

REPORT from fieldwork around the United Nations High-level meeting of the General Assembly on Disability and Development (September 2013)

“The way forward: A disability-inclusive development agenda towards 2015 and beyond“

by Daniel N. Pateisky

This stay in New York was initiated by an interest in following and researching the international community’s agenda set by the UN Convention on the Rights of Persons with Disabilities, which is being promoted as an essential part of the development framework since 2007 and has culminated in a joint declaration at this High-level Meeting. ‘Inclusive development’, hence, is being one of the matters brought forward very strongly by many national governments, advocated for by non-governmental organisations and made a crucial argument by rights groups and some legislative bodies in the propagation of the Millennium Development Goals (MDGs). My Ph.D. project has at the centre of its empirical investigation a set of interviews with experts in this particular field, falling into either one of three categories – be they political representatives and decision-makers; NGOs and civil rights advocacy groups; or academics with experience working in disability rights, active in bottom-up advocacy since the 1970s that contributed to the ADA’s elaboration, researching disability representation and legislation in particular.

Since each of these groups of persons is able to provide my research with insight from a different perspective, I have attempted to contact as wide an array of potential interviewees as I could. The NGOs attending who had received consultative status with the Economic and Social Council (ECOSOC), and the organisers on the side of DESA (Department on Economic and Social Affairs) themselves, were my initial points of interfacing in order to arrange for personal appointments. NGO delegates had already spent a few days with the UN prior to the HLMDD, so I made sure to write and call a selected number of groups and individuals. This included such entities as Action for Mental Illness; Arab Organization of People with Disabilities (Lebanon); Asia Pacific Disability Forum; Beit Noam (Israel); Centre of Independent Living of People with Disability of Serbia; Development and Ability Organization (Afghanistan); Down Syndrome Society of Kenya; Gambia Future Hands on Disabled People; Japan Disability Forum; National Grassroots Disability Organization (Bangladesh); National Union of Disabled Persons of Uganda; Projet de Réadaptation à Base Communautaire des Aveugles et Autres Personnes Handicapées du Niger; the World Network of Users and Survivors of Psychiatry, and many others.

The process of interfacing with said interview partners was already quite exhaustive in preparation of my flight to the United States, and with my arrival it became the most challenging and time-consuming effort. For many delegates and representatives who had originally – before my arrival in the U.S. – assured me that they would find

time, ended up telling me on short notice that they would be unable to meet with me, despite my endeavours to accommodate for all their respective time schedules. Fortunately, I have remained patient and persistent in approaching them, wherefore some interviews could eventually be conducted, and others have been only postponed – these are to be done via online telephony in the upcoming weeks, by December of 2013.

Following the HLMDD event at the United Nations Headquarters, my (primarily) politically active interviewees included the UN Special Rapporteur on Disability of the Commission for Social Development (South Africa); the World Bank's Institute on Disability and Public Policy Speaker (Chile); as well as the UN ad hoc Committee on the CRPD's present and former speakers (Argentina/Germany), both involved in the forging and particularisation of said Convention. On the side of NGOs, the persons consulted are active in working with the Independent Living movement and as regional advocates of Rehabilitation International – from Sweden, Nigeria, Serbia and the United States. The researchers involved – affiliated with the University of Illinois, Cornell, Harvard and Columbia University respectively – are well versed in the genealogy of Disability Studies as an academic field since the 1970s, while additionally praxis-oriented as activists with regard to the Americans with Disabilities Act (ADA, 1990). All this has brought together a wide range of perspectives I am able to include in my on-going project work. The dissertation will take into account how the views brought forward are in decisive parts impacting on and are shaped by the respective positions and points of interfacing, not to mention the personal involvement often implied.

As for the question of language-related challenges arising in the communication of rights-based terminology and individual perception of it on the side of the interviewees consulted, two running threads emerged that appeared to contrast one another: For one, the mainly transnational political spectrum seems to tend towards acceptance of the wording set by the common UN agenda, while arguing for it through its overarching acceptability; on the other hand, the bottom-up—activism-experienced professionals have been fairly unanimous in their critique of that which has been declared the present-day norm of language to be followed, with a strong focus on the constant change that they see the terminology incessantly undergoing. Whether this speaks for a vague gist of present disability discourse in one direction or another – complacent acceptance of an international consensus among the 'international community', or an approach towards its uprooting and the propagation of ideas heretofore unknown, unaccepted – remains to be investigated further. As far as the interaction of all actors observed until now is concerned, with the inclusion of arenas of interfacing that seem most crucial, I have observed a fairly distinctive line that can be drawn between the grass-roots ambitions and those on the level of international debate. Yet, I am watching out for further instances that might possibly speak for an entirely different manner of interaction.

For this reason, the outcome document of the High-level Meeting will be inspected more closely, seeing as “[the international community] seeks to translate the international commitment to disability-inclusive society” (HLMDD Agenda, 05 September 2103). Since I believe such translation – particularly when viewed in light of the weight presently put on matters of accessibility¹ and language’s role I see therein – needs to take into account all matters of linguistic understanding and multi-directional interaction with all constituents concerned. Therefore, I intend to further consult legal scholars (necessary contacts have already been established) knowledgeable in this field, so as to inquire about which portions of said legislation underlie any linguistic requirements or are subject to multilingual ‘cross-checking’ for comprehensibility. For this reason, means of accommodation, as campaigned for by legislators, would in the case of my praxis-orientation be sought largely in the sphere of interfacing, not with sole regard to adjustments granting individuals a ‘specialised’ position (the meta-message carried by ‘special needs’ policies).

I am grateful for the Graduate School’s support in funding of my travel expenses. As wasn’t at all surprising though, living expenses were unfortunately very high in a city like New York is. This of course is why an additional per diem would have surely been helpful, and might be taken into consideration for potential future investigations at destinations such as this. I have established conducts, presentations and talks of on-going research results are to be scheduled with research institutions and political groups, as well as in the course of disability studies and social sciences studies conferences.

¹ Resolution 66/124, paragraphs 2 and 4