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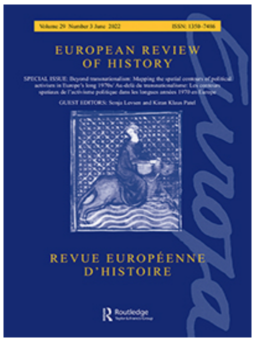

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Seeking inclusion through redefining expertise: the changing spatial contours of disability activism in the long 1970s

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ABSTRACT
This article focuses on European transnational activism in the long 1970s. Using the independent living movement as a case study, it illuminates how new spaces of knowledge production, social experience and political activism often emerged from informal contacts. Such initiatives challenged the medical understanding of disability and questioned the expertise of medical and rehabilitation personnel: activists fighting for the elimination of spatial segregation redefined disability into a social condition and asserted that the source of expertise was above all the lived experience. More conventional professional spaces of exchange also intensified and diversified in this period, as the example of two networks representing people with intellectual and developmental disabilities reveals: one fashioned itself as a space of neutral professional exchange, whereas the other also engaged in activism. Yet another instance of diversification is the coming into being of the world's first cross-disability organization in 1981. The article reveals the ideological tensions and practical obstacles that restricted international exchange and the manifestations of solidarity. In particular, it points to the mismatched expectations between activists from Europe and North America who defined solidarity in terms of identity politics, and those from the Global South who tended to equate it with financial aid.

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The chronological and ideological contours of transnational disability activism

Disability is by its very nature a transnational phenomenon: it is a condition and an identity which connects people across borders. This article argues that the 1970s saw the intensification and diversification of transnational disability activism and the emergence of new spaces of knowledge production, together with new spaces of social experience and political activism. Alternative networks emerged and novel organizations were founded which challenged their earlier counterparts that were typically characterized by a medical understanding and were run by medical and rehabilitation experts. Instead, the new networks and organizations were informed by an alternative, social model, which shifted the attention away from the individual's impairment to the discriminatory social attitudes such as physical barriers and the lack of educational and work

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opportunities. In its new incarnation, the condition was no longer perceived as an individual deficit, but a collective identity of a marginalized community struggling for equality and full citizenship.[1] Motivated by this approach, the emerging organizations were expected to be formed of and run not (exclusively) by medical and rehabilitation 'experts', but by disabled people themselves. Their concerns included the opportunity to make independent decisions about how to live their lives, while parents wanted educational opportunities for their disabled children. It was also at this time that the need for a new 'cross-disability' movement was voiced by activists. Although a certain common sense of belonging had always existed, earlier on no unified platform could come into being and organizations were typically confined to representing one specific type of disability.

The article reveals that the disability movement was in this period dominated by Western European and North American groups and, accordingly, the spaces of transnational encounters were also confined mostly to these regions. Subsequently, to a limited degree, activism opened up to other parts of Europe and to other continents in the developing world, but this process was not without limitations and contradictions. Some of these were logistical and financial, whereas others were ideological in nature. The majority of activists were white, well-educated, heterosexual males with physical (rather than mental) disabilities. Concerns that were crucial for their purposes did not necessarily resonate with the preoccupations of other activists worldwide. For example, as we shall see, the concept of independent living made very little sense in environments where independence was not unquestionably considered a desirable condition. Moreover, the understanding of disability as a positive identity could hardly be relevant for people who were first and foremost in need of material and technical assistance.

Unlike other social movements, the study of disability activism, which never had a very broad social basis, has hitherto received very limited attention in mainstream historical scholarship; its transnational and spatial dimensions have received even less attention. Moreover, disability is yet to be more broadly acknowledged as a category of analysis in scholarship. What new insights may be gained from examining, in line with the rationale of this special issue, the transnational spaces of knowledge production, spaces of social experience and political activism, and spaces of imagined solidarity, as well as the clashes and overlaps between these in the context of the disability movement? Such a study may revisit and complicate established knowledge about the 1970s as a period of emerging globalization and technological change, as well as also illuminate transnational engagements in the 1970s from a hitherto overlooked vantage point. It can help us reflect on the forms of internationalism that emerged during the Cold War and their various dimensions, such as ideology, cooperation and circulation.[2] It resonates with the warning of current academic scholarship that the phenomenon of internationalism cannot be reduced merely to the antithesis of nationalism.[3] Of particular relevance is also the conclusion drawn from the results of recent research into health, welfare and social policy: the emerging new platforms of internationalism were not so much actors in global governance, but sites of internationalization.[4] Disability activism in the 1970s also has relevance for studying the significant expansion of professional networks in this period, particularly a phenomenon which has often been referred to as 'NGO-isation' (non-governmental organization). It may inspire us to reflect on the frequently made observation in the literature that many of the nominally international endeavours were actually European.[5] The study of disability internationalism may also contribute to the integration of the (spatial) trajectories of disability activism into the overall framework of the history of social movements and inspire comparisons on the subject in future research: what were the similarities, differences and overlaps in the spatial contours as the respective social movements were coming onto the stage in different time periods? Disability activists were confronted with the paradox that also characterizes other identity-based social movements. On the one hand, they fought for emancipation and integration, an intention which in their case involved entering 'mainstream' public spaces and workplaces to which up to that time they enjoyed limited access or no access at all. On the other hand, they sought to cherish a distinct identity which involved the maintenance and creation of separate spheres of community. Thus, they were simultaneously juggling their intention to seek inclusion and their desire to celebrate difference: the former aim implies integration into existing networks; the latter required the creation of new spaces.[6]

For the purposes of disability activism, the conceptualization of the period under discussion as the 'long 1970s' proves entirely justified, not only because of the significance of certain events and developments, but also because in this way interactions with other social movements can be better traced. The influence of the youth movement and the legacy of 1968 manifested itself, for example, in demands for more autonomy and in the critique of the 'infantilization' of people with disabilities. It may also not be a coincidence that it was precisely in 1968 that a new organization evolved from the International Federation of Hard of Hearing People: the International Federation of Hard of Hearing *Young* People.[7] The 1970s saw various legal developments which strengthened the foundations of the transnational disability movement. These included the United Nations' Declaration on the Rights of Mentally Retarded Persons (1971) and the Declaration on the Rights of Disabled Persons (1975). The decade also saw the passing of the United Nations' resolution to dedicate the Year 1981 as the International Year of Disabled Persons, which led to the acceptance of the World Programme of Action in 1982. In order to be able to account for these legal developments, which were both the results of earlier advocacy and the catalysts for subsequent activism, it appears justified to include the early 1980s in this analysis.

Apart from parallels with the youth movement, a natural alliance developed with the peace movement: both because of the disabling nature of wars and because of the enormous costs of weapons of destruction at the expense of welfare budgets. It is hardly surprising that shortly after its inception, in 1982, Disabled People's International, the world's first global cross-disability organization (of which more later in this article) issued a peace statement in which it called on world leaders to redirect their resources from producing weapons to creating the instruments of life.[8] An important correspondence with the women's movement was the special agency of the 'power of the powerless' which activists could rely on in their protest activities: the sight of people in wheelchairs could embarrass the security forces just as much as a crowd composed of 'fragile' women and make them more reluctant to intervene.[9] Lastly, parallels with the US Civil Rights movement and the anti-apartheid movement were also established. As shall be demonstrated later in this article, South African activist Vic Finkelstein (1938–2011) pursued the argument that spatial and political segregation in both cases implied inferior status and followed a similar logic. The knowledge base of the disability movement drew on common theoretical considerations, on the one hand, and practical hands-on experiences, on the other. Lifelong segregation constituted a typical experience for people with various types of disabilities. Isolated institutionalized settings, away from the public eye, created conditions that were ripe for abuse and misuse. The uncovering of what turned out to be structural abuse of power in institutions by investigative journalists, family members of patients and committed medical personnel gave a significant impetus to the fledging disability movement at national and transnational levels. The ideological foundations of anti-institutionalism which challenged this inhumane, segregated environment were provided by some of the key thinkers of the 1960s. In 1961 Michel Foucault published his epochal book *Folie et Déraison: Histoire de la folie à l'âge lassique* (first English edition as *Madness and Civilization* in 1964), which argued that the demarcation line between madness and reason constituted a crucial factor for the development of modern societies. Moreover, the book implied that madness was not necessarily the symptom of the 'deviation of the soul', but a perfectly natural reaction to repressive living conditions.[10] Another key text was Ervin Goffman's *Stigma: Notes on the Management of a Spoiled Identity* (1963) and *Asylums: Essays on Social Situations of Mental Patients* (1961) which pointed out that institutionalized settings created symptoms that were very much akin to the behaviour of 'abnormal' patients and thereby implied that the cause of their madness could actually be their environment. The Italian psychiatrist Franco Basaglia (1924–80) developed a reputation as the 'man who closed down the asylums'. It was first and foremost thanks to his efforts that in 1978 the world's most radical mental health law was passed in Italy, redirecting the care of mental health patients to the community.[11] Basaglia's anti-institutionalist writings were influenced by Marxist ideas and the legacy of Italy's anti-fascist generation, especially Primo Levi. They exerted significant impact in several European countries, as well as in Latin America. While some activists, especially those educated at university level, were influenced by these academic accounts, for the purpose of winning over public opinion they relied on (or they themselves produced) journalistic accounts and films that exposed the inhumane and unacceptable conditions in institutions and boarding schools. Albeit not produced with activist intentions, Milos Forman's *One Flew Over the Cuckoo's Nest* (1975), based on Ken Kesey's eponymous novel (1962), was read not only as an allegory of the 'paranoid' tendencies of McCarthyism in the 1950s in the United States, but also as a concrete critique of what Goffman termed 'total institutions'.[12] In several countries scandals broke out because of the deplorable situation in segregated residential institutions, the 'ultimate scrap-heaps' of society. In Norway, Arne Skouen, a film director who had first-hand experience of these conditions because of his autistic daughter, framed the problem in terms of the violation of human rights and went so far as to make comparisons with concentration camps. While the ensuing legal investigation found this claim exaggerated, the fact that immediately thereafter reforms were introduced reveals that the authorities acknowledged the serious nature of the problem. In Britain, Nigel Evans's undercover documentary *The Silent Minority* (1981) exposed psychiatric abuse and neglect with such force that it compelled the government to close down most long-stay hospitals and move their residents to small group homes.[13] While these incidents occurred at the national level, information about them was circulated transnationally at meetings and conferences, sparking the realization that misuse and abuse were inherent in the system. Accordingly, activists concluded that those problems needed to be addressed at the international level, as the section following outlining how the issue of people with mental disabilities was placed on the agenda of the United Nations (UN) is going to demonstrate. Yet, what looked to these experts and activists like a universal problem that needed to be brought to the attention of the UN was often not even necessarily perceived as a 'concern' in developing regions: anti-institutionalism could constitute a problem only where institutions existed in the first place. On the other hand, the deplorable treatment of people with mental health problems, regardless of whether they were institutionalized or not, was a phenomenon that could be observed across the globe.

From informal transnational encounters to more formalized networks

While the experiences amassed at the local and national levels contributed to the formulation of international agendas, the process of transnational exchanges helped to illuminate that disability is culturally contingent and also closely tied to the traditions of the welfare state and social welfare.[14] An extract from the memoirs of the foremost US activist Irving Kenneth Zola (1934–94) about his experiences in the Netherlands provides a case in point:

> 1971–72 was my sabbatical year and I was spending it as a consultant-in-residence to the Netherlands Institute of Prevention Medicine in Leiden. Trying to speak Dutch was difficult enough (at the end of a year my Dutch friends noted how much my German had improved!) but hearing them use my language in unaccustomed ways was more disturbing. A particular shock came from their pronunciation of the world for a handicapped person, someone we Americans call an invalid. My Dutch friends, however, enunciated it in accord with its derivation – from the word 'valid'. To them, this was the only natural way to refer to a reality – the difference between healthy people and the handicapped lay in the latter's invalidity. Every time I heard it – and given my work was at a medical institution that was often – it made me shudder. The pain stirred was very deep but I put it aside until what I thought was a series of chance events catalysed me to greater probing.[15]

Zola's *Missing Pieces: A Chronicle of Living with a Disability*, from which this extract has been drawn, did more than to point to misunderstandings that could occur in the course of transnational exchange. It documented how his stay in the Netherlands provided him, in his own words, 'the stimulus for the search for my missing piece, my physical handicap'.[16] Zola gained this experience, which became the foundation for his new identity as a wheelchair-using disabled person (earlier on he had worn a long leg brace and a steel-reinforced back support), in *Het Dorp* ('the Village'), a self-contained residential community near the Dutch city of Arnhem that was specifically designed to house 400 severely disabled adults. Initiated in 1962 by the largest telethon in Dutch history, the Village opened its doors in 1972. As a product of the expanding Dutch welfare state, it was founded with the aim of helping its inhabitants achieve 'optimal human development and optimal human happiness'.[17] There existed 'therapeutic communities' for disabled people elsewhere in Europe, but *Het Dorp* was unique because it was free-standing and exclusively intended for physically disabled people. Impressed as he was with the services and opportunities in *Het Dorp*, Zola quickly came to the conclusion that it was very far both geographically and socially from the United States. His Dutch conversation partners expressed surprise that a nation as rich as the United

States, where the emphasis on independence was even stronger than in Europe, did not have a place comparable to the Village. But the level of social commitment that allowed for the support of 400 disabled people and nearly the same number of staff to assist them would have been unimaginable in a society based on individual achievement and where supporting disabled people would have been seen as an illegitimate way of spending the taxpayers' money.[18] Moreover, from a US perspective there was something paradoxical about the existence of *Het Dorp*: despite the fact that *de facto* dependence and segregation were widespread in the United States in this period, a place with its visibly dependent population and *de jure* segregation would have been considered an anathema.[19]

Unsurprisingly then, the concept of independent living was taken up in a radically different way by a group of wheelchair users in the United States. In the 1970s, relying on the motto 'Nothing about us without us', they instigated an initiative with which they ultimately redefined the contours of disability expertise: they asserted that it had to be based on the lived experience and not on the policy-makers' ideas and priorities. They were (at least initially) organized from below and created so-called centres of independent living, consumer organizations and self-help groups which evolved into sites of social experience and political engagement. The most prominent role was played by the world's first Independent Living Centre at Berkeley, which was founded in 1972 and pioneered legally defined rights for disabled people. The Berkeley centre was run by and for people with disabilities who demanded to take control over their lives by arranging support on the basis of their individual needs. It emerged as a genuine transnational centre of exchange. For example, visitors from West Germany transplanted a version of the 'Berkeley model' in their country: in 1978 they opened a centre in Munich which was supported by conscientious objectors and sought to help disabled people move out of segregated institutions, while the first independent living centre in Germany was opened in Bremen in 1986.

Although Berkeley was frequently referred to as 'the Mecca of the Independent Living Movement', this did not mean that those who returned from a pilgrimage could directly transplant that model into their own countries. As one of the foremost West German activists Theresia Degener noted in her report, based on interviewing Judy Heumann, a foremost US activist, there were various differences both between the two movements and in the circumstances under which they operated.[20] The Berkeley initiative provided certain services that were in West Germany normally expected to be provided by the state. Regulations were also different: for example, electric wheelchairs up to the speed limit of 16 km could be used freely, whereas in Germany they required a driving licence. Moreover, the environment was much more accessible around the Berkeley region than anywhere in Germany (and probably most parts of the United States), to such an extent that a disabled visitor concluded that returning from Berkeley to Germany equalled 'self-mutilation' (*Selbstverstümmelüng*).[21]

The concept of independent living was eagerly embraced and transplanted to Western Europe by a German Berkeley graduate, Adolf Ratzka, whose motivation to move to the United States was the lack of accessible universities at home. The high degree of autonomy when making decisions about his living conditions and the positive experience about the potentials of activism for achieving change exerted a deep impact on Ratzka. As he put it: 'I was catapulted from the vegetable existence of a German hospital to the hotbed of flower-power activism.'[22] Once back to Europe, Ratzka settled in Sweden and together with another activist, Bente Skansgard from Norway, they put the idea of independent living into practice. In 1981 they organized an international conference on the topic in Gothenburg and thereafter they laid down the foundations of the Stockholm cooperative for independent living – a pilot project for personal assistance for 22 people.[23] Activities at Berkeley revealed several similarities with movements for equality and civil rights by and for racial minorities, women and gay people. One of the major parallels included the turning of 'deviance' into a positive force and into a new identity. Just as representatives of the Civil Rights movement took pride in their otherness rather than concealing it – their different hair, skin complexion and so on – disabled activists transformed the negative connotations attached to their condition into something that could be seen as attractive rather than pitiable.

The intersections between the segregation of disabled people and the segregation caused by racism became a concrete reference in the work of the South African activist Vic Finkelstein, who was born to a Jewish family in Johannesburg and became paralysed in his youth due to an accident. After facing discrimination and torture because of his anti-apartheid activism in South Africa, Finkelstein moved to Britain as a refugee. When he became aware of the complaints of disabled British activists about their segregated 'special' provision in residential homes, he was reminded of Nelson Mandela's Rivonia Trial Speech (1964) in which Mandela emphasized that Africans wanted to perform work and be paid a living wage and they wanted to be part of the mainstream population and not be confined to their own ghettoes. Moreover, he added: 'Above all, we want equal political rights, because without them our disabilities will be permanent.'[24]

Finkelstein was the driving force behind the document published in 1975 by the Union of the Physically Impaired Against Segregation (UPIAS) and the Disability Alliance. He argued that the problems faced by disabled people were caused by society's failure to take account of their needs and not their impairment. He drew parallels between the spatial, economic and cultural segregation of black and white South Africa and the limits placed on disabled people at that time: disabled people and black people alike were considered 'problems' and as inferior populations that needed to be kept apart from mainstream life.[25] In line with this realization, the programme of the UPIAS declared that:

> We reject also the whole idea of 'experts' and professionals holding forth on how we should accept our disabilities or giving learned lectures about the 'psychology' of disablement. We already know what it feels like to be poor, isolated, segregated, done good, stared at, and talked down to – far better than any able-bodied expert. … We look forward to the day when the army of 'experts' on our social and psychological problems can find more productive work.[26]

Diversification and globalization of networks

In addition to the emergence and stabilization of activist networks of people with physical disabilities that sought to differentiate themselves from the circuits of medical and rehabilitation experts, new spaces were carved out among the ranks of 'traditional' international organizations: from the 1960s they started to diversify and expand their outreach. It is true that international organizations representing veterans, blind people and deaf people that emerged after the Second World War collaborated with the United

Nations and its affiliated agencies from their inception, in the spirit of the idealistic internationalism of the post-war period. Yet, they usually remained in the background and rarely exerted direct impact on major legislative change. The alternative organizations emerging from the 1960s onwards addressed the need to pay more attention to hitherto ignored groups of people with disabilities.

The rights of people with intellectual and developmental disabilities were advocated by two bodies: the first was the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), an organization born out of three international congresses held in London, Vienna and Copenhagen in 1960, 1961 and 1964 respectively. The second was the International League of Societies for the Mentally Handicapped (today Inclusion International), which was founded in 1960 during the World Mental Health Year and which operated in collaboration with experts, parents and volunteers. It succeeded in bringing together associations from across the world: in 1975 it had some 85 member societies in 60 different countries. These included the United Kingdom, France, Yugoslavia, New Zealand, Ghana, Kenya, Japan, Ghana, Poland, India, Lebanon, Spain and the Caribbean Islands among many others.

But why was it necessary to maintain two different spatial circuits – for example in separate meetings and conferences – and did this not weaken the chances of successful advocacy? IASSID met every three years for congresses and acted as a forum where experts shared new knowledge and evaluated services. It, however, neither formulated policies nor proposed new services. Instead, it sought to offer a neutral ground for professional exchanges. On the other hand, the League operated as an unofficial knowledge hub, as it gathered experiences and best practices from all over the world. As one of its leaders explained in 1973:

> The strength of the League lies in the fact that it brings together from some 60 countries parent organizations concerned with mental retardation, and it is on their combined wisdom, energy, resourcefulness and commitment that I pin my hopes for a brighter future which indeed will assure to all retarded citizens their basic human rights – not as a myth but as a reality.[27]

The comparison and contrasting of national practices provided a useful basis for the formulation of international recommendations. The League can be seen as more action-oriented, and it consciously fashioned itself as representing an alternative to IASSID. It defined its mission:

> There is no one country which has all the answers for coping with the problem of mental retardation. New discoveries are made, new developments take place in many countries and one of the main functions of the parents' associations has been to act as an international communication network to make new developments more widely known and to insist – and insist – that the authorities put this new knowledge to use.[28]

Initially, three of the United Nations' specialized agencies, the ILO (International Labour Organization), WHO (World Health Organization) and UNICEF (the United Nations Children's Fund), addressed issues related to some aspects of disability, including education, work and rehabilitation opportunities. In 1969, the General Assembly adopted a declaration that signalled a shift. For the first time it emphasized the need to protect not only the welfare, but also the rights of persons with disabilities; it also called for their full participation in society.[29] That grassroots organizations gradually started to gather momentum and could exert an impact on the UN is also evidenced by the General Assembly's adoption of the above-mentioned Declaration on the Rights of Mentally Retarded Persons in 1971. As we have seen, the activities of IASSID and the International League of Societies for the Mentally Handicapped (today Inclusion International) were instrumental in placing the issue on the United Nations' agenda. More specifically, it was the League's Declaration on the General and Special Rights of Mentally Retarded Persons at its Jerusalem conference in 1968 which instigated the UN Declaration. The same applies to these organizations' contribution to the coming into being of the Declaration on the Rights of Disabled Persons in 1975.

One of the most striking and lasting developments towards the end of this period was the establishment in 1981 of the global cross-disability organization, Disabled People's International (DPI), which sought to create a more unified voice for disabled people whose organizations had been fragmented along specific impairments. DPI likewise legitimized itself by asserting this new form of expertise, and its inception provides yet another instance of an emerging space resulting from this assertion.

Its pre-history goes back to a scandal at the 1980 Winnipeg World Congress of Rehabilitation International, a traditional organization of medical and rehabilitation experts founded in 1922. It was during that meeting that Swedish delegates recommended amending the organization's constitution to require that at least 50% of the delegates should be a person with disabilities. When this amendment was rejected, some of the angry participants seceded from the conference, and held a parallel meeting at which they decided to form a separate world coalition of persons with disabilities. This ambition was realized at the 1981 inaugural meeting of DPI, with a constitution that was modelled after the ILO's constitution.[30] As these instances reveal, the 1970s saw the proliferation of new disability organizations and, accordingly, the multiplication of the number and nature of transnational activities. These developments naturally brought about the diversification of the spaces of transnational action. Whereas the majority of traditional organizations represented spaces of (medical) expertise, the new ones provided spaces that merged this new form of expertise with social experience and political activism. The gradual integration of disability into the UN's agenda was also to a large extent due to transnational activism. It provided proof that activists and their organizations were acknowledged as 'conversation partners' by representatives of international organizations. In other words, they were not merely self-declared experts, but their knowledge was deemed legitimate for initiating legislative change and even new legislation.

Spatial and ideological divides as limitations of global solidarity?

The emergence of new advocacy groups and organizations in the 1970s may at first glance imply the simultaneous emergence of new sites of knowledge, social experience and also expressions of solidarity, be they imagined or real. However, as activism increasingly acquired an international and even global scope, the limitations and the contested nature of the concept of solidarity became increasingly manifest. Moreover, the systemic competition during the Cold War influenced spatial configurations and manifestations of solidarity. A closer look at the locations and participants of conferences and international meetings discussed earlier reveals that in many cases, conscious efforts were undertaken by the organizing committees to alternate locations so that at least some of the events could take place 'behind the Iron Curtain'. In this way, solidarity across ideological divides was supposed to be fostered. To illustrate this pattern: in the 1950s and 1960s the World Federation of the Deaf organized its conference in Zagreb (1955), in Wiesbaden (1959), in Stockholm (1963) and in Warsaw (1967). In the 1970s the locations included Paris (1971), Washington, DC (1975), Varna (1979) and Palermo (1983).[31]

While in the 1970s often considerable restrictions were imposed on travel across the Iron Curtain, travel for official purposes on the international disability circuit could benefit from communist governments' willingness to keep up appearances and avoid embarrassing themselves by imposing restrictions on official travel for events that addressed issues concerning vulnerable people. But the events themselves often functioned as sites of the systemic competition: 'capitalist' and 'socialist' countries frequently used the international meetings to advance their respective political ideologies, for example by making funding dependent on holding the conference in a certain location or by hijacking the conference keynote speeches for political purposes.[32] As an episode from the history of the above-discussed IASSID testifies, Cold War conflicts could affect travel, especially at a time when a particular country was experiencing an internal crisis. At the third congress of the organization, which was held in Warsaw in 1970, the antisemitic trends in Poland in the late 1960s caused worries among members of the organization, but despite strong opposition, as an outcome of a postal ballot, the conference was given the go-ahead.[33] The decision was influenced by a previously published letter from a large group of Nobel laureates which appeared in *Nature* and which called for the maintenance of scientific links across the Iron Curtain. But after some visas (including one for an Israeli participant) were refused by the Polish bureaucracy, the organizing committee informed the state authorities that if the issue was not resolved, they would cancel the conference, and that would cause a considerable loss of prestige for the government. This had the desired effect and at the last minute the problematic issues were settled.

On other occasions, despite repression in one's home country, it was possible to overcome Cold War spatial divides and even to solicit support from international organizations, as the case of the Action Group to Defend the Rights of the Disabled in the USSR, led by Iuuri Kiselev and Valerii Fafelov, reveals.[34] Members of this group called attention to the deplorable conditions under which disabled people lived in the Soviet Union. They accused the Soviet government of failing to deliver on its promises and neglecting and oppressing disabled citizens. They applied for permission to establish a legally sanctioned cross-disability organization. When this request was rejected, they gradually relinquished their original hope that change could be achieved from within the existing system.

Access to samizdat and émigré publication venues helped the group to reach out to the international public. Moreover, the group's human rights rhetoric and appeal to international bodies was catalysed by references to the Helsinki Accord/Helsinki Conference on Security and Cooperation in Europe of 1975. In their programme of 1978, they expressed their intention to create contacts with international organizations for the disabled and also to garner help from 'world opinion'. That they were successful in these intentions was to a large measure due to the support coming from the Moscow Helsinki Watch Committee, which reached out on their behalf not only to Norman

Acton, the chairman of Rehabilitation International, but also to the United Nations' Human Rights Commission and UNESCO (the United Nations Economic, Social and Cultural Organization). The group was also successful in becoming a 'parallel voice' to the Soviet government, as its documents were given consideration at UN meetings in equal measure to the official ones.

Another pattern of the dynamics of transnational engagement in the 1970s occurred irrespective of Cold War divides and was more related to infrastructural circumstances that were requisites for international knowledge exchange. Practically all encounters took place in urban environments, and frequently they were held in capital cities or 'second cities'. This is not surprising: usually the infrastructure necessary for organizing international congresses, meetings or sporting events was available only in larger cities, where the headquarters of relevant organizations were also located. Such a programme was unlikely to be realizable in smaller towns, let alone in the countryside. This situation mirrored a fundamental divide: the educational and social opportunities and services were often restricted or were entirely unavailable outside the reach of these big cities, where isolation continued to remain the defining experience throughout the 1970s. This 'urban–rural' divide was present irrespective of ideological divides; for example, the documents of the Action Group to Defend the Rights of the Disabled in the USSR repeatedly pointed out that in rural areas the conditions for disabled people were even more difficult.[35] At international meetings, complaints were frequently raised that activism and activities revolved around a small number of 'islands of excellence', but these were in fact exceptional rather than representative. As such, they often remained unconnected to the 'mainland of practice'.[36]

New states in the Global South gained membership in international organizations as the process of decolonization unfolded. As the contours of imagined spaces of solidarity gradually expanded to these regions of the world, further difficulties and complications emerged. One telling example of the complications arising from this expansion is related, ironically, to the most significant new organization of the period, Disabled People's International. Precisely because DPI sought to achieve a global outreach, it soon became evident that people in different parts of the world have different needs and also different understandings of solidarity. For some, it was an abstract concept; for others it was invariably tied to financial support. DPI devised a Development Programme which offered a one-off financial contribution for developing nations. However, extreme poverty among disabled people was also a problem on the European continent, and the funds intended for the developing world did not always end up with those who needed them most. Another issue was that apart from modest concrete projects, overall, identity politics were prioritized as a focal point. But the discussions on full participation and social justice sounded entirely out of tune for those members for whom solidarity invariably equalled financial support and the promise of being introduced to new networks and to the concept of 'self-help' did not in itself prove attractive enough.[37]

Decolonization and the emergence of new independent states in Africa and Asia from the 1960s onwards created new geopolitical zones and, consequently, sites of rivalry within the transnational exchanges. Educational and rehabilitation institutions in these regions had formerly been run by the colonial governance or by the churches, and from now on they were expected to cater for the needs of an independent country. But they were extremely few in number. For example, in 1971 only 60 schools for the deaf existed on the African continent, serving less than 1.2% of the infant deaf population, as Cesare Magarotto, the Italian General Secretary of the World Federation of the Deaf, noted in his speech at the Sixth International Congress of the World Federation. Hence, the conditions in the 'developing world' became a central issue of the congress. During this event, some members of the Federation expressed their wish to counteract what they considered was the overwhelming influence of the United States in this new geopolitical zone.[38]

As this instance reveals, frequently, expressions of solidarity with disabled people among developing nations adopted a rhetoric comparable to that of humanitarian discourses: they focused on themes such as poverty and disenfranchisement. The 'globalization' of the disability movement coincided with the emergence of a global aid industry and the proliferation of non-governmental organizations (NGOs). In the absence of government funding and local sponsors in the developing world, the support of disabled people was frequently equated with expressions of Western compassion for poor people.[39] This was a somewhat paradoxical phenomenon, considering that what the disability movement intended to counter was precisely the perception of disability as a 'pitiable' state and suffering.

Conclusion

The transnational encounters discussed in this article indicate that during the 1970s the relevant contours of spaces of knowledge, spaces of social experience and political action, and spaces of (imagined) solidarity were constantly changing and evolving. As we have seen, even individual and informal exchanges could exert a significant impact and could lead to the creation of new identities and alternative spaces. Irving Kenneth Zola's stay in *Het Dorp* led to the reinterpretation of his own situation, which evolved from someone avoiding the use of a wheelchair to embracing it as part of his identity. The impact did not stop there: his stay inspired a book which not only documented his own social experience, but also encouraged others to follow suit. Adolf Ratzka had 'escaped' from his home country to the United States because of his lack of access to higher education as a physically disabled person, from where he returned to the European continent with an experience which was not merely practical in nature; it also provided the foundations for reconceptualizing the status of a person with a disability *and* a degree of independence. Ultimately, his and his peers' efforts created a formal network which has survived until the present day and acts as a consultation partner of various international organizations. Transnational encounters not only inspired people to view their own situations in a new light and to embark on activism; they were just as crucial in instigating life-long friendships and social networks that were *not limited* to the experience of disability.

Conventional spaces of knowledge – primarily the congress and conference circuits – became contested or redefined, as disabled activists started to emerge on the scene. But newly emerging hubs of knowledge relied heavily on the pre-existing networks and infrastructure. In fact, these were used to create 'counter-spaces' that contributed towards new goals and orientations. Most spaces do not neatly fall into one single category. For example, Disabled People's International was simultaneously a space of new knowledge, of social experience and political action, and of solidarity. The fact that DPI quickly acquired consultative status with the United Nations reveals that the expertise that activists claimed for themselves was also acknowledged in the international arena. Activists' fights for societal inclusion also embraced legal inclusion and a new framing of disability as a human rights issue, rather than merely a social welfare matter. Nevertheless, the extent to which manifestations of solidarity were real or imagined was very much dependent on concrete actions and events. As the outreach of organizations gradually expanded from Europe and North America to other parts of the world, not only the contours of spaces, but also the contours of concepts, became challenged. As has been shown, for some, solidarity made sense only if it were accompanied by tangible support: legal theories and ideas about identity and belonging alone did not resonate with the actual needs of disabled people in impoverished regions.

It will not come as a surprise that, as in the case of other social movements, new players in transnational activism typically came from 'elite' circles: many of them were in the position to go to university and they had access to support and resources that most of the people whose voices they claimed to represent could hardly even dream of. Moreover, white, heterosexual wheelchair-using men dominated the disability movement for a long time. This meant that women, gay and lesbian, and non-white people could experience multiple exclusion and rejection: they were marginalized in the disability movement because of their gender, sexual orientation and race, and they felt excluded from the other movements because of their disability. Later on, in the 1980s–90s, new initiatives emerged that represented the groups which had fallen through the cracks of existing networks.

As disability activism started to involve more and more groups, the emergence of tensions and conflicts could hardly be avoided. On the one hand, more and more particularistic spaces of knowledge, social experience and solidarity came into being; on the other, a certain implicit hierarchy evolved within these organizations. This phenomenon of horizontal hostility is by no means unprecedented in the history of social movements: it occurs precisely between groups who are expected to have close affinities.[40] At the outset, activists with physical disabilities, often playfully referred to as 'the wheelchair brigade', spearheaded the movement and its important spaces. As activists representing other groups gradually made their voices heard, some of the ingrained stereotypes and value judgements in the able-bodied world also made an appearance in mainstream disability activism: for example, the (implicit) stigmatization of people with mental disabilities.

When it comes to the intersections of local, regional, national and international spheres, it appears that transnational knowledge often emerged from local and national experiences which were accumulated as 'combined wisdom' and were taken to a new level in the course of exchanges. Striking parallels occurred across different welfare and ideological regimes. Whereas the relevance of the Iron Curtain was significant in the context of travel and access to information and infrastructure, across the systemic divide, disabled people mobilized for the same reasons, even if differences existed in the ways and extent to which they were able to express their opinions and protest. In that sense, the kind of Europe that emerges in this study is one which is socially more uniform than one would assume. It is a Europe that maintained strong cultural and academic ties with North America. The emancipatory efforts of the 1970s provided the framework for developments in the longer term, but uneven political and economic conditions greatly affected the opportunities for the 'globalization' of networks. In the subsequent period, in the 1980s, it was not so much the emergence of further new spaces that stood out, but the shift from grassroots participation to more professionalized strategies in the same spaces and the shift from the desire to overcome the existing system to the willingness to participate in the system.[41]

Notes

1. On the social model see Shakespeare, "The Social Model of Disability," 197–204. and Campbell J. and M. Oliver. *Disability Politics: Understanding our Past, Changing Our Future*, 11–24.
2. Kott, "Cold War Internationalism," 342. See also Keck and Sikkink, *Activists Beyond Borders*, 1–38.
3. Reinisch and Brydan, "Introduction: Internationalists of Europe," 2.
4. Kott, "Toward a Social History of International Organisations," 34.
5. Reinisch and Brydan, "Introduction. Internationalists of Europe," 10.
6. Shakespeare, "Disability, Identity and Difference," https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Shakespeare-Chap6.pdf accessed on June 4, 2020.
7. The organization's history is yet to be written. At present, apart from oral history evidence and information on their website, only their constitution is available https://web.archive.org/web/20120324180551/http://www.ifhohyp.org/site/front/documents/ifhohyp_constitution_2011.pdf accessed on August 1, 2020.
8. See https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-dpipeace.pdf accessed on February 2, 2020.
9. For more on this see Wappett, "Self-Determination and Disability Rights," https://doi.org/10.1177%2F10442073020130020801.
10. Klein, "Governing Madness -Transforming Psychiatry," 17.
11. On Basaglia's international legacy see Burns and Foot, eds., *Basaglia's International Legacy*. On Basaglia's British colleagues see Crossley, *Contesting Psychiatry*, 88–111.
12. See Lambe, "Memory Politics," 298–324.
13. On the parliamentary discussion of *The Silent Minority* see https://api.parliament.uk/historic-hansard/written-answers/1981/jun/09/silent-minority-documentary accessed on 4 June 2020.
14. Stoll, "Disability Movements," 7–8.
15. Zola, *Missing Pieces*, 3.
16. Ibid.
17. This was the intention of the initiator of *het Dorp*, Arie Klapwijk; see Zola, *Missing Pieces*, 5.
18. "Foreword," by Nancy Mairs to Zola, *Missing Pieces*, VIII–IX.
19. Zola, *Missing Pieces*, 120.
20. Degener, "US-Krüppel," 8–10.
21. Frehse, "Autonom Leben," 16–18.
22. See: https://www.independentliving.org/docs5/time.html accessed on June 4, 2020, and Fleischer and Zames, *The Disability Rights Movement*, 39–42.
23. Today this is the Stockholm Independent Living Institute.
24. https://www.speech.almeida.co.uk/nelson-mandela, accessed on February 20, 2020. For a more detailed analysis see also Finkelstein's book *Attitudes to Disabled Persons: Issues for Discussion*.
25. https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-Reflections-on-the-Social-Model-of-Disability.pdf, accessed on January 27, 2021.
26. "Union of the Physically Impaired Against Segregation," 446.
27. The term 'mental retardation' is no longer accepted in current usage. However, I chose not to change it in the quote given here because it illustrates a semantic change. Dybwad, *Human Rights*, 33, Friends of the Samuel Gridley Howe Library and the Dybwad Family, https://www.disabilitymuseum.org/dhm/lib/detail.html?id=2017&page=all.
28. Ibid., 33.

29. https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/01/History_Disability-in-the-UN_jan23.18-Clean.pdf accessed on June 4, 2020.
30. Driedger, *The Last Civil Rights Movement*, 67.
31. After each congress the respective proceedings were published.
32. Shaw, "Deaf in the USSR," 212.
33. Parmenter, "Contributions of IASSID," 71–8.
34. Raymond, "Disability as Dissidence," 236–37.
35. Ibid., 239.
36. Dybwad, "An International Look at Developmental Disabilities (1979)," Friends of the Samuel Gridley Howe Library and the Dybwad Family https://www.disabilitymuseum.org/dhm/lib/catcard.html?id=2013 accessed on August 2, 2020.
37. Driedger, *The Last Civil Rights Movement*, 67.
38. Sixth International Congress of the World Federation of Deaf, 1971, *Congress Proceedings*, 69.
39. On NGO-ization in the disability sphere see Meyers, "NGO-Ization and Human Rights Law: The CRPD's Civil Society Mandate," *Laws* 5, 2016 (2), 21.
40. Nina Littel, "Minority Consciousness Gone Mad? Exclusion, Inclusion and Self-Organization of Disabled LGBTI People in the Dutch and British LGBT+ and Disability Movements, in the Late Twentieth Century." MA thesis defended in 2019 at Leiden University, https://openaccess.leidenuniv.nl/bitstream/handle/1887/81154/Littel_MA%20Thesis_.pdf?sequence=3.
41. Stoll, *Disability Movements*, 84–5.

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