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DISABILITY, REPRESENTATION AND TRANSLATION: HOW CAN SOCIOLOGY MOVE BEYOND THE SOCIAL MODEL?

The aim of this article is to propose a new conceptual tool and an inspiration for sociological analysis of disability as an alternative to the predominant social model. It first discusses the social model and argues that in spite of its numerous merits it may be regarded as a manifestation of sociological reductionism of the actual complexity of disability. The notions of representation and translation are then contrasted, the former being the core of the social constructionist accounts and the latter being deeply rooted in a post-constructivist perspective of actor-network theory. Next, examples of translation, related to data visualization, disability simulation technologies and disability certification schemas are presented and discussed, emphasizing the action possibilities they enable by this impacting both the situation of people with disabilities and policy-making processes. Finally, it is argued that sociology could engage in not only the examination but also the development of translational tools, which could be an important and welcome contribution of the discipline to disability policies.

Keywords: disability, social model of disability, translation, actor-network theory

INTRODUCTION

This article stems from two main concerns. First, it draws on the premise that the mainstream sociological accounts of disability, culminating in the so-called 'social model of disability', although in many ways successful, may be also viewed as inherently reductionist and generally insufficient, both theoretically and practically. Second, it is concerned with the role of sociology as a discipline developing conceptual tools that may be utilized in actions and polices towards disability. These concerns allow to ask whether sociology can move beyond reductionist accounts to offer fresher ways to understand disability and provide input to policy-making. The article explores such a possibility.

It starts from outlining the social model of disability, now a predominant framework for sociological reflection and policy measures. Then, it discusses the model's weaknesses

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related to the actual complexity of disability, the practical necessity to reduce that complexity, and the consequences of such a move. In the next step, the paper contrasts the notion of representation, which is foundational for the social constructionist accounts and the social model, with the concept of translation, as it has been proposed within actor-network theory. It then offers a set of illustrations to show how the concept of translation may indeed impact the actions towards disability. Finally, it is argued that sociology could engage in examination and even development of existing and new forms of translation to move beyond the social model in theorizing and by this provide valuable practical input into policies and actions aimed at disability.

SOCIOLOGY AND DISABILITY: THE SOCIAL MODEL

The contemporary sociological understanding of disability is commonly regarded as having been developed in opposition to both understanding disability in medical terms and early sociological conceptualizations. The so-called 'medical' (also labelled as 'individual') model of disability emerged in the Western world along with scientific and medical progress as a replacement for traditional and religious perceptions (divine punishment, moral failing) (Shakespeare 2010: 266; Haegele and Hodge 2016). It assumed disability to be situated within an individual and her physical, sensory and intellectual impairments (French and Swain 2012). In this view, the sources of disability were attributed to disease process or individual tragedy, and efforts were directed towards normalization by 'fixing' the individual (her impaired body or mind), while 'those who may not want to be fixed are considered noncompliant and unmotivated' (Haegele and Hodge 2016: 195). Although embedded mostly in medical discourse, this account was also supported by the influential sociological framework proposed by Talcott Parsons in his functionalist analysis of sickness as social deviance controlled by medical professions (Barnes and Mercer 2010; Barnes 2012; Parsons 2009).

The medical model, now treated as an outdated approach, has been replaced by the social model of disability, stemming from the activists' debates dating back to the 1970s and 1980s (Shakespeare 2010). This approach is based upon the fundamental conceptual distinction between 'impairment' (physical, mental or intellectual restriction or malfunction) and 'disability' understood as 'disadvantage or activity caused by a contemporary social organization' (Union of Physically... 1975), excluding people with impairments from the mainstream of society. In this view disability is perceived as resulting not from the individual's impairment but from environmental and social barriers which impose limitations on people with disabilities and impede their inclusion. Importantly, the social model does not neglect the reality of impairment, but 'breaks the traditional causal link between impairment and disability' (Barnes and Mercer 2010: 30), strongly suggesting that corrective actions should be directed at society – as imposing external restrictions – not at the individual. It is also argued that it is possible to arrange the material and social environment in such a way that impairment would not substantially reduce the quality of life (Haegele and Hodge 2016).

The social model encompasses a range of theoretical and empirical studies focusing on different kinds of barriers – material, environmental, structural, institutional and attitudinal. Undoubtedly, some of them are related to the social perceptions of disability (Dewsbury et al. 2004), stemming from the old cultural bias dating back to Ancient Greece and Rome and the Judeo-Christian tradition. The domination of the non-disabled experience in culture is labelled as 'ableism', which is regarded as a form of discrimination favouring the able-bodied (Linton 2010). The symbolic discrimination of disability has a number of forms and aspects. The very term 'disability' is conventionally treated as something well-defined and concrete, as well as a strong marker of personal and group identity (ibid.). Impairments are commonly regarded as causal sources of disability and it is assumed that people with disabilities are victims of tragic circumstances who must adapt to the environment with the help of medical services (Oliver and Barnes 2012). Those who succeed are symbolically rewarded and those who fail 'are referred to as passive, apathetic or worse' (Barnes 2010: 30). 'Overcoming' disability is treated as a desirable aim, and the responsibility for such a 'success' is attributed to the individual, while at the same time stereotypes and language convey the perception of people with disabilities as 'more dependent, childlike, passive, sensitive, and miserable and [...] less competent than people who do not have disabilities' (Linton 2010: 232). In popular culture people with disabilities are typically portrayed as 'more than or less than humans, rarely as ordinary people doing ordinary things' (Oliver 1990: 61). Importantly, although there has been a growing recognition of the cultural representations of disability in recent decades, the dominant normalizing, media-friendly images which violate the actual experience of people with disabilities are still prevalent (Oliver and Barner 2012). The consequences of this situation are manifold, and they are not limited to undermining of self-worth and formation of identities around disabilities or attributing power to medical authorities, but also to the development of a wide range of institutional discriminatory practices upon this conceptual framework (Dewsbury et al. 2004: 148).

Undoubtedly, the social model, including the diagnosis of the discursive positioning of disability, has many advantages. It has been politically effective by shifting debates on disability and generating an agenda for social change (French and Swain 2012). It has also been useful as a practical instrument placing the moral responsibility on social oppression and exclusion, and in improving the self-esteem of people with disabilities (Shakespeare 2010). It has also, however, been a target of considerable criticism. One of the key arguments touches on the very distinction between impairment and disability which lies at the heart of the social model, arguing that it fails to reflect the experiences of individuals with disabilities (Haegele and Hodge 2016). It has also been argued that such a sharp distinction between the impact of impairment and the impact of disability is difficult to draw in practice (Shakespeare 2010). Moreover, the social model was criticized as failing to acknowledge the intersectionality of different forms of oppression as well as the differences between the situations of particular people with disabilities (Haegele and Hodge 2016). Another argument points out that what the social model proposes is in fact a utopia, while in reality many forms of impairments will practically remain disadvantageous to some extent. Thus it is argued that 'barrier free enclaves are possible, but not a barrier free world' (Shakespeare 2010: 271).

SOCIOLOGY AND DISABILITY: REDUCING THE COMPLEXITY

It seems, however, also possible to question the social model from the perspective of social theory. As the model locates 'the disabled person within the rhetoric of the socio-political framework in which disability is *socially constructed*' (Gewsbury et al. 2004: 146), it inevitably assumes a social constructionist position. Therefore, although it is undoubtedly radical in shifting the approach towards disability, the social model also inherits the weaknesses of social constructionism. Theorists of this orientation have been particularly successful in questioning the naturalist accounts, yet less so in defining where social constructionism begins and ends, or how thick the 'layer' of social construction is. Even if we adopt a weak version of social constructivism, the abovementioned problems in differentiating impairment from disability clearly show that drawing a sharp line between a material (physical) dysfunction and the way it is socially constructed is at best difficult. Last but definitely not least, although the social model is definitely liberating (on the individual and social levels) it is argued that people with disabilities found it as 'pertaining to part of their lives only' (Gewsbury et al. 2004: 152).

Therefore, it seems justifiable to regard the social constructionist perspective as resulting in a form of sociological reductionism. It is especially evident when the complexity and diversity of disability is fully taken into account. If we start from health conditions they may be 'visible or invisible; temporary or long term; static, episodic, or degenerating; painful or inconsequential' (WHO 2011: 8). Persons with disabilities differ in terms of gender, age, socioeconomic factors, sexuality, and ethnicity. They also have different lifestyles, habits, educations, professions, experiences, personalities, psychological characteristics and behaviour patterns. They live within different material environments, have access to varied facilities, technologies and services, and are geographically dispersed. They are included in different formal and informal social networks and are also subject to diverse legal regulations, ideologies and approaches. Thus, disability as a phenomenon can be described as 'complex, dynamic, multidimensional, and contested' (WHO 2011: 3; see also Wójtowicz-Pomierna 2010), while sociological accounts seem to reduce this complexity to social factors.

The acknowledgment of the complexity and diversity of disability has led to formulations in scientific and expert debates that move beyond the social model – one of them being WHO's definition of disability as a bio-psycho-social phenomenon (WHO 2011: 4) which seems a challenge to the social constructionist perspective on disability. At the same time, the difficulties faced by sociology in trying to offer non-reductionist, but theoretically coherent accounts seem to be rooted in some of the discipline's theoretical dilemmas, of which that of the dichotomy between naturalism and anti-naturalism seems to be the most important. The question then arises: can sociology progress further and go beyond the social model and its theoretical limitations in understanding disability?

REPRESENTATION AND TRANSLATION

In trying to answer this question I will draw on actor-network theory (ANT), treating this approach as a source of sensitizing concepts (Blumer 1954), rather than adhering to the whole set of its assumptions and vocabulary. It seems both unnecessary and impossible to

offer here any detailed account of actor-network theory as such (numerous sources offering this kind of explanation already exist). Instead, I will utilize only one of the ANT terms – that of translation – arguing that it differs from the notion of representation (fundamental for the social constructionist approach) and exploring some theoretical and practical consequences of applying it in developing a new understanding of disability and possible plans of action.

For the social constructionist perspective, which – as I argued above – may be regarded as a foundation of the social model of disability, the concept of *representation* is of crucial importance. It assumes that: (1) reality is represented in systems of meaning; (2) language and other systems of meaning are of social origin (not natural or objective); and (3) these determine our perception of reality and by this also our actions. Upon these assumptions discourse analysis is founded as a scientifically legitimized way to inquire into cultural representations of reality and is directed towards revealing the way reality is represented, how meaning emerges and is conditioned by and supportive of the social relations of power. The general aim of this endeavour is the increased consciousness of oppression and – as a result – a greater possibility of empowerment.

The notion of representation can now be contrasted with the concept of *translation*, one of the central terms within actor-network theory, developed primarily in studies on the production and application of scientific knowledge. As Bruno Latour (1999) shows, production of knowledge is a process in which the reality which is researched is translated into different objects. For example, to research a tropical forest scientists take samples, transport them to laboratories, turn them into preparations, subject them to laboratory testing, develop diagrams and charts showing their results, propose concepts and models, and finally write and publish scientific papers. This process, according to ANT theorists, is a chain of successive translations which simultaneously preserves the continuity of the object which is translated, but also involves some inconsistency and displacement (Callon 1984; Callon and Latour 1981; Law 2006). Translation often involves ontological 'shifts' in which an object is translated into another object of a different substance (e.g. a material tropical forest into immaterial numbers). Finally, it is important that translation is typically done with the help of some technological instruments ('inscription devices' as ANT calls them), like computers, machines etc.

Translation is clearly a broader term than representation (representation may be seen as a form of translation), but what is even more important is that the notion of translation explicitly acknowledges the relationship between material and immaterial objects as fundamental. It then stands in strong contrast with the notion of representation, which addresses reality only as represented in systems of meaning, thus foregrounding the conceptual and immaterial aspects and inevitably slipping into reductionism. The notion of translation, in turn, does not privilege any substance, but deliberately explores the way in which the material and immaterial are intertwined.

Another important difference is that the concept of representation assumes the fundamental role of the epistemological question of how reality is represented in discourse, which is often answered by arguing that reality is distorted in its symbolic representations and that such distortions sustain the existing distribution of power, inequality and discrimination. Translation, on the other hand, shifts our interest onto the ontological question – how does reality come into being? It may be well-illustrated by Annemarie Mol's study of atherosclerosis

(Mol 2002). In this work, deeply inspired by the actor-network theory approach, Mol is not focused on how the illness and the bodies of patients are socially constructed or how medical knowledge dominates in the discourse. Instead, she foregrounds the socio-material practices in which the body is 'done': talked about in an outpatient clinic, represented in numbers after angiography, cut in surgical rooms, and examined with a doctor's hands or through the lenses of a microscope. In this view, the body ceases to be a well-defined material entity (as it is treated in conventional wisdom), but at the same time it is not reduced to a symbolic representation (as in the social constructionists' accounts). Instead, it is shown as something multiple, enacted in the course of practices.

Even more important, regarding the aims of this article, is yet another difference between the notions of representation and translation. The former assumes that discourse has an effect on reality by shaping our perceptions and understandings, and by this also our actions. In this view, perception and understanding presuppose action. The notion of translation, however, assumes that the primordial feature of translation is enabling action. Translations are definitely not just transformations of symbolic meaning (which is perhaps somewhat confusingly suggested by the linguistic connotation of the term), but rather processes which result in the appearance of new action possibilities. For example, Latour (1983, 1987) shows how compasses, sextants and maps helped empires to visualize lands and exert power over conquered terrains, and how moving anthrax microbes from cattle farms to Pasteur's laboratory enabled testing and experimentation leading to the invention of a vaccine. The notion of translations, then, moves our interest from perception and representation of reality in discourse, to examining the forms of action it enables.

TRANSLATIONS OF DISABILITY

My central argument is that sociology can move beyond the reductionism inherent in the social model by moving from analysing the social construction of disability and its representations in discourse to examining translation of disability and the action possibilities they facilitate or constrain. In what follows I will provide a few examples to illustrate the possibility of such explorations.

GRAPHS

The process of measuring a phenomenon and representing it in numbers, diagrams and charts seems to lie at the very heart of scientific and expert practice – this is the legitimate way of inquiry and communication of its results. Nonetheless, my argument is that these processes are essentially translations of reality involving, by definition, both continuity and displacement, and granting us certain action possibilities. If we, for example, look at global disability prevalence estimates shown on a graph in *World Disability Report* published by WHO (2011: 31)[1], we can see a set of solid bars representing the average prevalence of

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[1] http://www.who.int/disabilities/world_report/2011/report.pdf.

disability according to different sources (World Health Survey, the Global Burden of Disease and other surveys) with the range lines indicating the 10th and 90th percentiles. The graph is divided into sections representing high-, middle-, low-income countries and the 'world'. It offers a clear picture indeed – the complexity of disability, of which we are extensively informed in the previous pages of the report, is now reduced to the solidity of bars and their sharp contours. As there are differences in the height of the bars, which are far higher in the group of middle- and low-income countries, the meaning conveyed is that 'there is an urgent need for more robust, comparable, and complete data collection' (WHO 2011). Importantly, such a recommendation is enabled by translation of disability as a real phenomenon, with all its embodied, mental and environmental aspects, into solid grey and blue bars showing different measures and income groups. It is the reduction and management of the complexity of disability, a betrayal of its real-life character, that makes statistics powerful by facilitating certain action possibilities: drawing a conclusion of a need for better measurement – a recommendation that may (should) potentially be implemented.

The limitations of access to reliable disability data has been recognized as one of the reasons for policy failures (Gąciarz, Kubicki and Rudnicki 2014; Kubicki 2017). We may, however, also approach the problem of data usage from a different perspective, if we allow a little experimentation and tinkering with translations. One of the possibilities is to resign from the ostensible solidity of bar charts and switch to the elusiveness of hand-drawn visualizations with shaky lines deliberately exposing the uncertainty of measurement (Chalabi 2017). This strategy is in contrast with a tendency to present data, especially in tables, often with decimal places which suggest the unrealistic accuracy of data, meeting the expectation of them as being results of some 'objective science'. A comprehensive report consistently using this approach could potentially not only reach a wide audience but also have an impact on our relationship with disability data. Another interesting effect may be obtained by 'unpacking' the clarity of averages by showing different distributions that may lie behind them (Chalabi 2017). Although it is not entirely clear what the results of the wider application of this approach would be, it seems justified to assume that a report on disability that would consistently present distributions not averages and show how results vary by categories (e.g. 'types' of disability) could be useful not only in education but also in decision-making processes.

PERSONAS

A different effect may be also obtained by using a form of visualization of disability other than charts and graphs – personas. These are heuristic tools, commonly used in so-called user-centred design and user experience design to stimulate empathetic thinking and guide the design process. Personas are prepared as human profiles (consisting of name, face and story) representing typical users with their goals, attitudes, values and frustrations. Although fictitious, they are preferably made after a user research phase of design process as composite models but also 'as human as possible to further enhance the sense that this is a real person with a messy life and quirky ways of coping with recognizable human situations' (Buley 2013: 132). In essence, they visualize data that are critical to the design process using storytelling to provoke emotional and humanistic understanding (Goodwin 2009). An example

of a persona used in the process of designing a version of a real estate website for people with disabilities shows the difference between the use of graphs and personas in visualizing data[2]. Instead of presenting an individual as just a wheelchair-bound woman in her forties (thus a representative of a certain category), the persona shows a context of a person's functioning using real-life details – a picture of a person, a story of her being a service worker in a grocery shop, living alone in a rented apartment far from her work place and needing a web application with functionalities allowing her to easily narrow down search results. Even such a relatively simple persona enables more empathetic understanding than would tables and graphs, and again it would be an interesting experiment to see a report on disability using personas as the dominant way of presenting data, and as a tool for developing more down-to-earth recommendations and solutions.

SIMULATIONS OF EXPERIENCE

Another way of translating disability may be facilitated by technologies that are intended to simulate the experiences of persons with disabilities. Such tools come in many different forms, and some of them are relatively popular, like wheelchair experience or blindness simulation exercises. Importantly, they may be developed as both high-tech Virtual or Augmented Reality devices that mimic the range of symptoms (even some symptoms of schizophrenia, depression or migraine (Couch 2016)) and low-tech on-the-spot arrangements (like wearing five pairs of latex gloves and trying to peel an orange to mimic the experience of elderly people with reduced flexibility of fingers (Schmieden, ns.)). Some of them are marketable products or are used to promote products developed with their help (like Blum's Age Explorer® full body suit simulating limitations of movement, sight, touch and hearing for testing kitchen furniture hinges, lift systems and related solutions[3]). Undoubtedly, such tools should not be mistaken as 'faithful' translations simulating the whole experience of impairment, not to mention its psychological or social effects. They do, however, seem effective in prompting the empathetic understanding believed to be essential in designing products (IDEO 2015), including those for people with disabilities. Although they may appear useful, mainly with regard to either industrial design or as ways to increase disability awareness in society, it may also be possible to use them when working with disability data, to provide deeper and more empathetic understanding. When combined with other heuristic tools such as empathy maps or customer journey maps (IDEO 2015), they may be also useful in public service design or even in drafting institutional regulations and disability policies.

CERTIFICATION

Assessment and certification of disability is of crucial importance, as it is the only way to secure official recognition of disability and become legally entitled to benefits or other forms of institutional support (which, by the way, may be regarded as a form of discrimination (Waszkielewicz 2008)). The deficiencies of institutional systems certifying disability have been

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[2] http://sonalsrivastavaux.com/portfolio-item/user-research-ux-design-front-end-development/.
[3] https://www.blum.com/us/en/03/30/10/.

highlighted in a number of studies (Bartkowski 2014; Gąciarz, Kubicki and Rudnicki 2014; Golinowska, Sowa and Wilmowska-Pietruszyńska 2012; Kubicki 2017) and there is definitely not enough space here to discuss them in detail. What should be highlighted, however, is the critical character of certification of disability (as a condition for receiving institutional support) as well as its inevitably reductionist logic – the experience of disability, with all its complexities, dynamics and intersections becomes reduced to an official certificate specifying the kind and severity of dysfunction.

The certification process is clearly an example of translation reflecting the practical domination of the medical model in the process of assigning to an individual a certain degree of decreased ability to work (see also Meershoek, Krumeich and Vos 2007; Mladenov 2011). While there is a growing importance of disability classification schemes that are sensitive not only to bodily functions but also to real-life activities of a person and her participation in social life and encompass the environmental and psychological aspects (of which probably the most influential is the International Classification of Functioning, Disability and Health[4]), there is also a concern that more inclusive schemes will result in greater financial burdens and social problems. One of the consequences may be that the task of reconciliation of these diverse criteria may be delegated to physicians and committees conducting assessment procedures in practice. However, it has been shown that equipping doctors with explicit criteria and formal procedures, intended to provide objectivity and transparency to the process, will actually 'make the assessment process even more arbitrary because objectifying procedures covers up the contextual reasoning and normative dimension of the evaluations' (Meershoek, Krumeich and Vos 2007). We may be then facing a necessity to develop assessment and certification procedures involving qualitative aspects and allowing the expression of dilemmas in peer review, intra-professional audits and stakeholders' consultations (Meershoek, Krumeich and Vos 2007). This task calls for development and examination of yet more ways of translation of disability – instruments and procedures of assessment that could work as practical interfaces allowing communication between the reality of disability and the reality of the institutional system. This task remains a challenge and would most probably require not only acknowledging the complexity of disability but also the complexity of institutional systems with all their human, expert, legal and mechanical aspects.

CONCLUSION: THE ALTERNATIVE ROLE OF SOCIOLOGY

The article started by showing the social model as an important contribution of sociology to disability debates, but also an inevitably reductionist account. Then, I contrasted the notions of representation and translation to propose the latter as a conceptual tool for understanding the way disability becomes articulated in different ways which are inevitably 'unfaithful' to its complexity and diversity, but also open up certain action possibilities. Then, a brief exploration of some mainstream, niche and postulated translations of disability was proposed to show their omnipresence and practical importance for understanding and actions towards disability.

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[4] https://www.icf-research-branch.org/index.php.

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My final argument concerns a role of sociology which may not be limited to the description and theoretical examination of the translation processes but also encompasses active participation in the development of new translations of disability. In this proposal I draw on the notion of 'socio-technics' as proposed by Łukasz Afeltowicz and Krzysztof Pietrowicz (2013). In contrast to the popular positivistic meaning of 'sociotechnics', they argue that sociology may mirror the natural sciences not in its alleged objectivity but in its ability to tinker with objects in laboratories and in its orientation to both practical and theoretical aims. It is my contention that sociology may move beyond the social constructionist account and its limitations by engagement in exploration of new possibilities of translation of disability by experimenting with new conceptual and material tools like measurements, visualisations, simulations and certification schemes. Exposing both their 'betrayal' of the real-life complexity of disability but also the action possibilities they offer may provide useful input into policy-making processes. Although it would require different forms of engagement that are only analytical (most probably related to hands-on development and experimentation with new translations), it may be an important way in which sociology could expand from participation in the debates to actually working out solutions.

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NIEPEŁNOSPRAWNOŚĆ, REPREZENTACJA I TRANSLACJA:
JAK SOCJOLOGIA MOŻE WYJŚĆ POZA MODEL SPOŁECZNY NIEPEŁNOSPRAWNOŚCI?

Celem tego artykułu jest zaproponowanie nowych narzędzi pojęciowych do socjologicznych analiz niepełnosprawności, alternatywnych wobec tzw. społecznego modelu tego zjawiska. Artykuł rozpoczyna się od krytyki modelu społecznego, który mimo wielu zalet może być uznany za przykład socjologicznego redukcjonizmu złożoności zjawiska niepełnosprawności. Następnie przeciwstawione są pojęcia "reprezentacja" i "translacja" jako zakorzenione w – odpowiednio – w społecznym konstruktywizmie i postkontruktywistycznym nurcie teoretycznym nazywanym teorią aktora-sieci. W dalszej części przedstawione i przedyskutowane są przykłady rezultatów procesów translacji związane z wizualizacją danych, technikami symulacji doświadczenia niepełnosprawności oraz orzecznictwem niepełnosprawności; podkreślony zostaje także ich wpływ na sytuację osób z niepełnosprawnościami i polityki publiczne. Artykuł kończy się zachętą dla socjologii nie tylko do analizowania, ale także twórczego rozwijania narzędzi translacyjnych, które mogłyby stać się ważnym i pożądanym wkładem tej dyscypliny do tworzenia polityk społecznych wobec niepełnosprawności.

Słowa kluczowe: niepełnosprawność, społeczny model niepełnosprawności, translacja, teoria aktora-sieci