

ERC Research Project 'Rethinking Disability'

Monika Baár received an ERC Consolidator Grant for her research project "Rethinking Disability: the Global Impact of the International Year of Disabled Persons (1981) in Historical Perspective."

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Hypothesis

Approximately 10% of the world's population is estimated to be disabled and this number is expected to rise in the next few decades. Disability has consequences not only for the individuals concerned, but also for their families and their environment, it is a human and social issue that touches us all. People in different cultural settings ascribe different meanings to disability; consequently, its repercussions are both culturally contingent and universal. This project brings together the local and global dimensions of disability and examines the interaction, tension and conflict between these two aspects by undertaking the first comprehensive study of the far-reaching political, societal and cultural implications of the International Year of Disabled Persons (IYDP), a landmark event organized by the United Nations in 1981, which appears to have gone virtually unrecognized in scholarship.

The hypothesis of this project is that the International Year, together with its counterpart, the International Decade of Disabled Persons (1982-1993) was the most significant watershed in the modern history of disability. It was the first occasion to place disability into a global context by endorsing it authoritatively as a human rights issue and thereby raising the question as to how the concept may be understood in a multicultural world. The project's innovative contribution lies in connecting the IYDP to broader political, social and cultural processes in the last quarter of the twentieth century and thereby bringing disability in a global context to the attention of mainstream historical scholarship.

Background

IYDP as a catalyst for change. The International Year was marked not only by celebrations, but also by vigorous protests in several countries: the official rhetoric associated with the event raised expectations significantly, but these could not be met in a period which coincided with the first major financial crisis in post-war history. This project purports that the vast gap between official discourses and everyday realities at the grassroots level produced a creative tension, from which a new paradigm started to emerge. Historical time became 'compressed' and, by accelerating pre-existing tendencies, the International Year led to the kind of fundamental changes, which would, under normal circumstances, take several decades to occur. It became a major catalyst for the politicization of disabled citizens, who were at the time still not regarded as part of the 'general public', but as people with separate and special needs.

IYDP and the formation of a new identity. The International Year inspired disabled people to think about their status in new ways. It encouraged them to no longer hide their condition and take pride in it. As a result, in several countries disabled people came to reject traditional approaches of charity and pity and realized that they were better equipped than anyone else to understand their own needs. They

came to feel a sense of belonging together and disability gradually evolved into a distinct identity, giving rise to an alternative lifestyle and unleashing artistic potentials. Frequent meetings and an intensive exchange of ideas informed this period and - in addition to the transnational networks of medical experts, politicians and policymakers - for the first time disabled people themselves started to contribute to those exchanges, forming *Disabled People's International*, the first global organization entirely run by disabled citizens.

IYDP and the developing world. It was in preparation for the IDYP that, in 1980 the World Health Organization (WHO) produced the first classification of disability designed for universal application. This classification was based on an ideological framework which reflected the standards of the modern 'Western world' It focused on the individual and assumed that equality, independence, self-reliance and personal self-fulfilment are universally desirable and applicable values and that dependence constitutes a problem. The conscience of the international community was stirred during the International Year, spawning numerous governmental and non-governmental initiatives in 'developing' countries, in which approximately 80% of the world's disabled population lives. These initiatives brought into sharp relief the notion that focusing on individual rights runs contrary to accepted norms and practices found in many developing countries, where the disabled person is seen as part of a larger whole: the care-giving family and kinship networks. Given that such projects are never purely philanthropic ventures and that they were often pursued by former colonizing powers, it is unsurprising that some of IYDP initiatives came to be criticized as impositions of neo-colonialism.

Scope and Approach

The research intends to illuminate how disability became a global concern. It will do so by identifying the contribution of international agencies, governmental and non-governmental organizations and, just as importantly, disabled people themselves, to the IYDP and by showing the connections, interactions and entanglements between these various agents. To that end, the novel feature of this project lies in its understanding of human rights in the context of disability as a *universalizing*, and *not (necessarily) a universal* discourse, which was conceived in the 'modern Western world'; and subsequently 'transferred' to developing regions. The ambition of this research is to historicize and 'provincialize' the prevailing Western concept of disability and to discover how it can be rendered meaningful and relevant in diverse cultural settings.

A myriad of events connected with the IYDP took place both in formal and informal arenas, both on an official and a grassroots basis and on multiple levels: local-national; regional-continental; international and supranational. All UN member states were expected to take part in the IYDP and in addition to the contribution made by already existing international and national institutions, an International Directorate (located in the UN's Vienna headquarters) and so-called National Directorates were formed in several UN member states specifically for the purpose of the IYDP. Co-operative ventures between governmental and non-governmental bodies abounded, grassroots organizations went from strength to strength, and prominent religious leaders issued statements on the IYDP.

This project will offer a *cross-sectional view* of these activities. At the *international and supranational levels* it will involve archival study of the role of the UN and its specialized agencies: WHO, UNICEF, UNESCO, UNHCR; as well as of the Red Cross, ILO, the World Bank, IMF and OECD, the European Community, Rehabilitation International, Disabled People's International and the various churches and religious movements. At the *regional-national level* comparative case studies will be undertaken on different welfare contexts: Anglo-Saxon, continental, Nordic, Latin and socialist; in a variety of political contexts: established democracies with- and without colonial legacies, transitional democracies following the end of authoritarian regimes and authoritarian states which subsequently became transitional post-communist states. The transfer of knowledge, technology and ideologies from these states to developing countries will also be investigated. Here the primary sources will be provided by the archives of the National Directorates of the IYDP which were formed in over hundred

countries and are typically held in the national archives in the respective countries. At the *grassroots level and in the informal sphere* the everyday experiences of disabled people and their contribution to the IYDP will be studied by having recourse to published memoirs, artwork (photographs, comic strips, posters, protest songs etc.), and by studying events such as exhibitions, wheelchair discos and cabarets. In addition, oral history interviews will be conducted with contributors to the IYDP at both official and ‘unofficial’ levels. Lastly, the project will include a historiographical component to examine how the IYDP influenced academic scholarship and a curriculum development component with the aim to raise awareness of the subject in secondary and higher education.

Time Span and Broader Context

While the IYDP is at the heart of this research, its chronological scope extends from the early 1970s, when the issue of disability first emerged on the UN’s agenda and activism gained momentum, to approximately the end of the millennium, by which time most IYDP-initiated activities had been completed and their impact (or lack thereof) had become visible. This timeline also reflects the programming goal put forward by the WHO in 1981: ‘Health for all by the year 2000’. With this time scale in mind, the project will provide an unconventional lens through which to better understand how the final stages of the Cold War and the evolution of the new world order played out globally; in addition to illuminating how the care of disabled citizens constituted a point of ideological rivalry between the two superpowers as well as between different ideologies (such as ‘health for all’ through primary healthcare versus neoliberalism, comprehensive versus selective healthcare). The project’s findings on the experiences of disabled citizens will be related and compared to those of other vulnerable groups, including women, children and refugees. Last but not least, by historicizing and relativizing the concepts of autonomy, independence and self-determination, this research will be of relevance to contemporary posthumanist debates which question the agency of the autonomous self-willed individual and instead emphasize shared vulnerability and *interdependence*.

Objectives and Research Themes

There will be four closely-related objectives

1. to examine the IYDP’s impact on human rights discourses and to scrutinize their applicability within global settings;
2. to document the IYDP’s contribution to emancipation and social change and to consider the different trajectories of emancipation in various parts of the world;
3. to assess the ways in which the IYDP influenced everyday life experiences, galvanized identity formation and inspired the emergence of a distinct subculture;
4. to analyze the transnational exchanges and knowledge transfer in conjunction with the IYDP and to examine how the ‘Western’- oriented discourses penetrating the developing world interacted with the local environment

Research theme 1. The IYDP’s contribution to human rights discourses

At the core of this theme is an analysis of the process of how the IYDP shifted disability from the margins to the mainstream of the international human rights agenda in the programmes of the UN, European Community and other organizations and how the original non-binding resolutions paved the way for the first legally enforceable UN Convention on the Rights of Persons with Disabilities in 2006. These documents were based on a ‘prototypical person with disability’ and reflected the circumstances of Western citizens and, to a limited extent, members of the urban elite of activists in developing countries. What kind of challenges did political and cultural diversity present to human rights discourses on disability and how applicable were those discourses within different local contexts, especially in countries characterized by repressive regimes, extreme poverty, displacement and violence and lack of access to healthcare and basic education?

Research theme 2. The IYDP's contribution to social change

In the focus of this theme is the creative tension between the authorities and grassroots organizations formed by disabled people which often triggered vigorous and under repressive regimes subtler protests. What was the role of the state, charities (or lack thereof), 'celebrities' (royalties, media personalities, sportsmen etc.) in these events? How did disabled people react to the 'celebration from above' and what form did their own contribution take? What frictions and hierarchies emerged among different disabled groups, what were the manifestations and limitations of solidarity? It was at the time of the IYDP that the concept of disability as a social identity was invented in non-Western countries: through surveys, rehabilitation programs and government policy. What forms did social embodiment take in the postcolonial world and did these lead to 'hybrid' identities?

Research theme 3. The IYDP's impact on culture and identity formation

By offering a platform for disabled people to voice their concerns publicly, the IDYP contributed to the formation of an alternative cultural identity, which no longer viewed disability as a form of deviance but as something to value and celebrate. The impetus provided by the IYDP, even if that often took the form of frustration, inspired a host of artistic activities, many of which addressed taboos. What was the role of arts in developing this new cultural (and by interference) political identity? Paradoxically, in the non-Western world, disability was still widely associated with injustice and suffering and was therefore presented as something undesirable that needed to be prevented and eradicated rather than being celebrated. In response to this, some efforts were made by international organizations to inspire disabled people in developing countries, for example by hosting workshops on 'artistic creativity'. However, this raises the question of how the Western concept of 'creativity' translated into contexts where self-expression was not a constituent of personhood.

Research theme 4. Transnational exchanges, knowledge transfer and entanglements during the IYDP

This research theme focuses on transnational communication, collaboration and entanglements. It also explores the dynamics between recipients and providers in humanitarian efforts. It includes medical programmes (e.g. polio prevention), rehabilitation programmes, especially community based rehabilitation (CBR), which was developed by the WHO in order to integrate rehabilitation services into health care at the local level and a related initiative developed by the ILO designed to focus specifically on vocational training. What was the outcome of these initiatives, was there any resistance to them and what kind of 'entangled modernities' came into being as a result?

The team

The core team will comprise the project leader, three PhD students and two post-doctoral fellows. The project will also engage six non-resident research associates whose expertise includes the history of human rights and of the welfare state, refugee studies, special education, literature and gender studies, global health, visual and media studies.