional disablism (for example how a disabled person may internalise frequent comments about their impairment (Reeve, 2014a).

2.2 History, power, oppression and the legacy of non-affirmative practice

'Disability struggle' is human struggle, so not unique to disabled people (Watermeyer, 2013). However, certain experiences are more likely if a person is disabled and are rooted in the inequality of power when that person is seen as 'other'. 'Othering' (Powel and Menendian, 2016) occurs across societies and throughout history. Disability history is however often missing from educational and cultural content.

Disability and work are charged issues politically and socially. The exclusion from many workplaces and factories stems from increased industrialisation of agricultural practices in the 18th century which led to the classification of 'non-standard' bodies (Roulstone, 2014).

Historically, the medical profession assigned categories of people who could access support within the new residential spaces of hospitals, asylums and residential homes, influencing current welfare state systems. Categories of who could access support were (and are) drawn and redrawn. The medical model influenced many contemporary therapy approaches, developed during the 20th century when disabled people were routinely segregated (Barnes and Mercer, 2010).

Many disabled people have considerable contact with bodies such as Social Services, NHS, Motability, Access to Work and DWP. Generally, this involves someone assessing a disabled person's needs against criteria and deciding what support they are given (often requiring demonstration of the need). Despite the move towards person-centred support, the power in these situations rests with the assessor: the disabled person is often 'unseen'.

Disabled adults, including those with full mental capacity, are classed by the Department of Health as 'vulnerable adults'. Yet many do not describe themselves nor like to be defined as such. In England and Wales, the Care Act 2014 sets out a legal framework for how local authorities and the healthcare system should protect adults at risk of abuse or neglect.

Though this classification is supposed to protect, in some cases the need to safeguard has disempowered disabled people and the often imposed 'sick role' of the medical model (Devore and Schlesinger, 1999) has prevented disabled adults from taking the same risks and learning from mistakes as other adults (Mackelprang and Salsgiver, 2016).

Important side note: the classification as 'vulnerable adult' can cause therapeutic dilemmas around disclosure. For example, how does the principle of autonomy interact with the classification of 'vulnerable adult' and safeguarding? If an adult client has autonomy over their life and choices, when/if/how would/should you as a therapist intervene in a consenting sexual relationship between a disabled adult with full mental capacity and a paid PA who is abusive (the abuse is the safeguarding issue here)? There is an expectation that you should report this to Social Services because the person is classified as a vulnerable adult.

Dependency, a universal human trait, means we are all dependent to some extent on the help and support of others (Asch et al., 2001, cited in Watermeyer, 2013) but it has become unconsciously denied to keep the myth of independence alive (Watermeyer and Swartz, 2016). The physical assistance that some disabled people need is therefore seen differently (Shakespeare, 2006) often associated with shame (Watermeyer, 2013), and oppression.

Particularly in the western world, we see ourselves as independent, using power, choice and control to express identity, helping us feel safe and secure (Watermeyer, 2013).

2.3 Impact on therapist and client

For many disabled people, this security is often (without choice or consent) shattered by the onset of impairment. Questions arise around how to live; knowing they are continually relinquishing power, control, independence; choices are limited, and there are frequent invasions of privacy and little dignity, assigned to a minority, stigmatised in society. An existential crisis may emerge:

'...we need therapists ...who are used to confronting the depth of despair with their clients, whilst keeping their eyes on the possibilities ahead. We can never fake authenticity or existential courage. We can only help people to go as far as we have gone ourselves in our own lives.' (Emmy van Deurzen, *Therapy Today*, June 2020:29)

The psychological effects of disempowering experiences and systematic exclusion of disabled people are called 'psycho-emotional disablism' (Reeve, 2014a). How does it impact one's wellbeing when someone acts/speaks/gestures in an invalidating way, or when access to a venue is through the back entrance where the rubbish is kept? One example is when negative messages turn into 'internalised oppression':

'We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives.' (Mason, 1992, cited in Reeve, 2014a)

Frequent exposure to multiple negative messages and experiences, systematic exclusion and microaggressions impact heavily. As well as internalised oppression there may be an external locus of control, learned/taught helplessness, low self-esteem, poor body image, anxiety and depression. Trying to hold on to power, choice and control, a person may appear difficult, controlling and angry (Olkin, 2017).

It's helpful to validate these normal responses as for many disabled people it is societal barriers, not their impairment, which affects their wellbeing. As Morris, 1991 says, perhaps 'emotional problems are a sane reaction to an unequal world?'

Therapists, disabled and non-disabled, are subject to these same negative connotations, images and symbols. We may feel ashamed of our reactions to disability or overwhelmed by a client's story or try to fix it. We may mistakenly put everything down to impairment ('disability-spread') (Wright 1960, cited in Marini and Stebnicki, 2012) or deny its existence.

History has created systems and approaches contributing to power imbalances (McLeod, 1998) and potential oppression in the therapist-client relationship (Reeve, 2000).

Historically, disability has largely been ignored in psychodynamic psychotherapy (Watermeyer 2013) and individual, loss and tragedy models dominate the social model (Swain et al., 2003).

'While many disabled people do experience counselling as helpful and enabling, others find counsellors who do not understand the complexity of the lived experience of disability' (Reeve, 2014b)

Some examples are therapist assumptions that relationship problems are caused by the presence of impairment, disbelief that a disabled client would consider refusing surgical intervention, inaccessible therapy rooms (Withers, 1996, cited in Reeve, 2002) and pathologising anger (Olkin, 1999). More recently, Ashley Cox describes being turned down for therapy eight times due to his visual impairment ('Dilemma: Disabled access', 2019).

As well as a disempowering history, lack of power can be experienced closer to home. Some adults, disabled since birth or youth, received disempowering messages and experiences in childhood. Consider the impact of being sent to 'special needs' or residential school when your siblings weren't. Older disabled clients may have lived through institutionalisation, while those younger live with awareness of being the first generation not routinely institutionalised. Institutional care has silenced and disenfranchised many disabled people.

Usually, disabled people are surrounded by non-disabled and don't see themselves reflected at home or in society (Gill, 2001). Disability is often portrayed in negative or caricatured ways in the media, for example through villains or superheroes who 'overcome' their disability (although real disabled role models are emerging).

Considering how much 'space' to give disability in therapy needs careful consideration to avoid 'disability-spread' and putting everything down to disability. For some clients, disability may not be something they want to discuss and it's good practice to follow their lead.

However, holding in awareness how society oppresses disabled people in a multitude of ways, and that this is a different experience from impairment effects, means we can recognise that disability issues may emerge in therapy in various ways.

In the same way practitioners may bring up 'the elephant in the room' with regards to race, they can gently elicit a discussion around their relationship with disability, power and oppression.

The safety of supervision offers us opportunities to explore our relationship with disability, power and oppression, to reflect and explore how clients impact us and bring unconscious processes into awareness. Processing our inherent biases and stereotypes helps increase therapeutic effectiveness (Kemp and Mallinckrodt, 1996). We can explore our role in offering clients a different experience: one that promotes inclusion, overcomes segregation and cultivates a sense in disabled clients of full entitlement to real inclusion and citizenship rights on an equal level to others.

2.4 Intersectional understanding

Cultural representations of disabled people are scarce, often stereotyped (Hodkinson and Park, 2017) and overwhelmingly white, straight, cis, middle-class and hearing (Thoreau, 2006). This can unintentionally carry into therapeutic work and do harm. If we can acknowledge different understandings of disability and the complex, layered differences between being, for example, a gay Ghanaian man living in south London and a third-generation immigrant south Asian woman in the north of England, a more culturally rounded and nuanced understanding can develop.

'Intersectionality' (the theory of how different forms of discrimination interact) has grown to encompass 'the set of overlapping social identities we all have, and the related systems of privilege and oppression that impact our lives'. (Barker, 2017:14). We all sit at intersections of privilege and marginalisation, identities we hold which are praised or penalised, unrelated to ourselves or behaviour. Our privileges and oppressions are often invisible; our treatment considered the norm, unrelated to our identities. Awareness of our places of power and vulnerability can help us recognise when we perpetuate structural inequity in and out of the therapy room. It also helps us consider the relevant framings clients bring.

Therapists strive to work in a culturally sensitive way with all clients. Clients may have multiple intersecting, marginalised or oppressed identities (Crenshaw, 1989).

They may also be part of a minority culture; for example, many Deaf people identify not as disabled but as a linguistic and cultural minority (Jones, 2002).

3 Common themes

3.1 Physical barriers are far-reaching

Addressing physical barriers to therapy is the first step towards inclusive practice. Impairments can cause physical barriers in less obvious ways. For example, clients who use PAs, have assistive devices or service animals, may need to arrive early to sessions to set up. Those with speech impairments or communication aids may need longer sessions or breaks.

Clients also need time, energy and a reflective space to make therapeutic changes and these can be challenged when living with impairment and could be a discussion point for therapy. Disability-related tasks (not only personal care tasks but also regular assessments for equipment, medication, vehicles) can take up many hours and emotional labour due to forced intimacy/personal disclosure. Fatigue intermingles with side effects from medication, poor sleep, pain or cognitive effects. Lack of privacy or alone-time as well as isolation (see 3.2) can be physical barriers.

Unique to disability, physical barriers are experienced in addition to the societal exclusions, prejudices and stigma experienced by all minority groups.

Therapists may have concerns about additional costs when working with disabled clients requiring longer sessions, particularly in private practice. Before offering or starting therapy, these valid concerns should be brought to supervision. Finances are an issue for many disabled clients too. Some therapists offer reduced rate slots for lower income clients and perhaps additional time could be similarly accommodated?

Likewise, it is important to contract what happens if a client cannot attend due to unexpected circumstances outside their control such as illness, hospital appointments or PA illness as these are often physical barriers to therapy. Offering alternative methods of therapy, e.g. online or by phone, can be useful.

3.2 Isolation

Disabled clients may be practically isolated, struggling to leave their home due to mobility, transport or PA issues. Impairment-related tasks, pain or fatigue may reduce social contact.

Psychological isolation arises when disabled people feel unable to share their inner thoughts, often feeling silenced/not heard, subsequently silencing themselves. They may have lost friendships because of physical barriers or because others struggle with their impairment.

Considering the issue of isolation is helpful as we plan our work. It can impact on therapy boundaries, client resources and therapist modelling. Some clients may not have been given the same opportunities of education, access, literacy or the learning opportunities of adolescence (for example risk-taking, sexual exploration and semi-independence) as non-disabled peers.

How clients take therapeutic learning back to their world is important. Making changes can be challenging when there is isolation due to little support or peer networks, poor literacy skills, communication difficulties, financial concerns or lack of privacy. We may have to be creative in helping clients find alternatives for change to occur.

3.3 Trauma

Historically, counselling and psychotherapy tended to adopt a medical or tragedy model with regards to disabled people (Reeve, 2014b; Swain and French, 2000) or see impairment as the root of issues.

However, trauma rather than impairment is often at the root. Common in the lives of disabled people, it can take many forms. The expanded social model of disability views trauma as a response not only to an accident or acquired impairment but also from cumulative (often daily) psycho-emotional disability (Reeve, 2014a; Watermeyer and Swartz, 2016) including hate crime ('Disability Hate Crime', 2019).

Trauma and loss are still considered through a non-disabled lens, locating both in the disabled person's body, as a consequence of their impairment (Reeve, 2014b).

Clients have reported previous therapists' presumption that the client is upset about 'being disabled'. There may be grief and loss, for example if impairment arose from an accident or injury.

The likelihood of abuse is increased for disabled people (Jones et al., 2012) and coercive abuse common. Disabled children and young people may be targets for sexual exploitation (Goldman, 1994).

Medical trauma can be significant and ongoing. Many disabled people relate to hospitals and medical professionals in a way that speaks of this. For example, a common experience is having been subjected to a medical procedure (often without consent because they were too young or not asked) that involved pain, restraint, trauma, nudity and isolation from caregivers.

The experience of disability and impairment may, for some, lead to development of new skills and abilities or chances to change direction (Smart and Smart, 2006).

'According to several Buddhist and Taoist traditions, sex, meditation, death and trauma share a common potential. These are the great portals – catalysts for ... surrender and awakening.' (Levine, 2005:79)

To increase wellbeing, disabled clients may need to develop skills and strategies to manage the impact of macro and micro trauma from situations such as poverty, claiming benefits, inaccessible environments, medical interactions and others' negative reactions. Therapist training in a trauma-informed approach is useful.

3.4 Third parties

In addition to interpreters in therapy, other third parties may be involved in clients' lives, such as family members, PAs, care home staff and service dogs. Most therapy training instils that the principle of autonomy and client privacy means third parties are not involved. For disabled clients, they may be necessary.

Sometimes, third-party relationships are controlling or abusive and it can be helpful in initial sessions to discuss with a client that this is their therapy and you will be working with them on their aims, not those of the third party. If there are control issues, it may be useful, with client consent, to include the third party at the start of therapy through a group meeting and/or progress updates.

Third parties can impact therapy despite agreements not to include them. For example, if an adult client enhances their assertiveness skills, third parties may disapprove, asking how therapy is helping if the client is now less compliant. If they assist with driving, they may refuse to accompany the client to therapy.

PAs may need to sit in on sessions, for example, if the client is anxious, their communication difficult to understand, or they need assistance with personal care tasks. For clients using communication aids such as pictures or talking computers, PAs may provide summaries of what the client wishes to discuss. Relationships with paid PAs can be complex and it may be difficult for clients to balance their needs with those of their PAs.

Some clients need to be in contact with their PA immediately after a session so may not have the usual 'reflection-while-travelling-home time'. It is useful to discuss what support a client may need before, during and after a session. If working online, it's important to discuss privacy, confidentiality and practical barriers at home.

Sexual relationships with PAs can happen. and clients may wish to explore in therapy the issue of informed consent to these sexual relationships.

Third party relationships can be challenging for therapy, and the complexity alongside safeguarding, autonomy, 'vulnerable adult' status (and for some, the Mental Capacity Act 2005) means it is advisable to seek additional specialist supervisory and legal support.

Some clients have service dogs, and it is important to ask and discuss how you and the client respond to and involve them in therapy. Some service dogs may react to a client's emotional state.

3.5 Bodies, sex, intimacy and relationships

Discussing intimate relationships can be a vital part of work. Sex has been called the 'forgotten activity of daily living' (Breske, 1996, cited in Olkin 1999:226).

As Barker writes:

...historically the project of categorising people's sexualities and genders into 'ordered' and 'disordered', 'normal' and 'abnormal' is intrinsically linked with the way in which certain bodies have been defined as normative in western culture, rendering other bodies disordered. We can see the legacy of this in the way that some disabled people experience others regarding them as non-sexual or inappropriate if they are sexual, not sexually attractive, and/or less of a man/woman... (Barker and Lantaffi, 2015, cited in Barker, 2017).

Sex, relationships, marriage and fertility may have been ignored as disabled clients grew up (reinforced by a lack of sex education at school) and ignored in assessments by Social Services or others who decide whether someone needs support to complete Activities of Daily Living. Sex and intimacy may be seen as unimportant or avoided in case it upsets the disabled person (Olkin, 1999).

Fertility is often ignored with assumptions that someone will (want to) remain single, is unable to have sex, children or adequately parent. Disabled people have been excluded from health and sexual screenings (WHO, 2018).

Discussions in therapy may include menstruation, personal grooming, involving PAs with preparation for sexual activity and consideration for gender identity and the intersectional crossover with sexual diversity.

Although partnerships (intimate as well as friends and children) confer many benefits, higher percentages of intimate relationships break down when one partner becomes disabled and more disabled people are single (Olkin, 1999 and 2017).

Having experienced frequent silencing, clients may not raise these issues and our anxieties around sex and disability may stop us asking. It can help to say, "I'm not an expert, but I want to acknowledge that I'm aware this might be an issue for you, and I am willing to assist you to explore it."

The PLISSIT model (Permission, Limited Information, Specific Suggestions, Intensive Therapy (Annon, 1976) and the more disability-affirmative Recognition Model (Couldrick et al., 2013) can help you decide what support to offer.

Many psychosexual therapists have little training/experience in disability so onward referral is not straightforward.

3.6 Touch

Trainees are often alerted to be careful when considering touching clients and encouraged to undertake further training when using touch. Working with clients whose mobility is affected can present challenges and, in some settings, (for example, hands-on signing) it may be essential. Consider what you might do if your client needed assistance to use a tissue to wipe their tears or to get into the toilet. Many clients ask for assistance on a 'needs must' basis and are used to the blurring of boundaries (see 5.4). It is helpful to discuss what assistance they may need in the session, including unplanned situations.

There may be a theme around 'touch deprivation', as mobility aids or pain may prevent getting close to loved ones. Others may avoid touching the disabled person to distance themselves due to discomfort with the impairment. Touch may be primarily in a medical or care-task related way, which impact clients' views of self, body and wellbeing.

Whilst acknowledging that abuse is more prevalent in this client group, with client consent and supportive supervision and/or additional training, touch in therapy can model power equalisation and be reparative. It is possible to widen the common 'no touch' viewpoint by considering: 'If I assist how will this help or hinder the therapeutic relationship?' or 'How can I prevent a negative impact if I do assist?'

3.7 Futures and death

Impairment reminds us of the reality of frailty, decline and death. Like illness, disability is often associated with death (Livneh, 1982) unconsciously triggering therapist death anxiety and influencing the service we provide (Fish, 1986).

These anxieties often underlie the medical model approach too: seeking to help the person with an impairment get better, find a cure or become as 'normal' or independent as possible (Olkin, 2017). Underneath, the message is that it's not OK to be different (Morris, 1991).

'Futures' are important for all clients and include topics like work, finances, housing, pensions and death, but also one's desire for friendship, love, intimacy, family and legacy. For some disabled clients, these themes are complexly intertwined with physical assistance requirements.

Many disabled people have low incomes (Scope, 2020). Financial concerns, often brought to therapy, include how to remain as independent and in control of one's life as possible as one ages, impairment worsens, or health deteriorates (and how to pay for therapy). This can cause anxieties for both client and therapist if outlooks seem bleak, difficult or hopeless.

Yet, clients report relief at being able to discuss their futures, particularly if those around them have been avoidant and they felt silenced.

The life-stage of reflecting on one's life and the time left can happen earlier in life when one is disabled. There may also be valid anxiety about the death of family members or PAs resulting in the client living in an institution.

4 Groups with distinctive themes

4.1 Congenital and acquired impairments

For people born with an impairment, this may or may not be an important part of their identity. Some identify as belonging to a cultural group of people with similar impairments, and often it is this cultural identity, rather than the impairment, which defines experience. Some may experience loss seeing peers grow up and do 'normal' things like working, having sex and becoming parents. There may be feelings of frustration and anger about impairment, but often these relate to access barriers rather than impairment.

Someone acquiring an impairment later in life may not experience the same connection with community or identity. If developed recently, there will be an adjustment period and possibly a sense of loss with grieving a previous lifestyle.

Some impairments may considerably impact on relationships, for example if these centred around activities no longer accessible, if people close to them take on the role of PA or impairment affects communication. For some, isolation, grief and loss of identity can be challenging.

4.2 Health-related chronic conditions

Chronic conditions may include pain, illnesses and life-limiting conditions, sometimes co-existing with being disabled. They can take a long time to diagnose and for many, diagnosis is a relief, validation or, in time a celebration; 'a diagnosis is comforting because it provides a framework - a community, a lineage' (Weijun Wang, 2019:3). Diagnosis can take time to process, offering potential for recovery and/or better management. From the medical model viewpoint, it might be seen as a 'hopeless' trajectory. There are also movements like *A Disorder For Everyone* (see Further Resources) that are challenging the culture of diagnosis.

Chronic conditions can vary in symptomology and what a client may be able to do one week may not be possible the next. Pain, fatigue, mobility, communication and cognitive issues may impact therapy and those with a symptom 'flare' can struggle with energy levels, perhaps needing recovery time. It can be challenging to navigate the uncertainty of what one's body will do next, as well as judgment from others regarding ability, all compounding the uncertainty of relapsing-remitting or variable chronic illness. Disabled people with chronic conditions may 'pass' as non-disabled and lead to concerns around being 'exposed' and when to 'come out' as disabled.

For those with life-limiting conditions, illness progression can be unpredictable, making it difficult to plan and thus, end of life reflections may feature in therapy.

4.3 Invisible impairments

Impairments can be visible, invisible, disabling or non-disabling, and fluctuating (or a combination). As with any client, what first presents may not be the whole story.

Many invisible impairments impact cognition. For example, cerebral palsy, multiple sclerosis, brain injury, neurodegenerative diseases and learning impairments may directly affect memory or processing. Medication and fatigue can also affect cognitive functioning, requiring adaptations to therapy (see Further resources).

Dominant cultural views of disability such as d/Deaf, hard of hearing (HoH) or visually impaired (VI) may not be experienced as such by a d/Deaf/HoH/VI person who might identify as belonging to a linguistic or cultural minority group.

There is scrutiny and surveillance on disabled people's behaviour around the narrative of 'benefit fraudsters', which can have a detrimental impact on wellbeing. Clients can experience their body and access needs being 'policed' or assessed by (predominantly) the non-disabled. Invisible, asymptomatic or hard to diagnose impairments may lead to more frequent experiences of surveillance and disbelief.

We may unintentionally subscribe to this surveillance narrative by asking clients to provide medical 'evidence' in response to their request for an adjustment to aid access. For example, if an invisibly disabled client (through brain injury, chronic fatigue or pain) takes a while to put on a coat at the session end, a therapist might wonder if this is about pushing therapeutic boundaries or seeking more time/contact. Equally, the therapist's response to a client 'taking up more space/time/energy' may also be in play. When such issues come to light, they can be brought to supervision to discuss if or how to bring this back to the client. Disability-informed supervision may be helpful here.

4.4 Mental health intersectionality

Mental health conditions are considered by many an impairment or 'illness' and can occur alongside a physical impairment. Mental health conditions are often viewed through the medical model that suggests the disturbance is located entirely or predominantly inside the individual (Kinouani, 2019), which is disabling. Many cultures associate mental 'illness' with 'madness' and destabilisation and it can intersect with (un)conscious fears around disability, vulnerability, helplessness and loss of self or roles. Some conditions like chronic pain or fatigue are seen as solely psychological (upsetting to those with these conditions).

Rather than dividing the mind and body, it can be more helpful to consider a holistic view including the psycho-emotional and social factors in distress (Kinderman et al., 2011). Not only does the experience of being disabled increase the chance of mental health difficulties (Cimpean and Drake, 2011, cited in Naylor et al., 2012), but physical impairment and cumulative trauma from disability experiences impact on mental health and vice versa.

5 Affirmative working

5.1 Transference and projection

As therapists, we all make mistakes, and prejudices we are unaware of arise unexpectedly, in some cases leading to therapy termination. We can prevent this by doing our own reflective work before meeting disabled clients and contracting with them that we are open to discussing our relationship with disability, including inviting them to inform us if we misunderstand, misinterpret or make a mistake. In this way, ruptures may be opportunities to move into a safer therapeutic relationship and break down any professional power-structure that may exist.

Working with disabled clients can bring powerful, often avoided aspects of human life into the therapeutic relationship. Many clients project unconscious processes onto us, for example they may project their valid anger at the 'disabling world' onto a non-disabled therapist. Equally, clients report that therapists make assumptions based on prejudices embedded in dominant culture, so it is also necessary to consider therapist countertransference.

We can demonstrate with an example around pregnancy. Disabled women's pregnancies have been forcibly terminated, children removed from disabled parents considered inept and disabled adults and young people sterilised against their will (Joseph, 2019; Tarleton, 2014; Rowlands and Amy, 2017). Media coverage influences us all and has led therapists to assume that disabled women can't have children or would terminate a pregnancy.

5.2 Exploring the individual or collective

Often, familial or societal issues become located in a disabled person rather than held in the family group; a convenient scapegoating of an individual with an explainable problem (Haydon-Laurelut, 2011). A disabled person can be encouraged or pulled into this by the group dynamic. Knowing this phenomenon is common helps us stay aware and able to maintain appropriate therapeutic distance.

For example, dominant narratives exist around the struggle of caring. Disabled people can be seen as burdens, their lives deemed not worth living. In some extreme cases, disabled people are abused or murdered by their paid or unpaid PAs and relatives (Kurchak, 2018; Weijun Wang, 2019) where escape or relief from the 'burden' is motive for murder (Young, 2013). All of this can impact a disabled client's identity and experiences.

5.3 Language and communication

It is empowering if language around disability involves respectful enquiry, supporting autonomous choice whilst being willing to 'get it wrong'. We are often scared of being 'politically incorrect', but, barring derogatory terms, often it is not the term but the purpose behind its use that is important. For example, a disabled person may identify as (and prefer to be referred to as) 'visually impaired' rather than 'blind'. In the same way we might ask how a client's name is pronounced, we can ask which disability words a client prefers.

Disability language is constantly in discussion which adds to the fear of 'getting it wrong'. As therapists we can be alert to this and use supervision to reflect on the language we use and find ways to break through a human being's natural drive towards stereotyping. We can also observe and discuss our client's language as it may change throughout the therapeutic process.

Some disabled people may describe themselves using what others consider derogatory language, for example, 'handicapped'. This may arise from historic use, shame, internalised oppression or self-judgment. Certain words may be more acceptable in other cultures or age brackets.

Conversely, disabled people may reclaim language that historically was used offensively and would not be appropriate for someone outside of that community to use, such as 'crip' (a similar process to the affirmative reclaiming of 'dyke' by many lesbians).

A separate issue is working with a client with communication difficulties. We may fear we won't understand them or be embarrassed to ask them to repeat themselves. This is usually about us being outside our comfort zone as the client will be familiar with repeating themselves and it is useful to discuss this at the start of therapy. PAs, friends or family members may assist/sit in the first few sessions to aid communication. It can take time to settle into working with someone who has a speech impediment, aphasia or uses a communication aid. It may be useful to consider offering longer sessions for therapy to be fruitful (see Further resources).

5.4 Changing and challenging boundaries

Being disabled commonly means boundaries are frequently ignored or overstepped, especially if there is a need for physical assistance (Watermeyer, 2013). As maintaining boundaries is a central part of therapy training, it is common for therapists to experience discomfort navigating more fluidity for fear of 'getting it wrong' or to have questions around how to maintain therapeutic boundaries whilst providing effective therapy. Sometimes therapeutic boundaries can be used defensively to protect against the uncomfortable, and it is advisable to bring boundaries in relation to disabled clients to supervision. Watermeyer (2013) writes about the distortion of boundaries in connection to disability. Halacre and Jalil (2017) discuss a more flexible and holistic therapy approach which remains safe and empowering, oftentimes leading to deepening of the therapeutic relationship.

5.5 Supervision and training

Throughout this resource the importance of supervision as a space to explore client work, including any uncomfortable feelings evoked in us when working with disability, has been stressed. We have an ethical responsibility to work within our area of competence and to increase our knowledge and skills.

Olkin, 1999:302, says:

'Saying that one doesn't treat clients with disabilities is rather like saying one doesn't treat depression - you never know when in therapy the issue will arise, and the ability to provide treatment for this problem is fundamental to our work.'

Themes we may wish to bring to supervision include:

- our own thoughts and experiences around disability, difference and oppression
- anxieties about complex impairments
- reliability of life-sustaining equipment
- existential fears about deteriorating conditions
- fear of 'getting it wrong'
- 'survivor guilt' for non-disabled therapists
- overwhelm from the client's story
- urges to create distance from the client or creating a 'them' and 'us'
- hopelessness stemming from a belief that a client's problems are unsurmountable
- 'rescuer' versus 'wounded healer'. The tragedy model positions the non-disabled helper as saviour or rescuer.

For the disabled therapist, supervision can also help explore our relationship with our impairment and shared experiences of oppression, when or how to disclose impairments, how our own and the client's view of disability impacts the work, and confidentiality and boundaries when working with clients from a similar community to ourselves. Disability is becoming more present in therapy training but Paluck (2006) suggests that short-term diversity training may reinforce stereotypes and awareness of difference. Perhaps longer-term reflection or training is better suited to change our natural unconscious biases.

Working with a disability affirmative supervisor is useful and sometimes essential, especially when moving into this area.

6 Summary

Disability is a unique experience. Though around 20% of the population have an impairment, the severity will vary and with it, experiences of prejudice and other socially engendered disadvantages. We can proactively meet the needs of this minority group in various ways by:

- creating a physically accessible environment
- learning about a specific impairment before therapy
- considering our initial (and very critical) response to a new client, who is disabled including body language, expression and tone of voice
- asking new clients how best to support them and how disability manifests for them instead of making assumptions – the themes in this resource may or may not apply
- being an ally by hearing and normalising clients' feelings and experiences, acknowledging social stigma and dominant narratives and providing a counterbalance, exploring social context instead of individualising
- being mindful of the potential of reinforcing social oppression through the power dynamics of the client-therapist relationship
- drawing on our own experiences of difference, disadvantage, discrimination, exclusion and belonging to minority groups
- considering whether our supervisor has the relevant expertise and if not, seeking additional support.

We can empower disabled clients and their families by continuing learning and reading and increasing our own awareness around disability, thereby avoiding the unfortunately common scenario of the disabled client educating the therapist.

It's possible that Ashley Cox (described in 2.3) was refused therapy because of discrimination or because it triggered therapists' fears around disability. It's also possible some felt they did not have the expertise or were fearful of how therapy could work when impairments can't be 'fixed' (assuming that was even the issue Ashley wanted to discuss).

Though we need to refer on if we feel we have not done sufficient work to offer a client an empowering space, we also need to weigh up the impact of not working with someone. By reflecting on and challenging our own conscious and unconscious assumptions, prejudices, biases and fears (whether we're disabled or non-disabled) we can strive to change these, thus minimising reinforcing stigmas. Ultimately, if our own processes take up less space in the therapy room, there is more space for the client to explore theirs.

As Olkin (1999:301) says:

There probably is no remedy for 'able-ism' more powerful than immersing oneself in disability culture, viewing over time persons with disabilities in 'normal' functional roles and social interactions. But this is possible only when we encounter the 'other' on an equal basis, not as a professional and client, helper and helpee.

About the author

Since 2009, Mel Halacre has been clinical director, founder and therapist at Spokz People CIC, a non-profit organisation developing a disability affirmative therapy approach. Spokz People offers consultancy, supervision and training for therapists and self-help resources for clients in person, via media contributions, website, Facebook and Twitter pages.

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Further resources

Spokz People CIC is developing training to work alongside this guide. Please contact them to register an interest. In the meantime, they offer ad hoc and regular supervision for therapists working with disabled clients, a directory of affirmative therapists, and support for clients. www.spokzpeople.org.uk (accessed 2 November 2020)

Disability and Sex: www.enhancetheUK.org (accessed 2 November 2020) – online resources for professionals and peer support for clients. The guide *Disability, Sexual Expression and the Law* is especially useful

Death anxiety: Yalom, I.D. (2011) *Staring at the Sun*. London: Piatkus

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Learning impairments: institute of psychotherapy and disability: <https://instpd.org.uk>