Disabled people’s perceptions and experiences of accessing and receiving counselling and psychotherapy: a scoping review protocol

Phaedra Longhurst,1,2 Wayne Full 2,3

ABSTRACT

Introduction Evidence indicates that, compared with their non-disabled counterparts, disabled people are likely to face greater mental health challenges as well as significant inequalities in accessing appropriate therapeutic support. Currently, little is known about how disabled people perceive and experience counselling and psychotherapy, what barriers/facilitators to therapy delivery and/or therapy participation exist for disabled clients and whether clinicians sufficiently adapt their practice to meet the needs of this diverse but marginalised population. In this paper, we outline a proposal for undertaking a scoping review that aims to identify and synthesise current research relating to disabled individuals’ perceptions of accessibility and experiences of counselling and psychotherapy. The review aims to identify current gaps in the evidence base and inform how future research, practice and policy may develop and foster inclusive strategies and approaches which will support the psychological well-being of disabled clients accessing counselling and psychotherapy.

Methods and analysis The undertaking and reporting of the proposed scoping review will be guided by the framework outlined by Arksey and O’Malley and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR) guidelines. Systematic searches of the PsycINFO, CINAHL, EMBASE, EBSCO and Cochrane Library electronic databases will be conducted. Reference lists of relevant studies will be reviewed to identify additional studies. Eligible studies will be limited to those published from 1 January 2010 to 31 December 2022 and in the English language. Empirical studies involving disabled individuals receiving and/or who have received a form of therapeutic intervention will be included. Data will be extracted, collated and charted, and will be summarised quantitatively through descriptive numerical analysis and qualitatively through a narrative synthesis.

Ethics and dissemination The proposed scoping review of published research will not require ethical approval. Results will be disseminated through publication in a peer-reviewed journal.

INTRODUCTION

Disability is a protected characteristic under the UK Equality Act 2010. Someone is considered to be 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.’ The Equality Act goes on to define ‘substantial’ as ‘more than minor or trivial, for example, it takes much longer than it usually would to complete a daily task like getting dressed’ and ‘long term’ as ‘12 months or more, for example, a breathing condition that develops as a result of a lung infection.’ Given that the focus of this paper is disability and
counselling/psychotherapy, we have opted for a definition proposed by the British Association for Counselling and Psychotherapy (BACP) and we understand disability as encompassing:

Individuals who have an impairment or identify as disabled, whether due to a physical or mental impairment. Some neurodivergent people (with or without an impairment) may also consider themselves disabled. 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. The words impairment and disability are used interchangeably in everyday language with people preferring one word over the other, or neither.2

This definition covers progressive disabilities, those conditions which get worse over time such as motor neuron disease, muscular dystrophy and forms of dementia.

Approximately 1 billion people in the world are considered to have a disability or impairment, and we are all likely to experience some form of disability during our lifetimes whether on a temporary or permanent basis.3 Disability often attracts negative attitudes based on prejudice or stereotype, and these attitudes are shaped from an early age.4 As Watermeier reflects:5, p5

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 […] as humans, difference is something we find hard.

Despite disability being commonplace and part of human diversity, it is a highly contested concept. Disability is difficult to define,6, p16 and there are competing models for conceptualising and thinking about it. Historically, the three most common models have been the medical, charity and moral models.2 The medical perspective posits that disability is an individual’s problem, pathology or deficit, which requires medical care, treatment, rehabilitation or fixing in some way.7, 8 Under this model, disability is perceived as a limiter and as reducing disabled people’s capacities to engage in normal daily activities, including tasks relative to daily living (eg, bathing, dressing), communication (eg, seeing words, hearing conversations) and mobility (eg, walking, climbing stairs, lifting/carrying).9 This model works on the assumption that disabled people are less able and less capable than non-disabled people and require extra support. The charity model positions disabled individuals as passive victims who are dependent on the community, and society more generally, to provide services, care and support for them.10 The moral model views disabled people as being responsible in some way for their own disability because of past sins or deeds. All three models are increasingly criticised, particularly for minimising environmental and social considerations, and for disempowering disabled people. More recently, a social model of disability has emerged, which situates disability not in the individual, but in a society which is designed with non-disabled people in mind. All previous models were imposed onto disabled people, whereas the social model was developed by disabled people and marked a turning point in disabled people becoming political and gaining more agency.

The social model of disability emerged in 1976 with the publication of The Fundamental Principles of Disability by the Union of the Physically Impaired Against Segregation.11 As Halacre outlines, the social model:

… 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.7 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.12

The social model has opened up a space for some bold and innovative thinking, exemplified by Carol Thomas who coined the term ‘disablism’, as a replacement for the term ‘disability’, to foreground and emphasise the oppression and barriers faced by people with impairments:

Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.13, p75

Although the social model is a more empowering framework for disabled people, it has received criticism for downplaying the personal and psychological impact of disability and for its emphasis on individual empowerment, which is a Eurocentric, Western concept and which may not be compatible with the collective norms of many low-income and middle-income countries.10, 14 The limitations inherent in the social model has led to the development of a more holistic perspective called the expanded social model. This perspective provides a more balanced position where disability is neither purely medical nor purely social. Instead, disability is understood as being shaped and influenced by multiple factors (ie, physical, psychological, emotional) and as interacting with wider structural and environmental barriers (eg, attitudinal, social, political, institutional).15 All these factors combined can potentially inhibit disabled people from fully and equally participating in society, and, in some cases, adversely affect their well-being and psychological health.

Although therapists are increasingly using an expanded social model when working with disabled clients and moving away from medicalised models, the evidence cannot be ignored that points to disabled people experiencing greater mental and physical health challenges.
than the rest of the population, across all age groups. Specifically, disabled people have been found to present the poorest rating for well-being and quality of life across the wider population, leading to greater rates of anxiety and depression. This disparity is attributable to several factors, including psychosocial and biological factors, as well as limited social networks and structural discrimination. This situation is further compounded by disabled individuals reporting unmet mental health needs. While some research has examined the use of psychological therapies among disabled people, findings appear to be limited to certain disabled groups, particularly those with physical and intellectual disabilities.

Compared with other protected characteristics, there is a comparative dearth in the literature and research when it comes to disability/disabled populations and counselling/psychotherapy. More generally, the historical focus on medicalised models within counselling and healthcare has meant that disabled people have often been viewed through an ableist lens, which, in turn, has influenced how services for the disabled population are organised and delivered. It is not surprising, therefore, that disabled people are reported to experience inadequate access to support, aggravated by systemic barriers such as inappropriate delivery of services, poor referral processes, lack of specialist knowledge and inadequate social support. Research exploring issues of accessibility for disabled individuals has also mostly been limited to a focus on primary care services. Smith has shone a particular spotlight on the lack of research on the mental health experiences of disabled women accessing therapy or mental health support, resulting in an inadequate knowledge base and support system for this client group.

Some research has identified factors which potentially facilitate disabled individuals’ access to and use of therapeutic services, including specialist knowledge and practitioner confidence in working with this population. Artman and Daniels emphasise the importance of understanding the conceptual models of disability (covered above) as well as developing cultural competence when working with this client group. Cultural competency for therapists could, for example, include developing a deeper understanding both of the complexity of lived experience of disability and of the high prevalence of ‘internalised oppression/ableism’ among disabled people who often take on and identify with some of the negative messages an ableist society projects onto disabled people. Halacar describes several key issues that therapists should be familiar with and comfortable exploring when treating disabled clients, including but not limited to: (1) intersectional understanding and recognising that disabled people may belong to other marginalised groups such as the LGBTQIA+ and/or racially minoritised communities; (2) acknowledging and working with isolation in the lives of disabled people (eg, not able to leave home due to mobility or psychological isolation from inability to share inner thoughts with others); (3) navigating some disabled people’s reliance on third parties/dual relationships (eg, family members, carers, advocate for needs) and how this might impact on the delivery of therapy if third parties may have to be present in sessions; and (4) discussing issues linked to bodies, sex, intimacy and relationships, issues often ignored or minimised when it comes to treating disabled clients. Olkin has proposed a nine-point disability-affirmative therapy model, covering many of the above issues as well as disabled people’s experiences of micro aggressions, how disability affects a disabled client’s interactions with others (including family members) and a disabled client’s engagement (or lack of engagement) with wider disability culture and communities.

Counsellors and psychotherapists are, however, becoming aware of potential practice adaptations and training needs when working with disabled individuals. The British Psychological Society (BPS) has made recommendations on how to adapt therapeutic practice for disabled clients (eg, the use of simple language and visual material, where relevant) and issues around access for disabled people are gaining more attention including wheelchair access, but also wider recognition that missed sessions or cancellations for disabled clients could be linked to illness, fatigue and reliance on carers/public transport. More considered attention must be paid to ethical issues when working with disabled people, including clinical competence, guardianship/third parties, and appropriate assessment practices. Davies highlights ethical issues particularly in relation to those clients with learning difficulties, such as power dynamics in the therapy relationship, capacity to give informed consent and, if relevant, exploring the effects of past abuse/trauma.

**Study aims and rationale**

The main aim of the proposed scoping review is to systematically explore how disabled individuals perceive and experience counselling and psychotherapy, and to identify what barriers and facilitators they face when accessing therapeutic support. We define ‘barriers’ as any factor that has been shown to prevent or discourage disabled individuals from accessing interventions for their mental health challenges (eg, lack of resources, stigma, communication barriers, internalised prejudice, attitudinal barriers, institutional barriers, limited knowledge/training among therapists). ‘Facilitators’ refers to factors which are shown to support or promote positive outcomes and/or improve mental health (eg, specialist practitioner knowledge and/or experience of disability, using respectful language, supporting autonomous client choice). We opted for a scoping review as it is a methodology which suits broad and exploratory research questions. The review will aim to provide an evidence base on the issues facing disabled individuals accessing counselling and psychotherapy and will aim to highlight some practice implications for clinicians and make recommendations on how therapeutic practice can be adapted to meet the needs of this diverse but marginalised population.
and how therapists can ensure they do not discriminate against disabled clients wanting to access their services.

METHODS AND ANALYSIS
The proposed review will be guided by the methodological framework proposed by Arksey and O’Malley, which consists of six steps: (1) identifying the research question, (2) identifying relevant studies, (3) selection of eligible studies, (4) charting the data, (5) collating and summarising the results and (6) consultation and the inclusion of disabled people with lived experience. It should be noted that stage 6 will not be a discrete stage but will overlap with and inform stages 1–5.

Stage 1: identifying the research question
For this systematic scoping review, the overarching research question is: what barriers and enablers do disabled individuals perceive and experience when trying to access counselling and psychotherapy as well as during the therapeutic work itself? The review will aim to identify existing evidence on the barriers and facilitators to accessing counselling and psychotherapy for disabled people, and on what adaptations to therapeutic practice are needed to better support the mental health needs of disabled clients.

Stage 2: identifying relevant studies
Identification of studies relevant to this review will be achieved by searching electronic databases of the published literature, which will include: PsycINFO, CINAHL, EMBASE, EBSCO and Cochrane Library. Title, abstract and keyword fields will be searched using a combination of the following MeSH terms (audit* OR physic* OR cognit* OR intellect* OR visual OR neurodiver* OR pain OR autism*) AND (disab* OR impair* OR illness OR life limiting OR chronic) AND (therap* OR counsel* OR psychotherapy* OR psychological therap* OR treat- ment* OR evidence-based treatment*) AND (barrier* OR experienc* OR facilitat* OR percep* OR access* OR discrimat* OR distress). The reference lists of included studies will also be reviewed to identify additional relevant studies. Additional searches may be incorporated as the review progresses and any additions or changes will be documented. Some preliminary searches have already been conducted. The search strategy and the full search string we will use to search each database (with keywords and operators) can be found in online supplemental file 1.

Stage 3: study selection
Inclusion criteria
The selection process will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines and will be mapped using the PRISMA flow chart. Articles with extractable research data will be eligible for inclusion. All study designs—quantitative, qualitative and mixed method—will be considered. The review will only include papers written and/or published in the English language and published between 1 January 2010 and 31 December 2022. All papers must refer to counselling, psychotherapy or any other form of therapeutic intervention, include disabled individuals and/or individuals with an impairment, report disabled individuals’ perceptions and experiences of therapy, and/or report on factors that enable or inhibit therapy among disabled individuals. Where they exist, papers exploring practitioners’ perceptions and experiences of working with the disabled population might also be useful. Grey literature, book reviews and/or commentaries and book publications will be excluded as a means of keeping the scope of the search manageable.

Screening
The results of the literature searches will be exported and managed in Zotero, a reference management software. Duplicate references will be removed. All identified citations will be assessed by two reviewers using a predefined relevance criteria form (see Inclusion Criteria). The review process will consist of two levels of screening: (1) a title and abstract review and (2) full-text review. For the first level of screening, two researchers will screen article titles and abstracts and exclude those that do not meet the eligibility criteria. For those which fulfil the eligibility criteria, the full article will be retrieved. A third member of the team will screen retrieved articles to ensure a consistent application of the eligibility criteria for inclusion in the review. Titles and abstracts of the articles for which the two reviewers could not determine eligibility for inclusion will also be reviewed. Disagreements about study eligibility of the article will be discussed between the three reviewers until consensus is reached or by arbitration of a fourth reviewer. The authors will consolidate the results of the searches and will upload all eligible articles to Zotero. The process of study selection and the number of studies at each stage of the selection process will be reported using the PRISMA flow chart.

Stage 4: charting the data
For each of the included papers, study characteristics will be extracted and recorded in a summary table. For empirical research, this will include: (1) study characteristics, including year of study, study design, methodology and measures; (2) participant characteristics, including population type (ie, disability/impairment type) and other personal demographics (eg, gender, age); (3) therapy characteristics, such as therapeutic approach (eg, humanistic, psychodynamic), session duration etc; (4) findings relating to factors which act as barriers or facilitate access to therapy and (5) identified gaps in the literature. We will also extract relevant implications for practice, key issues and recommendations.

Stage 5: data summary and synthesis of results
The PRISMA-ScR checklist for scoping reviews will be used to guide the collating, summarising and reporting of
results. A descriptive numerical summary of the scoping review will be presented in the PRISMA flow diagram, including the number of papers screened, included and excluded at each stage. Data will be summarised quantitatively through descriptive numerical analysis and qualitatively through a narrative synthesis. As the aim of this review is to provide an overview of the main sources and types of evidence available and to identify key concepts and issues relevant to the research questions, we will not be conducting an assessment on the methodological quality of the included empirical studies.

Stage 6: consultation
We will coproduce this scoping review with a disabled counsellor and researcher whose current research involves exploring clients’ experience of working with disabled counsellors in chronic pain and seeks to investigate the impact disability has on both the therapeutic relationship and the counselling process. We will also continue to consult with the four disabled therapists/clients we consulted to develop this protocol (see below under the sections Patient and public involvement. We will ask them to comment on our processes in stages 1–5 to ensure that these are robust, and we will seek their advice and guidance on the eligibility of the final papers we will include in the scoping review. We will also ask them to review initial drafts for the scoping review paper, and in particular, gather their views on the findings and potential recommendations emerging from the full scoping review and whether these resonate and reflect the lived experience of disabled people. We will also reach out to several disability organisations such as: Scope, the disability equality charity in England and Wales; Disability Rights UK, which challenges policy-makers, institutions and individuals to remove the barriers that exist for disabled people; and other specialist third sector/community organisations such as the Royal National Institute for Deaf People or the Royal National Institute for Blind People. We hope through this wider consultation to access and consult with a broader, more representative range of people with disabilities.

Reflexivity statement
One of the authors (PL) involved in developing and writing this protocol identifies as a neurodivergent woman diagnosed with autism spectrum condition. She received her diagnosis initially at approximately age 4 and again at age 19 under the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV). She predominantly received mainstream schooling, however, with assistance from trained professionals. Phaedra has been receiving counselling/therapeutic/mental health support for 15 years, both privately and within National Health Service services (eg, out-patient community services) across varying modalities/approaches (eg, integrative, cognitive behavioural). She is currently a PhD student who is conducting autism research, and therefore, has experience conducting research among marginalised, under-represented communities. The other author (WF) does not identify as disabled or neurodiverse but is an ally and advocate for disabled people and has cared for an older sibling with autistic spectrum condition and learning difficulties. Wayne’s involvement in this project forms part of his role as lead researcher on Equality, diversity and Inclusion at the BACP. As an openly gay man, he has experienced barriers in accessing LGBTQIA+ sensitive therapy and supports reducing barriers to accessing culturally sensitive therapy for other marginalised and minority groups.

Patient and public involvement
In the development of this protocol, we collaborated with four disabled people, all of whom have lived or personal experience of participating in and delivering counselling, psychotherapy or mental health services and/or of living with/caring for someone else using similar services. These collaborators reviewed an initial draft of the protocol and provided feedback on the following questions: (1) Is the rationale behind wanting to do this scoping work clear and robust? (2) Have we cited the most relevant and appropriate literature/evidence in the introduction? (3) What are we missing in terms of our proposed search terms for the scoping review? (4) Can the research question(s) be tightened up/refined? (5) Is the use of language and terminology appropriate throughout the protocol? and (6) Is there anything else important you would like to comment on? All feedback has been incorporated into this protocol paper.

Although we have tried to encourage a participatory approach to the design and development of this protocol, we recognise that the disabled community is as diverse and heterogeneous as wider society, and that it is impossible for us to fully capture the breadth of experience and opinion within this client group. We recognise that impairments differ hugely between individuals and affect the lives of disabled people in specific and unique ways. We hope that the inclusion and involvement of Scope, Disability Rights UK and other specialist disability organisations in the next stages will lead to more representative feedback and input from the disabled community on the full scoping review.

ETHICS AND DISSEMINATION
As this scoping review is intended to synthesise existing data, ethical approval is not required. The results of this scoping review will be disseminated through publication in a peer-reviewed journal.

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REFERENCES


10 Al Ju'beh K. Disability inclusive development toolkit. CBM. 2015.


34 Artman LK, Daniels JA. Disability and psychotherapy practice: cultural competence and practical tips. Professional Psychology: Research and Practice 2010;41:442–8.


42 Davies N. Equality, diversity and inclusion in the counselling professions. British Association for Counsellors and Psychotherapists (BACP), 2020.


