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Exploring the general trends in disability research: concepts and methods

Absztrakt

Disability Studies constitute a matrix of theories, pedagogies, and practices. Over the years, Disability Studies have undergone a series of adjustments in terms of definition, research output, methods, concepts, and theories. How disability is conceptualized not only differs across countries but also within a country with evolving legal, political, and social discourses. In this article, semi-systematic literature review is used to give a general historical overview of some of the trends in disability research. A thematic analysis found some common themes that define trends in disability research, including the definition and theoretical models of disability, disability language, methods and approaches to disability research, sources of data, disability research output, transdisciplinarity and heterogeneity in disability research, research funding, and the controversy surrounding the question: by whom, with whom and for whom should disability research be conducted? A brief discussion on the emerging trends is presented.

Key words: models of disability, disability language, methods, funding, emancipatory research, research output, transdisciplinarity and heterogeneity

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1. Introduction

1.1. Background of the study

Disability is part of the human condition, which may be experienced by anyone at some point in life, especially by those who live to old age (WHO and World Bank, 2011). Responses to disability are evolving as policies instituted by various nations and organizations shift towards community and educational inclusion (WHO and World Bank, 2011). Medically focussed solutions are giving way to more interactive approaches which recognise that people with disabilities face challenges due to environmental factors, as well as bodily impairments (WHO and World Bank, 2011). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) which has been ratified by most countries across the globe, is in the forefront in spearheading this evolution since 2006 (UN, 2006).

According to a WHO and World Bank (2011) report, more than 1 billion people live with disabilities, representing about 15% of the world's population. But disability is not evenly distributed across the world, as about 88% of people with disabilities live in the world's poorest countries (Gillian, 2014). Demographic, socioeconomic, and medical trends have direct links to rising numbers of people with disabilities, with aging, poverty, improved survival across a wide spectrum of diseases due to medical advances, identified as some of the indicators (Feldman & Aunos, 2020). In addition, pieces of legislation by some governments expand the disability spectrum, for example, the Americans with Disability Act (ADA) defines disability as a physical or mental impairment that limits one or more major life activities (Feldman & Aunos, 2020). The interpretation of this definition considers discriminatory decisions based on stereotypes rather than on actual limitations as part of disability, thus, it brings more people into the disability spectrum. As the issues around disability evolve, so does disability research.

Disability Studies as an academic discipline examines the nature, meaning, and consequences of disability (Society for Disability Studies, n.d.). As such, it is a multidisciplinary field steered by global perspectives of disability, learning from other contexts and cultures, and intersected by the sciences, social sciences, and humanities (Society for Disability Studies, n.d.). The focus of Disability Studies is the medical, political, and social constructs surrounding disability, with an aim of enhancing civil rights and improving the quality of life of individuals with disabilities (Schalk, 2022). It is believed that the concept of Disability Studies was born in the



1970s out of protests and self-advocacy of ordinary people, scholars with disabilities and those who are non-disabled, with the aim of conceptualising and interpreting the common complaints of people with disabilities and their families (Shapiro, 1993).

It may not be possible to locate the exact time of the beginning of Disability Studies as a distinct field of academic scholarship, however, some scholars trace its beginnings to 1982 (Ferguson & Nusbaum, 2012). But even before then, there were isolated cases of individual researchers and even entire programs which helped create the foundation for Disability Studies as a distinct academic field with different approaches to the study of both the concepts and the experiences of disability (Ferguson & Nusbaum, 2012). Since then, Disability Studies have grown exponentially extending beyond their origin in the social sciences into the fields of history, humanities, and arts (Garland-Thomson, 2002). Disability Studies recognize disability as a key aspect of the human experience with important political, social, and economic implications. Through research, Disability Studies seek to enhance the understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of people with disabilities, and to advocate for social change (Society for Disability Studies, n.d.).



1.2. Purpose of the study

It is important to map out the trajectory and influence of disability research since its formative stages. Accordingly, this study explores some of the trends in disability research with a focus on concepts, methods and approaches, the growth of disability research as a distinct discipline, the extent of interactions between disability research and other disciplines, and the factors which influence the interactions. Our aim is for the findings of this study to contribute to opening new possibilities in disability research within the framework of its conceptual, theoretical, and methodological approaches, and to open new opportunities for possible collaborations, not only between the developed and global south countries, but also between the subjects of research and the researchers.

1.3. Research questions

The study aims to address the following research questions:

- i) How has disability research evolved as a distinct discipline of academic scholarship, and to what extent has disability research grown beyond its origin in the social sciences?
- ii) How have the theoretical models of disability influenced the methods and approaches to disability research?
- iii) Is there a common language we can use to refer to people with disabilities?
- iv) By whom, with whom, and for whom should disability research be conducted?
- v) How has research funding influenced the growth and development of disability research?

2. Methods

This study was conducted between September, 2022 and July, 2023. The study employed a semi-systematic (narrative) literature review to analyze some of the trends in disability research. A semi-systematic review was preferred for this study because it is an approach that enables a researcher to detect common issues within a specific research discipline (Ward et al., 2009). The inclusion criteria used in this study were that the articles must have been published in peer-reviewed English journals from around 1980 to 2023, and the articles must be related to Disability Studies or disability research. The year 1980 is of significance since it is around this time that Disability Studies are thought to have been conceptualised as a distinct academic field (Ferguson & Nusbaum, 2012).

The database search was conducted using the search engines Google search, Google scholar, Bing, and ERIC. The search engines were preferred for this study because they allow searching for scholarly literature from one place; exploring related works, citations, authors, and publications; locating complete documents through the library or on the web; keeping up with recent developments in a particular area of research; and they are especially useful when searching for information across disciplines, in grey literature, including conference proceedings, and for multiple types of documents, such as articles and books (PUL, 2024). Physical sources of related literature were also reviewed, including books, journal articles, and conference proceedings obtained from the ELTE Eötvös Loránd University library.

The specific descriptor words and phrases used were *disability research*, *Disability Studies*, *trends in disability research*, *trends in Disability Studies*, *general trends in disability research/studies*, *global trends in disability research/studies*, *world trends in disability research/studies*, *issues in disability research/studies*. First, the selection of articles by reviewing titles and abstracts yielded over 100 articles, but further selection by reviewing full texts produced 69 articles. The articles were then re-read and categorized using thematic analysis. Thematic analysis is used in this study because of its strengths in identifying, analyzing, and reporting patterns in the form of themes (Braun & Clarke, 2006).

3. Results

The thematic analysis found some common themes which define the trends in disability research, including definitions and theoretical models of disability, disability language, methods and approaches to disability research, sources of data, disability research output, transdisciplinarity and heterogeneity in disability research, research funding, and the controversy surrounding the question of by whom, with whom, and for whom should disability research be conducted. The following section provides a brief discussion on the findings.

3.1. Definitions and theoretical models of disability

Disability Studies constitute a matrix of theories, pedagogies, and practices (Garland-Thomson, 2002). Over the years, Disability Studies have undergone a series of adjustments in terms of definition, research output, methods, concepts, and theories, but one main problem persists: disability is defined differently for different purposes, thus, there is no consistent overview of disability among populations, or of the implications for disability policies (Les, 2003). Disability definitions not only differ across countries, but also within a country with evolving legal, political, and social discourses. Singal (2010) notes that disability is a relative term because various cultures define their norms of 'being' and 'doing' differently. In most dialects there is no single word that translates into the English word *disability*. For example, the Kiswahili word *wasiojiweza* commonly used in Kenya to refer to persons living with disabilities embodies an assumption that the individual is incapable of gainful employment (Ndurumo, 2003).

The moral and medical models are some of the oldest models of disability (Goodley, 2011). The moral model, which is heavily influenced by religious doctrines, views disability as a product of sin, hence under this model, people with disabilities are referred to by using terms such as *moron*, *cripple*, *imbecilic* (Goodley, 2011). According to UN (2021), such terms are considered derogatory and unacceptable since they portray disability as an inferior and a pitiful status. In the 19th century, the medical (individual) model, in which disability is viewed not as a moral matter but as a medical problem, came to prominence (Dunn & Andrews, 2015). The medical model sees disability as a disadvantage experienced by an individual because of an impairment (Fisher & Goodley, 2007). According to medical theory, disability is caused by impairment and the solution is to cure the impairment (Gillian, 2014). Barnes (2004) reported that up until the 1990s disability was conceived in terms of rehabilitation, medicine, psychology, special educational needs, and social work. Opponents of the medical model argue that it fails to link the problems faced by people with disabilities to the social and physical or built environment. Davis (1997) explains that disability is situated within the larger social context, while impairment is a biological condition. Gillian (2014) argues that medicine makes promises it cannot keep, fails to cure the problem of disability, and creates dependency, denies individuals the use of their own self-care strategies, and may create side-effects and unforeseen complications.

The social model of disability, which emerged from disability activism in the 1970s in the United Kingdom (Schalk, 2022), attempts to address some of the weaknesses of the medical model, hence defines disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have impairments, and thus excludes them from participation in the mainstream of social activities (Barnes, 2004). The social model works to shift focus away from the body to the social structures and policies that people with disabilities perceive as impediments (Fisher, 2007). Thus, disability is primarily a social issue resulting from the refusal of society to accommodate and include people with disabilities (Schalk, 2022). In Britain, as observed by Watson et al. (2019), a social barrier approach has directed Disability Studies, thus, the social model remains the new idea of the British people with disabilities' movement. Barnes and Mercer (2005)



noted that the significance of disability theory and practice lies in its radical challenge to the medical or individual model of disability. As such, social model scholars refuse to look at disability as people's impairments, but as social, economic, cultural, political, rational, and psychological barriers that cause the exclusion of people with disabilities (Sherry, 2016).

The perspectives of the social model scholars acknowledge impairment but politicise disability, thus, disability is understood as an act of exclusion by contemporary society (Sherry, 2016). According to Barnes (2004), the social model is a paradigm leap offering a new vision in Disability Studies and providing a platform on which other theories are developed. The social model of disability has not only shaped the direction of research in Disability Studies, but also informed the policy formulation by most governments. Oliver's (2013) study reported that policies and practices developed by people with disabilities' movements and Disability Studies influence mainstream policy development in many countries. Shakespeare's (2013) study observed that the social model has informed disability policy developments in the European Union, the United Nations, the World Health Organization (WHO), the World Trade Organization, and the World Bank, as seen in their policies which increasingly tend to portray the concept of disability as a social construct. In contrast, Marks (1999) argues that the social model marginalises personal experiences of impairment, hence contributes to the maintenance of the individualistic and decontextualised perspective of the medical model. In addition, the social model has been criticised by many activists as being too academic, offering no practical solutions (Vehmas & Mietola, 2021).

The human rights model of disability, which is a progression of the social model, emphasizes the importance of the social determinants of disability and of upholding rights as an evaluation mechanism of equity (Shakespeare et al., 2009). The human rights model of disability addresses the marginalization of people with disabilities through the formulation of social and political policies (Barnes, 2003). The experiential citizenship model of disability is founded on social and human rights models of disability; however, it goes beyond the structural environment and legislative boundaries of both models by centralizing and utilizing the experience of acceptance, membership, inclusion, safety, and shared power as more precise measures of structural justice (Barnes & Sheldon, 2010).

The differing philosophies stemming from the disability models herein and from others, have led to controversy in the field of disability, with medical model proponents on one end of the spectrum, and proponents of social and minority models on the other end (Evans, 2004). The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) model attempts to bridge this opposition by coming up with a comprehensive biopsychosocial approach which integrates the strengths of the two main opposing models, the medical and the social models (WHO, 2001). The ICF attempts to provide a coherent view of different perspectives of health from biological, individual, and social perspectives, hence differentiates among disability, health, and functioning (WHO, 2001, p. 20). According to the ICF model, impairment is an anomaly, defect, loss, or it is constituted by other significant deviations in body structures from certain generally accepted population standards in the biomedical status of the body and its functions, and these are not considered as problems, but are just expressions of a health condition which does



not necessarily indicate that a disease is present or that the individual should be regarded as sick (WHO, 2001, pp. 12–13).

Activity limitations are difficulties an individual may have in executing certain activities (WHO, 2001, p. 14), for example, the inability to walk, problems with learning and trouble with communication among others, which may or may not get improved by assistive devices and environmental modifications. Participation restrictions are problems an individual may experience during involvement in life situations (WHO, 2001, p. 14), such as attending school, maintaining gainful employment, pursuing relationships among others. The term *participation restriction* is considered as a replacement to *handicap* in terms of life activities and roles. In the earlier 1980 ICF model, a handicap resided in the person (WHO, 1980), hence the common phrase *he is handicapped*, however, this is corrected in the 2001 ICF model which emphasises the role of the social and physical environments in either restricting or enabling participation (WHO, 2001).

In addition, the ICF incorporates the contextual factors which include environmental and personal factors that define the complete background of an individual's life and living (WHO, 2001, p. 16). The environmental factors are the physical, social, and attitudinal environments in which people live and conduct their lives. These factors are external to individuals and can have a positive or negative influence on their performance, capacity to execute actions and tasks, and on the individual's body function or structure (WHO, 2001, p. 16). Personal factors are the background of an individual's life and living which comprise features of the individual that are not parts of a health condition or status, and include race, gender, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education level, profession, past and current experience, overall behaviour patterns and character style, individual psychological assets among others, all or any of which may play a role in an individual's disability at any level (WHO, 2001, p. 17).

The ICF model therefore puts forward a better understanding of the dynamic nature of impairments and activity limitations, since its focus on the experiences of the individual is broadened by the accounts of medical and physical aspects of disability and the personal, social, and environmental factors. Therefore, under the ICF model, the term *disability* is used to describe impairments, activity limitations and participation restrictions of an individual. Despite the progress, Oliver's (2013) study reported that there is a great deal of concern that the original radical element of the social model theory has become diluted by the purported improvements by the subsequent theories. In addition, Shakespeare (2013) observed that disability remains an enigma; debates around definitions of disability, the role of impairment, and how best to theorise disability abound.

3.2. Disability language

The language that we use to refer to persons with disabilities has an impact, as it shapes our perception of the world. This language has evolved over time, and terms that were commonly used some years back are no longer acceptable. Inappropriate language can make people feel excluded or offended, and can be a barrier to full and meaningful participation (UN, 2021). The use of derogatory or

inappropriate language may amount to discrimination and infringes on the enjoyment of human rights (UN, 2021). Using language that is respectful, appropriate and that celebrates diversity plays a vital role in protecting disability rights and creates a more inclusive society (UN, 2021). The words and phrases used to describe or to refer to disability raise important questions. How should people with disabilities be respectfully and inclusively referred to in daily discourse? How can disability be meaningfully and appropriately presented in writing? Should people be referred to by their disabilities or independently of the disabilities? (Dunn & Andrews, 2015). Such questions underscore the importance of language in interpreting, understanding, and appreciating disability and the people living with disabilities.

The American Psychological Association [APA] (2012) advocates for the use, for example, using phrases such as *people with disabilities*, *a person with an amputation* among others to refer to individuals with disabilities in daily discourse and to reduce bias in psychological writing. But disability culture advocates and Disability Studies scholars challenge the exclusive use of person-first approach and advocate for the use of identity-first language, for example, *disabled people*, *amputee*, among others to characterise and refer to people with disabilities (Dunn & Andrews, 2015). The APA (2012) acknowledges that some organizations and people with disabilities prefer the identity-first approach, but insists that the person-first language is most appropriate. They argue that the person-first perspective is the most constructive way to counter negative and ambivalent attitudes toward people with disabilities by shifting them in positive directions, toward openness and understanding.

The person-first language is anchored in the social model of disability which shifts the problem away from the individual, impairments, and services by focusing on physical and social barriers, including attitudinal issues, such as prejudice and discrimination, which prevent people with disabilities from full participation in society. Wright (1983) applied the social model to object to language that dehumanizes people with disabilities. She argued that emphasis should be placed on the person, hence the person must always come first, and not his or her disability. As such, the reference should be, for example, *a person with a disability* and not a *disabled person*. Therefore, according to Wright (1983), person-first language puts emphasis on the person and not the impairment, and is thus believed to preserve the humanity of the people with disabilities while promoting their individuality. An individual's life experiences with a disability may differ significantly from that of another person with the same disability, thus, the focus on the person and not the disabling condition (impairment) is the most important (Dunn & Andrews, 2015). A human characteristic, whether favourable or unfavourable, should never be used to refer to an individual to the extent that it overshadows all the other characteristics.

In addition, monolithic terms should not be used to refer to people with disabilities. For example, terms such as *tetraplegic*, *amputee* among others should not be used because they objectify the person by focusing only on the impairment (Dunn & Andrews, 2015; UN, 2021). Such objectifying language is likened to segregating people by race, ethnicity, religion, and other labels that ignore individuality and promote stereotyping (Dunn & Andrews, 2015). Further, objectifying language promotes essentialism where people are viewed primarily by their disabilities and are perceived to be victims of such disabilities, for example, *stroke victim*, *epilepsy victim* among others, thereby creating an impression that a person with a disability is

suffering and has lost control over his or her life (Dunn & Andrews, 2015). Disability therefore becomes the essential aspect of one's identity so that one's personality, abilities, interests, and other personal qualities become subordinate and rarely a point of focus.

In contrast, outside psychology there is a growing movement of resistance to the universal use of the person-first language approach arising from the disability rights community and the academic field of Disability Studies (Davis, 2013; Goodley, 2011). Most disability scholars and activists promote an identity-first language approach, where disability becomes the focus (Davis, 2013; Goodley, 2011). Brueggemann (2013) argues that the identity-first language approach allows the individual or a group to accept the disability as a fact and reconfigure it as a point of pride. In addition, he explains that accepting and claiming disability promotes autonomy, agency, and indicates a decision to exercise choice and control over one's disability destiny. Goodley (2011) observes that some scholars within the disability culture prefer alternating the person-first language with the identity-first language, hence, for example, allow the use of *disabled people* or *disabled for people with disability*. Thus, from this perspective, one is not just a *person with an amputation* but rather an *amputated person* or an *amputee*.

The identity-first language approach is anchored in the minority (diversity) model of disability which portrays disability as either neutral or positive and a natural human attribute, not a medical problem or a representation of moral failing (Olkin & Pledger, 2003).

The minority model asserts that disability is a distinct and diverse cultural and socio-political experience, just like other demographic characteristics, such as race, gender, and sexual orientations, hence should be celebrated as part of one's identity and not overlooked, since it is an individual difference which occurs within the spectrum of human diversity (Andrews et al., 2013). The minority model considers "ableism" which is a prejudicial attitude and discriminatory behaviour favouring non-disabled people as the major impediment in the lives of people with disabilities, hence the model is a disability activist counter-response to the historical oppression and marginalisation of people with disabilities (Prilleltensky & Gonick, 1996). Accordingly, the concept of identity-first language is a means of counteracting the perceived oppression and marginalisation of people with disabilities, since it construes disability as a function of social and political experiences within an environment largely designed for non-disabled people. As such, emphasis is on disability and not on the person.

Disability activists and scholars who advocate for an identity-first approach discredit the exclusive use of the person-first approach by arguing that it subtly implies that there is something inherently negative about disability and that the use of the phrase *with a disability* unnecessarily dissociates the disability from the individual, with a consequence of promoting the view that disability is undesirable, thereby making it difficult to describe a positive disability identity (Dunn & Andrews, 2015).

According to the ICF model, the language that non-disabled people use to refer to disability and people with disabilities constitutes an environmental factor that is often attitudinal or even institutional, and that preference for person-first or identity-first language by people with disabilities is a personal choice (WHO, 2001). As such, both person-first and identity-first language is accommodated within the ICF model, thereby attempting to reconcile the opposition between proponents of either person-



first or identity-first language. Despite these developments, challenges in language use remain, affecting lay-people, professionals, and people with disabilities. Bickford's (2004) study conducted among persons who are visually impaired, observed that 37% of individuals had no language preference, while 76% of those who had language preference expressed satisfaction with identity-first language. However, in another study, 60% of respondents preferred the phrase *person with disability* over *disabled person*, implying that they prefer the person-first language approach, while another 26% had no preference (Lynch et al., 1994). Further, Rottenstein's (2014) survey conducted among people with disabilities reported that 70% of the respondents would like to be described as *person with disability*, 8% prefer *disabled person*, *non-disabled person* is preferred by 3%, while *able-bodied person* is a preference of 6% of the respondents. This survey could be conceptualised to mean that people with disabilities have a preference to person-first language. The contradictory findings could imply that the language question has not been settled.

Some scholars within the disability culture recommend alternating person-first with identity-first language, arguing that this flexibility acknowledges the roles and perspectives of both people with disabilities (insiders) and non-disabled people (outsiders) (Goodley, 2011). Others suggest that writers should use the term *Disabled* (with a capital *D*) to signify allegiance to disability culture instead of describing impairments (Gill, 1995). The Society for Disability Studies (n.d.) affirms that every individual with a disability has a right to choose the terminology that best represents their view, purpose, and identity. In addition, they recognise that identity-first and person-first language are both valid forms of reflecting one's personal preference and situated disability experience.

According to UN (2021), people-first language is the most widely accepted language for referring to persons with disabilities and is the language used in the *Convention on the Rights of Persons with Disabilities*. This preference is based on its emphasis on the person or group and not on disability. For example, *children with albinism*, *students with dyslexia*, *women with intellectual disabilities*. However, UN (2021) notes that there are some exceptions to this rule, as the identity-first rule may apply to other types of disabilities. For instance, when referring to persons who are blind, we can say either *blind persons* or *persons who are blind*, and the same applies to deaf or deafblind persons. In addition, UN (2021) cautions that if in doubt about the language to use with reference to disability, you should ask the person or group how they choose to identify, since persons with disabilities are not a homogeneous group, and they may self-identify in various ways. As Sándor et al. (2023) indicate, their preference for identity-first language was informed by the opinion of their disabled colleagues. As such, the identities should be respected and recognized. However, UN (2021) acknowledges that the rich diversity of identities may hinder efforts to establish a unified terminology.

Some expressions have gained popularity over time as alternatives to other terms considered inappropriate, however, many of them reflect the misguided idea that disability needs to be softened. For example, we should not use terms such as *differently abled*, *people of all abilities*, *disAbility* or *people of determination*, as they are all euphemistic and can be considered patronizing and offensive (UN, 2021). For instance, *differently abled* is problematic because all human beings are considered differently abled. Therefore, euphemisms are a denial of reality and a way to avoid

talking about disabilities (UN, 2021). Table 1 illustrates the terminologies that are commonly used and accepted.

TABLE 1. *DISABILITY-INCLUSIVE LANGUAGE GUIDELINES (SOURCE: UN, 2021)*

Recommended language	Language to be avoided
Person with disability Person with [type of impairment] Persons with disabilities People with disabilities (only in Easy Read documents, informal text, and oral speech)	Disabled person, handicapped, person with special needs, handicapable, atypical, person living with a disability, differently abled, people of all abilities, people of determination, person living with a disability
Person without disability The rest of the population	Normal, healthy, able-bodied, typical, whole, sound body/mind
Have [disability/impairment/condition]	Suffer from, afflicted by, stricken by, troubled with
Person with an intellectual disability Person with an intellectual impairment	Retarded, simple, slow, afflicted, brain-damaged, intellectually challenged, subnormal, of unsound mind, feeble-minded, mentally handicapped
Person with a psychosocial disability	Insane, crazy, maniac, psycho, hypersensitive, lunatic, demented, panicked, agitated, mentally deranged, mentally ill
Deaf person Person who is deaf Person with a hearing disability Person with a hearing impairment Person with hearing loss Hard-of-hearing person Deafblind person	The deaf, Hearing impaired and dumb, Deaf and mute
Blind person Person who is blind Person with a vision/visual disability Person with a vision/visual impairment Person with low vision Deafblind person	The blind, Partially-sighted
Person with a physical disability Person with a physical impairment	Crippled, invalid, deformed, lame, handicapped, physically challenged, person with physical limitations, limp
Wheelchair user Person who uses a Wheelchair Person with a mobility disability Person with a mobility impairment Person using a mobility device	Confined/restricted to a wheelchair, Wheelchair-bound
Person of short stature Little person Person with achondroplasia (only if the person has this condition)	Midget, Dwarf, Stunted
Person with Down syndrome Person with trisomy-21	Mongoloid, special person, Down
Person with albinism	Albino
Person affected by leprosy	Leper, Leprosy patient
Person who uses a communication device Person who uses an alternative method of communication	Non-verbal, can't talk
Accessible parking/Parking reserved for persons with disabilities. Accessible bathroom	Disabled/handicapped parking. Handicapped bathroom



Clearly, the language used to define and describe disability has evolved and is still evolving globally as various English-speaking nations adopt their preferences. For example, *disabled people* is predominantly used in the United Kingdom, *people living with disabilities* is a preference in the USA, *people with learning difficulties* is preferred in Britain, *people with developmental disabilities* in Australia, *people with intellectual disabilities*, in contrast to the previously used *the mentally retarded* or *mentally handicapped*, is preferred in North America (Feldman & Aunos, 2020).

Empowerment as a civic concept of citizenship emphasises the rights and duties of citizens (Osborne, 1994). Thus, inappropriate language could be an agent of disempowerment. Accordingly, disability researchers should desist from inappropriate language which facilitates elite researcher control and separates them from the people with disabilities who are the subjects of their research (Truman, et al., 1999).

Inappropriate language therefore goes against the tenets of emancipatory research which rests on the empowerment of research participants in all aspects of a study, including sharing decisions about the aims, methods, and conclusions (Truman, et al., 1999). Whatever the preferred language, all disability study scholars and researchers share an interest in using language that is culturally sensitive, recognises humanity and does not demean the people with disabilities (Feldman & Aunos, 2020).

3.3. *By whom, with whom, and for whom should disability research be conducted?*

Disability research is increasingly becoming popular, but questions are still being asked about by whom, with whom and for whom should the Disability Studies research be carried out? "What is the place of non-disabled scholars in disability research?" (Shakespeare et al., 2018). A significant challenge that any new research is supposed to address is how it could contribute to knowledge building, assist in critiquing the existing status quo and the extent to which it could influence changes in policies and practices. Therefore research, especially the researches focusing on disability should be driven by a belief that engages with the central question of "who will benefit from this research?" (Singal, 2010). Researchers with disabilities continue to embrace the contribution of non-disabled researchers. In Britain, Duckett and Fryer (1998) report that non-disabled people have been conditionally welcomed into the disability research fold. Schalk (2022) acknowledges the significant contributions non-disabled scholars continue to make in the field of disability justice. However, she advises that the expertise and leadership of people with disabilities should be prioritised.

Linton (1998) indicates that the medical model, which historically shaped research on disability, was often conducted by non-disabled people, and this could be contributing to some deficient understandings attributed to the medical model. He also noted that the majority of scholarship on disability either utilises or implies the third person plural *they*. For example, phrases such as *they do this*, *they are like that*, *they need such and such*, he explains contribute to the objection of people with disabilities and affirm their experience of alienation. In addition, Vehmas and

Mietola (2021) noted that Nordic relational models were heavily influenced by non-disabled academicians. However, Davis (1995) is dismissive of the imperative of being a person with a disability to be a disability researcher. Linton (1998) argues that it is important for non-disabled scholars to pay attention to issues of their identity, their own privilege as non-disabled people, and the relationship of these factors to their scholarship.

Barnes (2003) argues that researchers must work with disability organisations to develop user-led research with and for people with disabilities, thus enhancing the 'catalytic validity' of research. Shakespeare et al. (2018) argued that while they remain accountable to many of the aims of people with disabilities and their organisations, research can be academic by developing theories that can be used by those with emancipatory visions. Fernando et al. (2014) noted that emancipatory research requires profound reflection on how to involve people with disability in the definition and execution of the research, the methods used and the ways in which the results may contribute to social change. Whenever possible, scholarly work in the field of disability conducted by non-disabled researchers should adhere to an emancipatory stance, as researchers work with participants as co-researchers rather than as "subjects" (Connor, 2009). Oliver and Barnes (1998) assert that unless researchers work with people with disabilities towards their goals and ambitions, it will fail to be anything more than being an academic endeavour. Kitchin (2000) articulates a need for inclusive, action-based research strategies where people with disabilities are involved as consultants and partners not just as research subjects. However, he noted a few arguments in favour of an exclusive approach where disability research would be conducted solely by researchers with disabilities.

Halász (2022) explains that the interpretation of research impact as "the effective use of evidence produced by researchers" has brought controversies especially in the education sector. He noted that such controversies could be minimised if researchers put emphasis on mutual learning and co-creation of knowledge, where researchers use knowledge to support practitioners with challenging practical issues instead of producing context free evidence. The interpretation of Halász' (2022) idea is that to enhance research impact in Disability Studies cooperation between researchers and the people with disability is inevitable. This interpretation underscores the importance of emancipatory research which has an explicit concern in ending inequality and taking the side of the oppressed and marginalised groups, such as the people with disabilities (Truman, et al., 1999). Sándor et al. (2023), in their 'We teach together' method, chose to refer to the disabled participants as co-instructors or participatory co-instructors since they were careful to avoid reinforcing existing power dynamics which in most cases reduces the participation of people with disabilities to mere 'presence.' Accordingly, the collaborative and interactive methods recommended in emancipatory research oppose the distancing and objectifying strategies which disempower people with disabilities (Truman, et al., 1999).

3.4. Methods and approaches

Barnes (2004) explains that how you study disability depends on how you define good research, on the kind of questions you ask and the methods you use. He

acknowledges that while certain aspects of the obstacles to the participation of people with disabilities may be accessible to measurement, for example, physical access, other issues, such as 'prejudice,' are not, hence he calls for methodologies with meaning-making processes of everyday life. Brockley (1999) noted that behind any question of method is the question of priority, either to assess the social conditions of disablism or to measure the impacts of impairment. Alternative models of disability posed by Disability Studies have brought with them contrasting approaches to disability research. Theorists of the relational model study the fit between impairment and environment, cultural theorists question the ideology in the constitution of the disablism culture, while social model thinkers demand changes to the structural exclusion of the people with disabilities (Sherry, 2016). Abberley (1987) is against the framing of questions based on individualistic conceptions of disability, instead he advocates for framing questions based on the social model of disability.

Fernando et al. (2014) reported that 80% of the studies they reviewed were empirical studies, the rest (20%) were theoretical contributions. They noted that most of the empirical studies were quantitative (66%), almost a third were qualitative (30.9%) and the mixed methods approach with a tendency to triangulate quantitative and qualitative data was at 5.9%. In addition, they indicated that qualitative studies are increasingly gaining prominence in emancipatory research since they offer more opportunities to establish power-sharing between the researcher and the subject of the research, as opposed to a subject-object duality. Further, they observed that semi-structured interviews are the most widely used to gather qualitative data because they create room for discussion and validation by the interviewees. Although qualitative data and methodologies dominate emancipatory research, a consensus appears to be emerging on the use of a variety of research methodologies, types of data and data analysis techniques (Barnes, 2003).

According to Singal (2010), disability research, especially in global south countries, is largely dominated by quantitative analysis. She observes that there is a need for more qualitative approaches which would provide a wealth of data on the experiences of people with disabilities rather than aggregated classifications, categories, and characteristics of a disability phenomenon. She argues that in absence of such information, research remains inadequate and lifeless. Abberley (1987) stresses the importance of using a range of qualitative and quantitative methodologies as a means of capturing different aspects of oppression and social exclusion experienced by people with disabilities. Skrtic (1995) argued that the depth of understanding across the fields requires both macroscopic and microscopic units of analysis, as well as a breadth of research methodology from qualitative to quantitative. He asserted that a comprehensive application of research methods moves the field beyond considering a problem or describing a population to developing theories and interventions that can be implemented at a scale to improve outcomes.

Kitchin's (2000) study sought to find out how the people with disabilities view research and how they would want it to be conducted. The findings reveal that people with disabilities strongly support qualitative methods, especially open-ended interviews, since the methods provide them with opportunities to express and contextualize their feelings. There is a growing emphasis on the involvement of people with disabilities in the research process. People with disabilities should not be seen just as suppliers of information, but the focus should be to involve them in making

sense of the information produced by using their 'insider expertise' (Singal, 2010). As such, the use of participatory approaches should be a significant phenomenon in disability research. Participatory approaches are primarily anchored in the qualitative research tradition, with a focus on meaning, interpretation and giving the participants 'a right of voice' (Singal, 2010). The focus is on listening to the research participants, who are the real experts in knowing their situation (Helander & People, 1993). Thus, the role of a researcher is to get involved in a learning process from and within the locality. As such, the researcher acts as a means to facilitate the greater involvement of people with disabilities in the research process (Turmusani, 2004).

Oliver (1998) argues that any epistemology for a disability research practice should reject the discourse that sustains investigatory research, and replace it with a discourse of emancipation. In addition, Oliver (2002) advocates for the emancipatory approach to disability research, explaining that the ultimate control should be given to research subjects and that the research process and its products should be accessible to the participants. The fundamental principles shaping the emancipatory approach resonate closely with the issues in disability research, including poverty and disability citizenship, where questions, such as who participates in the research, how are the participants involved in the research, and what is the best way of allowing the voices of the research participants to be heard, are central (Bennet & Roberts, 2004). Bennet and Roberts (2004) emphasise that research not abiding to this tradition is likely to be regarded as unworthy. According to Stone and Priestley (1996), emancipatory research is strongly anchored in the social model of disability and is regarded as part of the struggle of people with disabilities to control the decision-making processes that shape their lives and to achieve full citizenship.

In contrast, Stone and Priestley (1996) also cast doubt on the universality of emancipatory approach, explaining that in methodological terms, emancipatory research focuses on political issues with no sufficient regard for practical considerations, hence its relevance could be challenged in the southern context where the struggles of people with disabilities revolve around daily survival rather than political emancipation. However, they emphasise that within the existing contextual realities, emancipatory approach should not hinder non-disabled researchers from being facilitators in disability research since it is their right to help make the lives of people with disabilities better. Oliver (1992), however, raises the issue of the limitations of this preoccupation with methodology, arguing that the commitment of a researcher is more decisive than the methodologies and techniques used. For Shakespeare and Watson (1997), researchers can lead research so long as they keep in mind that the aim of disability research is theorising and tackling the disabling society.

Demographic information of research respondents remains a thorny issue with most studies reporting scanty demographic information of their respondents. Oakley's (2003) study observes that many studies might have been well conducted, but this could not be surmised from the published papers because applicability and generalizability were limited by scant information about research samples. In addition, Faggella-Luby et al. (2014) observe that populations are identified in general terms, such as post-secondary students with disabilities, with no specific demographic or categorical identification.

3.5. Sources of data in disability research

Bredberg (1999) explains that primary sources of information on people with disabilities were used to reveal the rich historical fabric of the diverse varied existence of people with disabilities. Over the years research on disability has witnessed a decline in primary knowledge production. Scheerenberger (1983) asserts that published historical accounts mainly describe formal services and treatment approaches from the standpoint of professionals. He notes that institutional perspectives have often eclipsed the perspectives of persons with disabilities. The reliance on professional records has reflected and legitimised professional behaviour (Hirsch, 1995). Jackson's (1998) study reports that historians have tended to rely on the public records of residential institutions while largely ignoring the lay perspectives towards disability. Brockley (1999) indicates that the utilisation of primary sources of evidence is extremely limited in the literature, especially for the periods towards the end of the nineteenth century. Bredberg (1999) observes that while he was writing a disability history, he was forced to mostly use secondary sources.

Research involving parents of children with disabilities is on the rise and forms part of the secondary data. Efforts in disability research are restricted by the undue reliance on perspectives of parents and significant others, such as siblings and teachers of people with disabilities, and not engaging them directly to listen to their voices (Singal, 2010). Thus, there is a significant gap of research evidence that would capture the thoughts, feelings, and perspectives of people with disabilities. Feldman and Aunos (2020) report that research on assessment practices involving parents of children with intellectual and developmental disabilities suggests that the system is fraught with bias and invalid methods.

The credibility of secondary data sources has therefore been put to question despite their rising popularity. Jurado-Caraballo et al. (2022) indicate that the most common source of information involves the use of secondary data extracted from national public surveys (31.9%) and databases (25%). This, they note, is because most countries do not have specific registers or surveys dedicated to workers with disabilities and because of the lack of homogeneous global data. The findings are supported by Gibbons et al. (1994) reporting a shift from primary production of data and ideas to their configurations. In contrast, some journal reviews reveal a balanced use of primary and secondary sources of information. Faggella-Luby et al. (2014) examined methodological trends in disability research articles published in the *Journal of Post-secondary Education and Disability* (JPED) in the interval 1983–2012. They reported that 54.4% were original data (data from primary source). This finding is supported by Carter's (2013) review of disability research, which reported 55.6% of original data.

3.6. Disability research output

There is a tremendous increase in research articles in the field of disability, but this is not evidenced in prominent journals. Dwertmann and Boehm (2016) observe that most research articles in the field of disability have not been published in high-quality research media. Jurado-Caraballo et al. (2022) analysed trends in research articles published in respected journals between 1991 and 2017. Figure 1, which is part of their report, describes the quantitative evolution and the structure of literature in disability research.

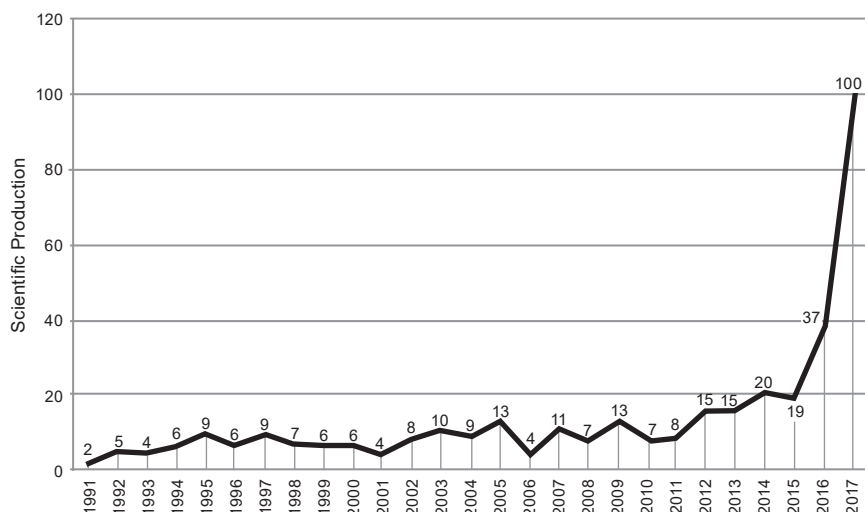


FIGURE 1. *THE ANNUAL TOTAL NUMBER OF ARTICLES ON DISABILITY AND WORK PER YEAR FOR THE PERIOD 1991–2017 (SOURCE: JURADO-CARABALLO ET AL., 2022)*

The findings show a progressive increase in research output, reaching the highest production level in 2017. They suggested that this increase could be due to an increase in the number of studies of high quality. The findings echo those of Faggella-Luby et al. (2014) which reported that both the number and percentage of data-based articles in the *JPED* have increased over its thirty-year history. They explain that this increase could be an indication that the journal's editorial leadership may be increasingly prioritizing the publication of data-based articles. The increase in the output of research articles is evidence of a continuous evolution of research on people with disabilities.

3.7. Transdisciplinarity and heterogeneity in disability research

Several scholars have pointed out the necessity of combining diverse approaches and findings from multiple disciplines to study complex and multifaceted social issues (Kessel & Rosenfield, 2008). Issues related to disability interface with many fields and operate at multiple levels. As such, solutions to disability problems call for informed perspectives from multiple backgrounds that the perspectives of disability as a discipline might not be able to provide (Bruyere et al., 2016). Accordingly, to effectively deal with emerging issues in disability, researchers need to think across disciplines, thereby viewing disability research as a transdisciplinary space which breaks boundaries between disciplines (Thomas, 2007).

Wickson et al. (2006) identify the main features of transdisciplinary research as evolving methodology, problem focus, and collaboration. For Pohl (2011), transdisciplinary research is not so much focused on the evolution of knowledge in a particular disciplinary field, but rather a comprehensive and multi-perspective

approach focused on a better understanding of the real-world problems. Still, other researchers see transdisciplinary research as the inclusion of non-academics, and a focus on the problem and not on individual disciplines. This perspective implies that no individual discipline has intellectual precedence over the others, and the role of researchers is to open up their approaches to creative ways of applying their perspectives to new ways of thinking (Bruyere et al., 2016).

The transdisciplinary approach creates in-roads into disciplines that have historically marginalised people with disabilities, such as medical sociology, philosophy, and psychology. Watson et al. (2019) observe that disability research has developed and moved its links beyond its original disciplinary basis in sociology and social policy. Marks (1999) reported that from the 1990s, British Disability Studies and research grew and enjoyed disciplinary residencies in sociology, social policy, and education. Watson et al. (2019) indicate that researchers increasingly work across disciplines such as social sciences and humanities. Across the world, disability researchers have developed ways of presenting global knowledge within a local context that respects the rights of people with disabilities (Watson et al., 2019). For example, Meekosha's (2004) work in Australia combined both Anglocentric social model analyses of class with North American cultural studies of colonial settler communities. Drawing from the literature across the social sciences, including economics, political science, psychology, Disability Studies, law, and sociology, Schur et al. (2013) focused on ways in which people with disabilities have historically been excluded from full participation in the community and economic life, thereby acknowledging the importance of transdisciplinary research.

Jurado-Caraballo et al. (2022) reported on the interdisciplinary nature of the disability field. Their findings show that disability research is gradually shifting from a disciplinary approach to a transdisciplinary approach, as disability related research gets published in journals of varied disciplines. Shakespeare (2013) observes that Disability Studies are undergoing a paradigm bust, subverting the normative tendencies of academic disciplines, testing respected research encounters and challenging theoretical formation. Ferguson and Nusbaum (2012) assert that if disability is truly social and foundational, then our efforts to understand the experiences and concepts behind disability must cut across traditional academic disciplines, hence Disability Studies must be as broad as the study of culture.

Schalk's (2022) study takes a broad interdisciplinary approach that uses disability as a method rather than an object-oriented area of study that focuses exclusively on the lives of people with disabilities and on representations of disability. In her approach, Disability Studies are conceptualised as a politicised approach to research that entails critical exploration of how disability operates historically, ideologically, materially, and socially in our world as a social system. Her expansive understanding of disability requires engagement not only with Disability Studies, but also with health sciences, medical humanities, and the history of science and medicine, as this would better the theorization and response to disability from the political and social positions (Schalk, 2022). This is a significant positive trend since transdisciplinary knowledge is not set within a particular discipline but cuts across disciplines in the context of application. Gibbons et al. (1994) explain that working in the application context creates pressure to draw from a diverse array of knowledge resources and to configure them according to the problem in mind.

It is evident from the findings that research in Disability Studies has evolved and is now characterised by a flow of knowledge across disciplinary boundaries. Many Disability Studies scholars see this trend as a move in the right direction, since it not only destabilises the perceived dominance of special education and rehabilitation sciences, but also provides an avenue for general education experts and experts from other diverse disciplines to interact with special education experts (Ferguson & Nusbaum, 2012). However, transdisciplinarity in Disability Studies can only flourish if the orientation and insights it creates are available to all parts of the academy (Ferguson and Nusbaum, 2012).

Heterogenous growth is characterised by an increase in the number of sites where knowledge can be created. Gibbons et al. (1994) refers to heterogenous growth as a process of differentiation and diffusion through which the arrangement of component elements takes place within a given process or set of activities. There is very little evidence of heterogeneous growth in disability research since most disability research is still institutionalised in universities. Fernando et al. (2014), in their study in Portugal reported that most research on disability is centralised in universities. They recommend that universities and funding institutions should be more open to alternative forms of knowledge and to the involvement of subjects who possess this alternative knowledge, and that they should provide time for broader discussions that focus on linking these forms of knowledge. Jurado-Caraballo et al. (2022) reported on individual institutions' contribution to disability work. The findings show that out of 25 institutions, 24 universities and 1 research institute produced at least three publications in the *Journal of Post-secondary Education and Disability* (JPED) for the period 1991–2017. This represents 32.6% of the total number of published articles in the period of their study. The fact that only one research institute managed to produce at least three disability research articles, underscores the dominance of universities in disability research.

3.8. Funding of disability research

The distribution of research output is related to the economic status of governments and the extent of collaboration between research institutions. Jurado-Caraballo et al. (2022) observe that developed countries ranked high in disability related research publications. They noted that the United States of America produced the highest number of publications at 44.2%, followed by the United Kingdom (10.8%), Canada (8.6%), Australia (6.9%), Spain and the Netherlands (both with 4.2%), and Sweden (3.1%). India is the only country which stood out among the developing countries at 1.9% of total publications. It is worth noting that no institution from Africa made it to the top 25 universities. Murray and Chen's (1992) study reported that disability assessments in developing country populations are extremely rare and are likely to contain serious biases and limitations compared to greater control in developed countries. Their observations could provide an explanation to the discrepancies in the findings of Jurado-Caraballo et al. (2022) which indicate a poor show in publications by global south countries. Enough funding is therefore an important aspect of research; hence countries need to collaborate as this would lower the cost of research due to shared responsibilities (Gibbons et al., 1994). Watson et al.

(2019) agree that the articles published by the developing country institutions were collaborations with institutions from high-income countries, usually American and European countries.

4. Conclusion

This study has unearthed some fundamental trends in disability research worth emphasising. The definitions of disability and the accompanying theoretical models still show controversy and a lack of congruence. As such, disability remains an enigma, and debates around the definition of disability and how to best theorise disability continue to evolve.

Language shapes perception, therefore using inappropriate language to refer to people with disabilities could be a barrier to full and meaningful participation, hence an agent of disempowerment. Consequently, there has been a desire to establish a unified language that is culturally sensitive, recognises humanity, and harbours respect to the people with disabilities. However, the rich diversity of disability identities has hindered the efforts to establish such a common language.

Disability scholars continue to express different views concerning emancipatory research. However, there seems to be a common understanding that unless disability researchers work closely with people with disabilities, their research findings will not be anything more than an academic endeavour. The focus should be on listening to the voices of people with disabilities since they are the experts of their situations.

Collaboration in research reduces unhealthy competition, hence improves the quality and output of research. Accordingly, a critical mass of trained researchers on disability needs to be built, research skills should be strengthened in a range of disciplines linking universities in developing countries with those in high-income and middle-income countries.

Despite the controversies, disability research continues to develop in ways that attempt to accommodate the aspirations of all the people with disabilities. The medical, social, cultural, and relational models of disability continue to provide philosophical and political backgrounds from which several social theories and forms of activism can be developed. Accordingly, Disability Studies and research occupy an area in which social theories of disability and impairment can be developed to promote inclusion of all the people with disabilities in the mainstream society.



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