

DEBATE

FAIR OPPORTUNITIES, SOCIAL PRODUCTIVITY AND WELLBEING IN DISABILITY: TOWARDS A THEORETICAL FOUNDATION

Johannes Siegrist, PhD¹ and Christine Fekete, PhD²

From the ¹Centre for Health and Society, Faculty of Medicine, University of Dusseldorf, Dusseldorf, Germany and ²Swiss Paraplegic Research, Guido A. Zäch Institute, Nottwil, Switzerland

Background: Theory-based approaches provide explanations of the impact of components of the International Classification of Functioning, Disability and Health (ICF) classification on outcomes such as health and wellbeing.

Methods: Here, one such approach is proposed, focusing on social participation and its association with wellbeing. In addition to elaborating a theoretical approach, a narrative review of research on labour market participation of persons with severe disability, spinal cord injury, is conducted to illustrate the utility of the proposed approach. Availability and good quality of productive activities, in particular paid work, are expected to improve wellbeing by strengthening favourable experiences of personal control and social recognition. As these opportunities are restricted among persons with disabilities, conditions that enable full social participation need to be strengthened.

Results: Research identified several such conditions at the individual (e.g. coping, social support, educational skills) and the contextual socio-political level (e.g. quality of care, medical and vocational rehabilitation), although their potential of improving wellbeing has not yet been sufficiently explored.

Discussion: In conclusion, supplementing the established ICF classification by theory-based approaches may advance explanations of adverse effects of reduced functioning and wellbeing in disability. This new knowledge can guide the development of interventions to improve participation in general and social productivity in particular.

Key words: International Classification of Functioning, Disability and Health; social participation; return to work; wellbeing; spinal cord injury; personal control; social recognition.

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Correspondence address: Johannes Siegrist, Centre for Health and Society, Faculty of Medicine, University of Dusseldorf, Dusseldorf, Germany. E-mail: johannes.siegrist@med.uni-duesseldorf.de

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INTRODUCTION

Amongst the 3 “Rs” proposed as major challenges for societies in the 21st century, “distribution of resources”, “regulation of economic growth”, and “securing basic social rights to all members” (1), the third challenge matters most for persons with disability. To date, disability is no longer interpreted as a fixed

attribute of an individual, but rather as a dynamic continuum of experiences at different levels of bodily impairments and restrictions in activity and social participation (2). Environmental factors may modify personal disability characteristics and their outcomes, such that people with functional limitations are disadvantaged in their opportunities of fair participation in social life (3). The fact that these restrictions contradict basic human rights has given rise to a broad range of policy interventions at different levels, including the United Nations *Convention on the Rights of Persons with Disabilities* (4). This convention was endorsed by the United Nations General Assembly in 2007, and it informed the *World Report on Disability* (5). Along these lines, a report on one relevant type of disability was more recently published, the *International Perspectives on Spinal Cord Injury* (6). As was the case in previous documents, this document is based on an extended model of functioning and disability, the WHO’s International Classification of Functioning, Disability and Health (ICF) (2). The ICF provides a universal descriptive tool of classification for data collection and clinical practice. It considers 3 core areas of function (body functions and structures, activities and participation) that interact with contextual factors (environmental, personal) and with the persons’ health condition (2). Importantly, the ICF distinguishes between a person’s capacities to perform actions and the actual performance of those actions, thus pointing to restrictions imposed by the social, natural and built environment. In keeping with a basic human rights perspective, these restrictions are particularly relevant as far as participation in social life is concerned. The ICF provides a very general definition of participation restriction as any kind of “problems with involvement in any area of life” (6, p. 8). Here, we argue that a more refined, theoretically grounded notion of social participation may be instrumental in advancing our understanding of links between social participation and wellbeing, as well as in supporting policies that aim at increasing social participation of persons with disabilities.

In the first part of this contribution, a theoretically grounded notion of social participation is explained. By emphasizing the role of social productivity we draw a link between the societal opportunity structure and the potential benefits of personal need satisfaction in terms of experiencing personal control and social recognition that, in turn, strengthen people’s wellbeing. Yet, lack of access to and poor quality of socially productive activities are associated with poor wellbeing, and these restric-

tions are often experienced in persons with functional limitations. This latter argument is illustrated in the second part of this paper, exploring the case of labour market participation among persons with spinal cord injury (SCI) on the basis of a narrative review of respective research findings.

THEORY: SOCIAL PARTICIPATION AND SOCIAL PRODUCTIVITY

Whereas the ICF provides a useful and comprehensive classification scheme, it is generally recognized that this important achievement needs to be supplemented by theory-based approaches that may provide explanations of the relationships between its components, its determinants and longer-term outcomes (7–10). Several such developments have been initiated recently. For instance, in 2 papers addressing environmental factors within the ICF, Hammel et al. (11) and Magasi et al. (8) propose a concept that depicts environmental factors at the macro-, meso- and micro-level, and that requires an analysis of their dynamic interactions with 4 areas of participation (home, community, work & economic, and social) (8, 11). They also emphasize the fundamental role of environmental factors “in shaping participation through the creation of opportunities for action” (8, p. 571).

In an attempt to focus on the specific opportunities for action provided by the social environment, and in order to elucidate the contribution of *full participation in social life* to subjective wellbeing, the unique benefits of performing activities in a social environment need to be elaborated. To this end, it is important to argue that the notion of “full participation in social life” is consistent with current thinking on common human values (12, 13). This notion points to the fact that some fundamental, widely prevalent human needs cannot be adequately met without a continued exchange of individuals with their proximal social environment. Beyond biological survival, reproduction and social affiliation, these fundamental needs include the development of personal control or autonomy and related self-efficacy through goal-oriented activities (14), and the recurrent experience of social recognition by significant others and associated favourable self-esteem (14–16). Thus, full participation in social life offers personal need satisfaction by enabling people to experience *personal control and social recognition*. However, meeting these needs largely depends on the availability of opportunities to act and to be recognized, and on the quality of respective activities. In keeping with Norman Daniels’ notion of *fair opportunities* (17), we propose to label those opportunities “fair” that are instrumental in satisfying people’s relevant needs, such as the need for personal control and recognition.

An influential sociological theory maintains that these opportunities are institutionalized in every society in terms of *core social roles* (18). Social roles are defined as sets of obligations expected to be observed by groups of persons holding a distinct position or status within a social structure. Obligations fulfilled in core social roles concern the family and partnership, work and employment, and additional types

of social engagement (e.g. volunteering, civic obligations). By providing access to the social opportunity structure and by fulfilling respective obligations, these roles offer a *dual utility*. For individuals acting in these roles the utility manifests itself in the satisfaction of material and non-material personal needs, as mentioned above. For the partners of persons acting in social roles, and for society at large, the utility consists in sharing the outcomes of respective activities. Thus, the notion of full participation in social life reflects the intimate links of personal need satisfaction with the provision of benefits to significant others through acting in social roles.

Importantly, personal needs satisfaction through social participation is likely to exert beneficial effects on *wellbeing*. These salutary effects are largely due to the positive emotional responses resulting from the recurrent experience of activity-based autonomy or personal control, and social recognition or reward. These experiences are strengthening people’s *self-efficacy and self-esteem* (19, 20). In consequence, people who are excluded from accessing fair opportunities in terms of core social roles, and people who are confined to activities in core social roles that contain a poor quality preventing these positive emotional responses, are expected to experience poorer wellbeing.

In modern societies, the work role is considered the leading model of social activity resulting in dual utility, given its crucial significance for maintaining employment and economic growth and for securing the working person’s continuous income and social status. Yet, other types of role-based social activities may also produce dual utility. Volunteering, providing informal help, caring, working as homemaker, civic engagement, and related forms of social participation are examples (21). While the benefits of those who profit from these types of engagement are obvious, the provider’s benefit is less well defined and is often experienced in non-material rather than material terms. Yet, to further elaborate the communalities between these different types of role-based engagement and their effects on wellbeing, the term “social productivity” is introduced as a common denominator.

“Productivity” is mainly used in economics to describe the value and utility of goods or services generated on the basis of paid work, where optimal cost-benefit relations are of interest. By extending the term to include non-economic costly transactions, social productivity was defined as “any agreed-upon continued activity that generates goods or services that are socially or economically valued by the recipient(s), whether or not based upon a formal contract” (22, p. 3f.). The definition points to the dual utility (“generating” and “valuing” goods or services) inherent in the transactions between providers and recipients. This transaction reflects a fundamental social principle, the norm of reciprocity (23). According to this norm, any action of service provided by person A to person B that has some utility to B is expected to be returned by person B to A. Exchange expectancy does not implicate that the service in return corresponds exactly to the service provided, but is assumed to meet some agreed-upon standard of equivalence. The norm of reciprocity is thus considered a

general principle governing voluntary social exchange that includes productive activities. Valuing productive activities through rewards, whether material or non-material, occurs both in formal and informal transactions. Thus, under favourable conditions, persons engaged in social productivity benefit from experiencing personal control, and from experiencing social recognition resulting from the value reciprocated by recipients. The recurrent co-manifestation of these 2 types of personal benefit resulting from providers' productive activities exerts positive effects on wellbeing as these feelings are paralleled by neuro-endocrine and immune responses that preserve and protect health and that activate reward-sensitive structures in the brain (24). As a result, wellbeing is experienced as a motivating state of happiness, flourishing, and self-fulfilment (25). Conversely, being confined to provide productive social activities that offer little or no experience of personal control, and that prevent the experience of recognition due to failed reciprocity, result in the providers' poorer wellbeing and its negative consequences.

To summarize, availability and favourable quality of core social roles through which productivity is performed can offer beneficial effects on the providers' wellbeing. These effects are mainly attributable to experienced personal control, and to material and non-material rewards received from recipients. Lack of access to these roles, or poor quality of socially productive activities goes along with adverse effects on people's wellbeing, given the restricted experiences of personal control, and given the absence or frustration of expected rewards. These theoretical propositions hold equally true for persons with and without disabilities. Yet, in case of *disability*, lack of access to, and poor quality of, socially productive activities are more often experienced, and this fact is expected to result in lower overall levels of wellbeing. It is therefore essential to strengthen *enabling conditions* that increase opportunities of full participation in disability and related favourable effects on wellbeing.

Several such enabling conditions have been identified by previous research. They include distinct personal coping patterns, such as optimism and purpose in life (e.g. 16), options of receiving tangible social support (26), holding a favourable socioeconomic position, as well as having access to specific healthcare, employment and policy arrangements. For instance, optimistic persons with disabilities may be more motivated to undergo retraining and acquire new skills (27). Likewise, social networks may facilitate their access to new types of social engagement (28). Furthermore, having a high level of educational or vocational qualification increases rates of return to work among disabled people. Similarly, affordable financial means improve transportation and coping with environmental hazards, thus facilitating full social participation of persons with functional limitations (29). Concerning specific welfare and health policies, evidence obtained from cross-country comparisons confirms that disability-related restrictions can be substantially reduced by improvements

in medical and vocational rehabilitation, by coordinated (re) employment programmes, and by specific integrative labour market policies at national levels (5, 30). In conclusion, we propose a theoretical approach towards linking access, and quality of socially productive activities to wellbeing. This approach is assumed to hold equally true for persons with or without disabilities. However, in the former case, enabling conditions are more often required in order to experience fair opportunities of full social participation (Fig. 1).

Therefore, as less access to, and quality of, productive activity is expected in case of disability, special emphasis must be put on enabling factors that offer entry points for preventive and rehabilitative measures at the personal, interpersonal, socio-structural and socio-political level. Such measures might improve full participation in social life and full realization of human rights amongst persons with functional limitations. Lack of access to, and poor quality of, *paid work* is probably the most important, and relatively best studied, case of restricted participation in social life amongst persons with disabilities. In the second part, we illustrate this case with reference to an important condition of disability; SCI.

ILLUSTRATION: THE CASE OF LABOUR MARKET PARTICIPATION AMONG PERSONS WITH SCI

SCI may offer an informative case in point, as it has a far-reaching impact on a person's functioning and health. Persons with SCI experience loss of sensory and motor function below the lesion level (31) and are therefore particularly vulnerable to participation restrictions in social life. SCI may be a convincing case of testing a hypothesis that also applies to other types of disabilities, specifically those characterized by mobility limitations and dependency (e.g. frailty in older populations).

There is an impressive body of research on labour market participation of persons with SCI (30, 32–35). Based on this information, we first examine to what extent persons with SCI are restricted from entering or returning to paid work. Secondly, we explore factors that prevent or enable access to this core social role. Finally, in line with the notion that access to, and good quality of, work are prerequisites of full social

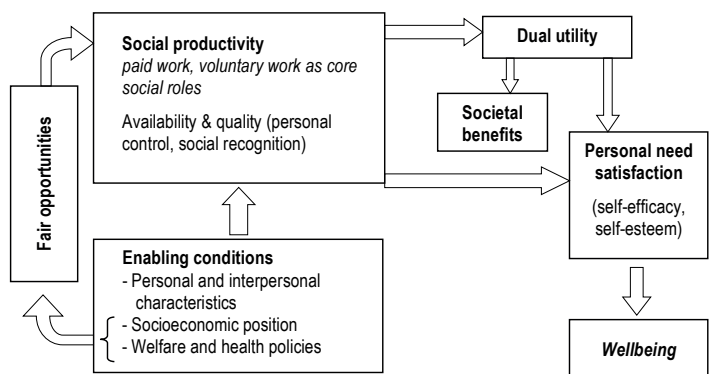


Fig. 1. Theoretical model of the social production of wellbeing.

participation and their favourable effects on wellbeing, we review studies that address type and quality of work among persons with SCI.

Entering or returning to paid work is a major societal goal and rehabilitation aim after SCI. Due to advances in treatment and medical rehabilitation of SCI, in combination with progress in vocational rehabilitation and insurance support, employment rates among persons with SCI increased during the past few decades (32). However, substantial differences both within and between countries remain. The largest differences are observed when comparing low- and middle-income countries with high-income countries, although reliable data in the former countries are sparse (30). Even within high-income countries, overall employment rates, as well as return to work rates among individuals with SCI working at the time of injury, vary substantially, as indicated in recent reviews (32–36). Studies from distinct European countries and from the USA document clear differences in the availability of paid work between persons with and without SCI. In the USA, a difference of 35% vs 79% was reported (33). This difference is much smaller in Switzerland, where, according to 1 report, 63.8% of persons with SCI were employed, compared with 79.5% in the general population (37). Scandinavian countries and the Netherlands also demonstrate relatively high employment rates of persons with SCI, averaging approximately 50% (32), whereas these rates are much lower in Southern Europe (34). In consequence, unemployment rates are relatively high after SCI and associated negative consequences on health and wellbeing (33). Persons with disabilities are also more vulnerable to job loss in times of economic instability, e.g. following the 2007–2009 financial crisis (38). An interpretation of these variations is difficult, as it seems almost impossible to disentangle methodological influences related to differences in the definition of employment, the time-frame under consideration, or the inclusion of pre-injury employment status from those factors that determine employment status (33).

A large body of literature is concerned with the second topic of interest in this illustration, i.e. the identification of enabling and limiting factors in (re)entering the labour market after SCI (33, 34, 36). These factors can be classified into 4 broad categories. The first category contains socio-demographic and socio-economic factors, such as age, sex, ethnic background, education, income, pre-injury occupational or professional status, marital status, and area of residence. The second category concerns health conditions, in particular severity of disability and functional limitations, number and severity of secondary health conditions (e.g. pain or pressure sores), and impaired mental health. These health characteristics determine not only the probability of returning to work, but also the time required from onset of SCI to employment as well as the amount of work accomplished (e.g. number of hours, part-time). A third category contains personal and interpersonal coping characteristics, such as optimism, purpose in life, work motivation, and availability of close social relationships and social support (see above). Finally, system-related factors are relevant, specifically availability and quality of treatment and medical rehabilitation, vocational rehabilitation, role of employers, features of the

insurance system, labour market opportunities, obstacles due to societal discrimination and lack of accessible transportation.

It is not possible to rank the importance of these factors, given the low degree of standardization of study designs, the limited comparability of measurement of core variables, the differences in the samples selected and the difficulty of comparing different socio-political contexts of respective countries. Despite these limitations of current knowledge, the following factors have been recurrently identified as enabling return to work among persons with SCI: (i) availability of a pre-injury employment history; (ii) low level of functional limitations; (iii) favourable socioeconomic position, specifically high level of educational and vocational skills, high income; and (iv) system-related factors, in particular an established comprehensive and early medical and vocational rehabilitation, and an implemented anti-discrimination policy removing major barriers to social participation. Thus, this evidence defines some entry points of interventions that aim at strengthening access to a core socially productive activity.

In contrast to a wide, still heterogeneous, body of research on determinants of return to work after SCI, few studies analysed the third topic mentioned, i.e. the type and quality of work accessed after SCI (33, 39). These few studies indicate that persons who are able to return to their pre-injury employment are privileged, as they usually take less time before re-assuming work, and as the threats of uncertainty and the costs of re-training are reduced. However, rather few are able to return to their pre-injury employment (40–42). A second finding of research shows that most commonly obtained occupations following SCI include technical, administrative, office, clerical and professional jobs (43–45). In many cases, these jobs offer an acceptable or good quality of work as the efforts of coping with the demands on the job in the presence of physical limitations are manageable. Obviously, these jobs are more easily accessible to white-collar workers and those with higher education (39). Yet, more recently, with advances in assistive and information technologies, there is some promise that return to work rates in disability may have increased independent of level of educational skills, given extended options of home- and tele-working in a labour market that offers more integration of work and home environments (46).

What is known about the benefits of worksite interventions, such as vocational counselling, supported employment, or on-the-job training, on work performance and wellbeing among persons with SCI? This question is best answered by randomized controlled trials. To date, only 2 such randomized controlled trials were identified by a recent review (47). In both cases, distinct positive outcomes were demonstrated (i.e. more work hours); however, no data on health and wellbeing are available (48, 49). To our knowledge, the quality of psychosocial work environments in employees with SCI has been explored in only 1 study. This study observed significantly poorer wellbeing among those SCI participants who reported high levels of stressful work, specifically in case of failed social recognition, measured as an imbalance between high effort spent and low reward received in turn, and in case of low personal control (50).

In summary, the utility of a theoretical concept outlined above has been illustrated by the case of access to paid work among persons with SCI. Three major findings are noteworthy. First, strong evidence of restricted participation was found, and these restrictions confer unfavourable consequences for health and wellbeing (33, 35). Secondly, distinct factors enabling return to work were identified, and returning to work was generally associated with higher levels of wellbeing and mental health (35). Thirdly, as the quality of paid work matters as much as its availability, at least 1 study demonstrated that failed social recognition at work is associated with poor wellbeing. More research is needed to demonstrate favourable effects on wellbeing of employed persons with disabilities that are attributable to the recurrent experience of personal control and recognition at work (50).

DISCUSSION

In this contribution we argue that a more refined, theoretically grounded notion of social participation may be instrumental in advancing our understanding of links between social participation and wellbeing as well as in supporting policies that aim at increasing fair opportunities of social participation amongst persons with functional limitations. Starting from the ICF's general notion of participation, we claimed that focusing on socially productive activities in core social roles conferring dual utility opens a window of opportunity to analyse their beneficial effects on wellbeing in terms of personal need satisfaction, specifically personal control and recognition. As lack of access to these activities as well as poor quality in case of access are more often experienced amongst persons with disabilities, the available enabling conditions need to be strengthened at personal, interpersonal, and structural levels.

This latter argument was illustrated by a brief narrative review of research on return to work amongst persons with SCI, a particular, rather severe, case of disability. Findings reported lower labour market participation after SCI compared with non-disabled populations. Persons with SCI who were unemployed or who were granted a disability pension reported lower wellbeing than those who were able to return to work. However, this summary revealed a substantial lack of homogeneity and comparability of study designs, of definition of employment, of the range and measurement of variables included, and of time frames analysed. Given a low degree of cumulative knowledge resulting from this fact, it was difficult to identify those enabling conditions of labour market participation after SCI that exerted the strongest effects and that would then instruct the choice of priority in implementing interventions. Moreover, a remarkable lack of research on the adaptive challenges of returning to work after SCI and on the quality of work available to persons with SCI became evident. In view of the burden of adjusting to new job arrangements and of coping with stressful experience in increasingly competitive work environments, more investments into this line of research are required, particularly as promising preliminary evidence on beneficial effects of distinct models of vocational rehabilitation

and support is available (30). In the context of the proposed theoretical approach, it is noteworthy to learn that types of socially productive activities other than paid work received little attention so far in research on social participation in disability. This is the case for volunteering, informal help, and different forms of civic engagement. Given the options of experiencing favourable effects on wellbeing resulting from full engagement in these types of social participation, there is a need to learn more about fair opportunities of disabled people for full social participation. For instance, several large-scale studies of older men and women from different European countries found that both the frequency and quality of volunteering were positively associated with wellbeing, where quality was assessed in terms of personal control and social recognition (51). There is no reason why similar effects should not be expected among persons with SCI or other types of disability as efforts to compensate for the loss of a core social role in adult life, the work role, matter in either case.

In conclusion, the theoretical approach outlined here might help to enrich the fundamental descriptive ICF framework with regard to the notion of participation by focusing on a core type of participation provided by the social environment, i.e. social productivity. More specifically, by linking the availability and quality of different types of social productivity, in particular paid work, with personal need satisfaction, direct tangible effects on wellbeing are expected. Improved research evidence along these lines could support policy initiatives that aim at widening fair opportunities of social participation and their salutary effects on the wellbeing of persons with disability.

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