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Vegetables of the World Unite! Grassroots Internationalization of Disabled Citizens in the Post-War Period

Approximately 15% of the world's population is estimated to have a form of disability: they constitute the world's largest minority.[1] Moreover, family members, carers and the environment are also affected by their condition. Precise numbers prove difficult to estimate because definitions and categorizations are constantly evolving and shifting.

Because of the volume and the societal significance of the issue, it may appear surprising that 'disability internationalism' (a phrase coined for the purposes of this essay) has remained a virtually unstudied field and has yet to be written into the canon of internationalism.[2] Little attention has so far been paid to this topic for a variety of reasons. A crucial one is that the process of internationalization itself commenced at a relatively late stage: until the 1970s and in several cases even well beyond that period, the majority of persons with disabilities had lived in isolation and segregation –whether because they were confined to institutionalized settings or because of the physical and attitudinal barriers which prevented them from leaving their homes and contributing to societal life in the first place. Legislation, policies and decision-making were typically confined to the national or municipal-local level.

Even in those instances when a certain degree of internationalization could be observed prior to the 1970s –for example in the case of deaf and blind people – these were not grassroots initiatives, but organizations intended *for* disabled people which were managed by experts and policy-makers. Characterized by a charitable mentality, and by the perception of disability as a 'personal deficit', leaders of these organizations usually took it for granted that

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1 The author acknowledges the support of the ERC Consolidator Grant *Rethinking Disability* contract nr. 648115 and the support of the Brocher Foundation in the form of a residential fellowship for writing this article.

2 The available literature is written nearly exclusively from an Anglophone perspective and as such cannot provide an adequate framework for the study of Europe.

disabled people, regardless of the type and severity of their condition, were not in the position to make decisions about their own fate, so these needed to be taken on their behalf.

By contrast, the emerging grassroots organizations, which were inspired by and often revealed parallels with other social movements –be they the women's movement, youth movement or gay liberation– started to 'talk back' by claiming agency for themselves and asserting that they were best qualified to make decisions about their own needs, and proposing ideas about how to eliminate the obstacles (whether physical or social) that stood in the way of equality with their able-bodied counterparts. These organizations were formed *of* and run by disabled people themselves. In the course of this politicization and internationalization members of the disabled community started to question the 'cripple' or 'abnormal' status assigned to them by society and gradually started to perceive themselves as a collective body of people. This resulted in enhanced social visibility and a new form of self-confidence which made it possible for disability activists on many occasions to contest the expertise of medical professionals and policy makers. As shall be outlined below, these developments led to the redefinition of disability from being a merely medical category into a social concept and from being a charitable matter into an issue of human rights and in some cases, even as an identity which can be a source of pride. This development allowed for the emergence of new international networks in addition to the already existing medical-professional ones.

A major barrier in the way of writing the history of grassroots disability internationalism is of practical in nature: the dearth of available sources. Grassroots initiatives typically emerge in the informal sphere, leaving behind only a limited amount of documentation and often none at all, which makes the reconstruction of their early histories difficult. Typically, relevant information can only be traced in 'grey materials': leaflets, pamphlets and newsletters which did not make it into archival collections, but are stored in the cellars and attics of activists and as such have limited accessibility and are vulnerable to destruction. Existing literature on the topic is not only extremely limited, but it nearly exclusively focuses on developments in the Anglo-American world. Often –however inadvertently– these studies take it for granted that developments in Britain and North America were invariably pioneering and as such must have served as models to be reiterated in other parts of Europe and the rest of the world. As this essay will demonstrate, such instances definitely existed. However, upon closer study a more complex overall picture emerges. This reveals the prominent role and the ‘connected status’ of non-Anglophone activists and organisations from continental Europe and from the ‘peripheries’. One reason for initiatives in continental Europe was that the first disability organisations were typically formed of veterans and hence their presence was particularly strong in the countries which were seriously hit by the war. Here expertise in the field of rehabilitation was particularly necessary and this need motivated the establishment of international networks. Although these were not yet bottom-up organisations, the contacts developed in this way could form the basis of genuinely grassroots initiatives at a later stage. Another example is the Nordic countries’ leading role in the institutionalization of international networks of organisations intended initially *for*, but later also *of* people with cognitive disabilities and their families. One potential circumstance that could trigger this activism may have been the stark contrast between the famously generous nature of the Nordic welfare states and the often astonishingly bad treatment to which especially people with serious disabilities were subjected: such a discrepancy could even prove harmful for the image of these countries.

Moreover, in the majority of the cases it may not even be meaningful to trace the origins of an idea or initiative, because activism and internationalisation evolved in polycentric ways. Reactions to the ‘Zeitgeist’ could result in the expression of similar ideas and in similar developments across different parts of Europe and even globally. But even when intentions were shared, the process of internationalization could trigger tensions: the broader its scope, the larger the number of the involved organisations and individuals; the more difficult it became to reach consensual decisions. Such cleavages could arise about ideological issues, priorities and even practicalities. Often, one single formula was not sufficient; particularly when the scope of European activism expanded into a global one. The fundamental principles of the disability movement: independence, ‘rights not charity’ and equal opportunities did not translate easily (if at all) to non-Western environments. It was at that stage that the implicit assumption hitherto shared by representatives of the disability movement– that the desires and needs of disabled people were universal– needed to be questioned. ‘Identity politics’, something that formed the core of the ‘Western’ disability movement often clashed with the perceptions of activists elsewhere, who typically lobbied for project funding to support the local communities, rather than for more abstract rights. Moreover, aside from the ideological issues, technical matters also caused complications. One of those related to communication: not everyone was ready to accept that English should be the sole means of communication in international meetings and correspondence.

This essay argues that by moving beyond the ‘usual suspects’ and embarking on the study of the somewhat‘ unusual suspect’ of disability activism has potential to complicate and nuance both received knowledge about the history of internationalism and about our perception of the post-war period in Europe, including the Cold War and its aftermath. The pursuance of this topic also aligns with recent calls for diversifying existing research on the forging of international connections which has so far primarily focused on the internationalism of liberal elites. Furthermore, because this research weaves initiatives and developments at the individual, local and national levels into the international context, it aligns with the recent historiographical shift which has been described as ‘history in between'.[3] Studying disability internationalism adds a fresh perspective on the contribution of individuals who are typically qualified as 'recipients' of internationalism, but who have claimed themselves the expertise which is drawn not from medical or administrative knowledge but from the lived experience. It also helps recent ambitions to geographical de-center the history of internationalism.[4] While the main sites of international legislation are certainly located in New York, Geneva and Brussels*, the steps* that lead to the realization of new law-making often happen at different sites. All in all, the study of 'disability internationalism' contests binary divisions and monolithic views on expert versus lay knowledge, top-down and bottom-up action, the formal and the informal sphere.

Studying disability internationalism may help us rethink established labels and categorizations in the field. In that context, it represents a somewhat porous and often chameleon-like variant of internationalism which escapes straightforward categorizations. In many cases, this type of internationalism forms part of a social movement. In others it constitutes part of medical internationalism. This ambiguity is to a large extent due to the fact that while disability is a condition that connects people across borders, it is also an extremely heterogeneous condition: some people are born with it, while others acquire the condition during the course of their life. It may be permanent or temporary. It can manifest as a physical or cognitive condition, arising from a range of factors – genetics, accident, external circumstances, or advancing age. Often, people with such divergent conditions have nothing much in common other than the label of 'disability'. Some internationalization projects revolve around one single impairment type, such as Down syndrome and autism, while others are cross-disability initiatives involving a broader or a full spectrum of the condition. Whereas some 'internationalists' demonstratively reject the notion that disability is a medical

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3 A. Antic, J. Conterio D. Vargha D., 'Conclusion: Beyond Liberal Internationalism', *Contemporary European History*, 25:2, :361.
4 A. Antic, J. Conterio D. Vargha D., 'Conclusion' :365.

condition –for example sign language users who consider themselves to form part of a linguistic minority, others, such as AIDS activists, frame their condition as an ‘illness identity’. While bonds of solidarity, a *Schicksaalgenossenschaft* frequently emerged among these groups in the process of internationalization, it should not be denied that conflict and factions likewise frequently occurred. For example, people with physical disabilities often tended to distance themselves from those with cognitive or mental disabilities, a phenomenon which is usually referred to as ‘horizontal hostility’.[5]

Moreover, disability could be combined with additional identities. For example, in some countries, gay and lesbian disability groups also came into being. They often experienced double marginalization or exclusion: they felt that while the disability movement was dominated by heteronormative tendencies, the gay and lesbian movement by ableist tendencies. Forming a network of their own within either these communities was however not necessarily useful because of the small size of their groups.[6] Such shared experiences fostered internationalization and motivated the organization of the European Conference on Homosexuality and Disability, held in Uddel, the Netherlands in 1991.

Yet, it is precisely this ambiguity and multifariousness which may allow for adding new nuances to received knowledge on the history of internationalism.

Disability internationalism also provides an excellent platform to study the interaction between activities undertaken at the local, national and international levels. It reminds us that the national framework is neither irrelevant nor can it be discarded: many initiatives first evolve at the national level (often simultaneously) and the specificities of respective welfare states also hold relevance. At the same time, by constituting a shared experience which

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5 Eli Clare, *Exile and Pride. Disability, Queerness and Liberation* (North Carolina, 2015), 92.

6 See Nina Little’s MA thesis “Minority Consciousness Gone Mad?’ Exclusion, Inclusion and Self-Organisation of Disabled LGBTI People in the Dutch and British LGBT+ and Disability Movements in the Late Twentieth Century” (Institute for History, Leiden, 2019)

connects people across the world, irrespective of the region and political system in which they live, the adoption of transnational and international perspectives on the study of disability is not an option but a must.

This essay outlines the emergence of disability internationalism in the second half of the twentieth century, first and foremost in the European context, but also paying attention to regional specificities and global entanglements. It reveals that internationalisation has been a gradual process, and certainly not a teleological one: it was characterized by conflicts and detours, and the changing nature of the concept of disability has required the constant redefinition of its remit. At times it was characterized by certain shorter periods when an unusual density of activities could be observed. Typically, semantic shifts in disability-related terminologies in different languages provide a good indication of when those 'compressed periods' occurred. From this point of view, the 1970s were significant because it was in this decade that disability became problematized as a social and legal matter, while in the 1980s, the International Year of Disabled Persons (1981) and the subsequent International Decade of Disabled Persons (1993-2003) accelerated and intensified activities at the grassroots level. The topic provides new angles on the role of citizens' initiatives in the process of European integration by revealing how their lobbying contributed to a ground-breaking development on the global scale: the integration of disability into the framework of human rights, which culminated in the adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006. Moreover, the study of disability internationalism promises to provide fresh perspectives on the rising influence of non-state actors and impact of the proliferation of NGOs in the second half of the twentieth century. Last but not least, it may help us ponder at what stage and with what consequences grassroots organizations transformed into formalized institutions and how that process which typically involves the acceptance of certain superimposed expectations and a great deal of bureaucratization - changes their very nature.

Legacies of the war

The most gruelling legacy of the Second World War for disabled people was *Aktion Gnadentod* (Action Merciful Death), or *Aktion T4*, in the course of which altogether approximately 210 000 individuals with intellectual or psychological disabilities in the German Reich and a further 80, 000 in occupied Poland and the Soviet Union were murdered through deliberate medication overdose, poisoning or systematic starvation. [7] An initiative which evolved into an early instance of disability internationalism in a religious stetting, and has been referred to as 'a kind of inverse reflection to Nazism and an anti-fascist alternative to concentration camps'[8] was the Camphill movement founded by the Austrian Jewish paediatrician Karl König. Compelled to seek refuge in Scotland after the Anschluss and inspired by Rudolf Steiner's anthroposophy and the ideas of the Welsh utopian socialist Robert Owen, König established a life-sharing community model in which abled-bodied people lived together initially with severely disabled children and later also with adults in a spiritually curative environment.[9] Representatives of the Camphill movement considered the status of disability as a meaningful one and disabled individuals as capable of fully contributing to society. König believed that spiritual courage can help to make the 'mountain of handicap' irrelevant: in a supportive and sympathetic environment even those with a learning disability could develop self -confidence. Moreover, he viewed disabled children as social refugees who had been expelled from society in a similar way he had been forced out

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7 The literature on this topic is enormous. A suitable point of departure is Michael Burleigh, *Death and Deliverance: "Euthanasia" in Germany c. 1900-1945* (Cambridge, 1994).

8 Dagmar Herzog, *Unlearning Eugenics. Sexuality, Politics and Reproduction in Post-Nazi Europe* (Wisconsin MA.2018), 88.

9 For an analysis see Dan McKanan, *Touching the World: Christian Communities Transforming Society* (Collegeville, MN, 2007).

of his homeland. The initiative quickly spread throughout the world, at present there exist over one hundred communities in twenty countries.

A further instance of religious disability internationalism was the progressive Catholic *fraternité catholique des maladies*, founded by father Henri François in France in 1942. The first initiative in France was quickly followed by numerous autonomous groups in Western Europe and in Latin America and they have been in existence ever since. From the late sixties onwards, many of these fraternities became influenced by the spirit of the Vatican II synod and liberation theology. They were run by priests and layman who often themselves had a disability and while performing an evangelizing role, they were open to every denomination and even to atheists. The fraternities sought to liberate themselves from what they considered the paternalism of healthy people and they encouraged their membership to fight for disability rights and legislative changes in their respective countries. The various fraternities which were originally dispersed in different countries today operate in coordination and are known as the Intercontinental Christian Fraternity of People with Disabilities. [10]

Yet another community which grew out of religious roots is the initially Catholic and subsequently ecumenical *L'Arche.*[11] It was started in France in 1964, in Trosly-Breuil, a small village north of Paris by the philosopher and religious leader Jan Varnier who invited two people with intellectual disabilities to leave their institution and live with him.[12] From this micro-community a global movement emerged: in 2019 it involved 149 communities in 38 countries across the world. Like in the case of Christian fraternities, the unexpected expansion also necessitated a greater degree of coordination, which was realized by the

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10 Gildas Brégain, 'An entangled perspective on disability history: The disability protests in Argentina, Brazil and Spain, 1968-1982', in A. Klein, P. Verstraete and S. Barsch (eds.), *The Imperfect Historian: Disability Histories in Europe* (Frankfurt am Main, 2013), T. D'Argenlieu, *La fraternité catholique des malades* (Bourges, 1953).

11 Jean Varnier, *The Challenge of L'Arche* (London, 1982), Frances Young, *Encounter with Mystery: Reflections on L'Arche and Living with Disability* (London, 1997).

12 Unfortunately, a recent investigation has confirmed that Varnier abused his power and was guilty of sexual assaults of women.

establishment of an International Board. The novelty of *L'Arche*'s approach is that it went beyond traditional models of care and charity and created communities which are simultaneously protective and stimulating. It considers people with intellectual disabilities not as clients or patients but as companions who can undertake work, therapeutic and leisure activities in dignity.

Apart from resulting in the murder of hundred thousands of disabled adults and children, the war also disabled millions of soldiers and civilians. Of them, the ex-servicemen's assertion that they had sacrificed their health 'on the altar of the fatherland' could be utilized to forge a new form of agency: they were not get satisfied with the promise of mere survival and did not shy away from voicing their dissatisfaction with their conditions. Another group to assert their agency in a special way were people whose disability occurred in the course of industrial accidents – in a similar manner to the veterans, they were in the position to claim that they had sacrificed their able bodies in the service of their employers. Insurance companies and welfare states typically handled them as a separate category. By contrast, civilians, whose condition was neither due to war nor to accident, were treated as a burden that was draining the resources of the state. The relationship between these different types of groups was not always harmonious, particularly when they needed to compete for limited resources.

Disabled veterans –whose first experience of 'internationalization' often commenced on the front and victims of work accidents could also use their 'comparative advantage' for forging international contacts: theirs was the first organisation that connected national or local ones at the international level. FIMITIC (Fédération Internationale des Mutiles, des Invalids du Travail et des Invalides Civics) was established in 1953 as an umbrella association connecting already existing national organizations.[13] Associations for blind and deaf people which had come into being well before their equivalents for other types of impairment were next in the line to internationalize. The World Council for the Welfare of the Blind was established in 1949, while the World Federation of Deaf was founded in 1951 and both of them regularly organized congresses, some of which took place in Eastern Europe. These were however, organisations intended *for* blind people without including them in management and leadership. In 1964 a grassroots attempt was undertaken to turn World Council for the Welfare of the Blind into an organization *of* blind people by advancing the proposition that at least 50% of the leadership should be comprised of blind people themselves. This was however rejected by the leadership and as a result, a group seceded and formed an alternative platform, International Federation of the Blind. These two organizations then merged into the World Blind Union in 1984 during IFB's conference in Saudi Arabia.

Sport events provided a prominent site for internationalization. In 1952 the International Stoke Mandeville Wheelchair Sport Federation was formed to cater for the sporting interests of tetraplegic and paraplegic athletes and it initiated the first Paralympics Games that was held in Rome in 1960.[14] Under the aegis of the World Veterans Federation, International Sports Organisation for the Disabled (ISOD) was formed in 1964 with twelve participating countries and it acted as an umbrella organization that sought to unite participants with different types of disabilities, both from veteran and civilian groups.[15] The first Winter Paralympic Games were held in Sweden in 1976. Deaf people also have their

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[13] Despite its crucial role, there exists virtually no academic literature on the history of FIMITIC. A small pamphlet published by the organization dating back to 1977*, The FIMITIC's Social and Socio-Political Programme* gives a short overview.

[14] The first event to be officially called Paralympics was held in Tokyo in 1964. The Rome games initially run under the title 9th International Stoke Mandeville Games, it was then designated as the first Paralympics with retroactive effect.

[15] For a comprehensive account of the Paralympic games see Steve Bailey, *Athlete First. A History of the Paralymics Movement* (Chichester, West Sussex, 2008).

own tradition of organizing international sports games, the first such event – today known as Deaflympics – was organised in Paris in 1924, while the inaugural Winter Deaflympics was held in Austria in 1949, with the exclusive participation of male participants.

Professionals, parents, grassroots: the remaking of mental retardation

As has been hinted above, isolation and segregation belonged to the fundamental experiences of persons with disabilities for a very long time. Their status was considered to hold relevance for social policy and charity, in line with the general assumption that they were in fact eternal children and decisions needed to be taken on their behalf. Although international contacts did occur between medical personnel and policy makers –for example, in the form of conferences and visits – such contacts between disabled people themselves were at first largely unheard of and even unthinkable. While the status of persons with any type of impairment carried a stigma with it, this was especially the case for people with mental and intellectual disabilities. They constituted 'a hidden society' confined to an indefinitely prolonged childhood, whose situation was deplorable even in the world's most coveted welfare states. This situation was recognized by the (progressive) members of the scientific-medical community, by parents and families, in addition to the representatives of the concerned groups.

At the grassroots level, unsurprisingly, parents were the first 'agents' to initiate change by forming organizations that brought these issues out of the private, family sphere to the public realm and then aligned themselves with professionals to solicit help from the state. Parents' organizations in the Nordic countries evolved out of the paradox that while these countries fashioned themselves as norm entrepreneurs in welfare matters, they neglected the needs of disabled people, particularly if were not in employment. Like in several other countries, the inhuman and unacceptable conditions in institutions and boarding schools caring for children and adults with intellectual disabilities became disclosed with methods ranging from undercover journalism to full-fledged documentary films. As is often the case with grassroots organizations, a well-known public figure may find himself in a good position to give impetus to sparking a 'movement'. This happened in Norway in the 1960s when Arne Skouen, a film director with an autistic daughter demanded 'Justice for the Disabled' and criticized the Norwegian state for violating human rights. He compared conditions in institutions to concentration camps which led to two legal cases: a defamation case against him, and an investigation on the conditions of institutions. The outcome of the investigation was that while Skouen exaggerated his claims, living conditions in institutionalized settings were definitely unacceptable.[16]

Parents' struggles yielded significant results: the principle of normalization, i.e. that the living conditions of those with disabilities should become as close as possible to 'regular' life (rhythm of life, choices, provisions) became increasingly accepted as a desideratum: 'If an equality viewpoint is not acknowledged, there is a risk of ending simply in sentimental pity, in theories of overprotection, in group-discrimination or something else.'[17] Nordic parental groups easily connected across borders because of the absence of the language barrier, but similar problems elsewhere triggered similar responses. For example, the Greek Panhellenic Union of Parents and Guardians of Unadjusted Children was confronted with identical problems and as a nonprofessional voluntary association it contributed to the 'politicization of the private' from the grassroots level in late twentieth-century Greece.[18]

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[16] Egilson B. Berg et alii, *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging* (London, 2015), 30. , see also Jan Tøssebro, 'Scandinavian disability policy: from deinstitutionalization to non-discrimination and beyond,' *Alter,* 10:2 (2016), 111-123, Marie Sepulchre, 'Tensions and Unity in the Struggle for Citizenship: Swedish Disability Rights Activists Claim: Full Citizenship!', *Disability & Society*, 33:4 (2018): 539-561.

[17] Tossebro, 'Scandinavian disability policy',. 3.

[18] Despo Kritsotaki, 'Turning Private Concerns into Public Issues: Mental Retardation and the Parents' Movement in Post-War Greece, c. 1950-80, *Journal of Social History*, 49:4:1 (2016): 990.

The ‘remaking’ of mental retardation[19] required the dissociation from the earlier notions of degeneration and eugenics and framing it as an issue of rights and social integration – the latter of which required special educational opportunities. This transformation provided the foundations for the emergence of international self-advocacy. The rights of people with intellectual and developmental disabilities were taken up by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), an organization which was born out of three international congresses held in London, Vienna and Copenhagen in 1960, 1961 and 1964 respectively. The International Association and its constitution were formalized at the 1964 Congress. Another important association that contributed to the coming into being of new international legislation was the International League of Societies for the Mentally Handicapped (today Inclusion International) which was established in 1960 during the World Mental Health Year and which operated in collaboration with experts, parents and volunteers. Moreover, a symposium organized in Stockholm in 1967 on legal aspects addressed the role that parents associations can play in ensuring that new legal provisions would be fully implemented. It also pointed to the ‘limits’ of internationally imposed norms: political cultures and welfare provision differed from country to country, so no single ‘winning formula’ could be proposed. Instead, a variety of methods were suggested, including 1. the creation of a favourable public opinion; 2, active dialogue with public authorities and members of the practising professions; 3. appeals to members of legislative bodies; 4. appeals to the courts, where feasible; 5. the nomination of parents on Boards of Control by the responsible authority, agency or ministry concerned.[20] Both IASSIDD and the League played crucial

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[19] Kritsotaki, ‘Turning Private Concerns into Public Issues’: 990.

[20] Symposium, ‘Legal Aspects of Mental Retardation, Stockholm, 1967, Conclusion’, Section II/2, pages 7-8, https://mn.gov/mnddc/parallels2/pdf/60s/67/67-ILS-ILS.pdf

roles in placing the issue onto the UN's agenda. To that end, at its Jerusalem conference of 1968 the League formerly passed the Declaration on the General and Special Rights of Mentally Retarded Persons which directly influenced the 1971 UN Declaration on the Rights of Mentally Retarded Persons.

A new dynamic in these discussions occurred when some (elite) representatives of the groups with intellectual and learning disabilities, surely also inspired by the spirit of the student movement of 1968, started to 'talk back' to what they considered to be the misrepresentation of their cause by professional and even parents' organizations. The most significant instance of such counter-initiatives was *People First*, which had its origins in Sweden and in the United States. It was the reaction of a group of young people with intellectual disabilities to the well-meaning, but in their view patronizing impact of parents' organisations which were formed across Europe and the world. They no longer found the Swedish parents' organizations' motto: 'We speak for them' acceptable because they wanted to *speak for themselves*. They prepared a list of changes that they wanted to their services. Similar groups formed in the Britain, Canada, New Zeeland and many other countries including one in 1974 in the United States. Here, one member, whose name and person had fallen into oblivion, grew tired of being called 'retarded' and burst out declaring: 'We are people first' and hence, the name of the self-advocacy movement was spontaneously born. One of the significant achievements of the People First movement has been the creation of an easy language variant in several languages. In Sweden, the idea to publish easy-to-read texts was first proposed in 1968 by the Swedish National Agency for Education. The first journal in simple language was published in 1984 and since then *8Sidor* appears on a weekly basis and contains 8 pages (hence the title). The initiative gained recognition at regional and international meetings and became 'Europeanized' when in 1998 the first European guidelines were established and in 2009 Inclusion International adopted it.[21] Easy language – understandable and accessible information– is considered a political issue, because it dismantles barriers which are created by difficult and inaccessible language. On the other hand, it is not intended to be patronizing, this is why one of the remarkable recommendations in the European guidelines is not to use the familiar form ('dutzen') in these texts. [22]

The social model of disability and the emergence of a human rights-based framework

As we have seen, the emergence of self-advocacy groups had been preceded and accompanied by a host of developments which led to the redefinition of disability from being an exclusively medical concept into a social category and from a status of 'burden' on the state into a condition which offered the possibility of active citizenship. According to this new understanding, disability could no longer be merely considered a personal 'defect' in need of rehabilitation but was perceived as a collective issue of a marginalized community struggling for equality. As the old, medical model of disability was gradually replaced by the social one, attention shifted away from the individual's impairment to the discriminatory social attitudes and physical barriers that prevented disabled people from participating fully in the community. The upsurge in disability activism led to a new, rights-based approach which required an entirely new way of thinking: rather than just ensuring the mere survival of disabled people, it acknowledges that they are entitled to a quality of life. Instead of being objects, patients, eternal children, they became subjects, active agents in their own fate. Grassroots movements started to 'talk back' to the mainstream of society by refusing the 'abnormal' and 'crippled' label. This process of politicization went hand in hand with the recognition that disability can become the basis of a social movement and a social identity.

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21 Gudrun Kellermann:,'Die Rolle der Leichten Sprache aus wissenschaftlicher Sicht', https://www.zedis-ev-hochschule-hh.de/files/kellermann_08042013.pdf

22 Kellermann, 'Die Rolle der Leichten Sprache'.

Like other social movements, the disability movement was characterized by a paradox: on the one hand it was fighting for equalization and integration, and such claims for recognition implied the abolition of differentiation. On the other hand, it sought to obtain parity of participation and made claims for redistribution and this presupposed that disability is a distinct movement and identity. This 'bivalent' character of the social movement – emphasizing integration versus emphasizing difference – led to a certain tension in citizenship claims.[23]

The world's most significant cross-disability organization, Disabled People's International (DPI), owes its existence to a scandal at the 1980 Winnipeg World Congress of Rehabilitation International, a traditional organization of medical and rehabilitation experts founded in 1922. The tension that emerged during this conference provides a good illustration of changing perceptions. It was during that meeting that Swedish delegates recommended amending the organization's constitution in such a way that at least 50% of the delegates should be a person with disabilities. This amendment was rejected, much to the irritation of many participants who seceded the meeting and organized an alternative one, 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 in Singapore. In its draft constitution –which was modelled after the ILO's constitution– DPI complimented Rehabilitation International 'for making possible the vehicle for the formulation of the world coalition' and in that way contributing to acquiring a voice of their own.[24] Due to an unexpected turn of events, it became possible for Henry Enns, one of the founding members to attend the United Nations Advisory Committee meeting for the International Year of Disabled Persons in Vienna held

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[23] Nancy Fraser, 'From Redistribution to Recognition? Dilemmas of Justice in a 'Post-Socialist' Age.' *New Left Review*, 1995, 212: 68–93.

[24] Diane Driedger, *The Last Civil Rights Movement. Disabled People's International* (London, 1989), 36.

in August, 1981 and to contribute to the drafting of the World Program of Action Concerning Disabled Persons (WPA) as well as to publicize DPI's philosophy.[25]

The history of DPI provides a remarkable instance for the study of internationalization because it reveals that the trajectories, interests and opportunities of European internationalists at times converge, but on other occasions conflict with those of non-European internationalists. DPI was compelled to set certain priorities: for example, it devised a Development Program which only included developing regions. This was understandable given the scarce resources, but on the other hand it did not reflect on the fact that even in Europe disabled people constituted the poorest of the poor. Moreover, the existence of an array of disability-related organizations in Europe initially weakened the motivation to collaborate with DPI. Especially the leaders of FIMTIC, which had a consultative status with the UN's affiliated organizations, were reluctant to collaborate at the outset. Differences in ideology also caused frictions: members from 'Western regions' debated prioritized debates about identity politics, much to the dismay of members from developing regions who wanted concrete action and financial support. Notions of equal opportunity and full participation and demands for justice rather than charity did not necessarily resonate in their local environments. They were also disappointed by DPI's attitude: it did not raise funds itself, rather, it sought to provide contacts, so that disability organisations can find their own funding for their projects. [26] Moreover, fundraising itself proved difficult, as funds were usually controlled either by governments or charities. In order to be able to compete for funding, the disability organisations were compelled to exploit stereotypes of pity and helplessness – the very stereotypes they were seeking to counter with their activities.

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25 Driedger, *The Last Civil Rights Movement*, 43-45.
26 Driedger, *The Last Civil Rights Movement*, 67.

Developments in the 1970s and early 1980s, which led to a breakthrough in disability legislation at the UN level, also made their mark within the European Community, albeit somewhat slowly. In 1980 the Disability Intergroup of the European Parliament was established, one of the earliest intergroups in the history of the Parliament. Initially, the focus was on market integration and this was stimulated by two Community Action Programmes for Disabled People: HELIOS I (1988-1991) and II (1993-1996). These initiatives and policy measures intended to help disabled people from above, but it was not before long that the motto 'nothing about us without us' entered discourses within the European community.

A crucial concept which provided the main rationale for the establishment of the European Network of Independent Living in 1989 (ENIL) was *independent living*. It entails that disabled people, if they so wish, should be able to lead a life which does not make them subject to paternalistic tutelage, but enables them to exercise their autonomy. In addition to the accessibility of the environment, at the core of the concept is the notion of individualized *personal assistance* which increases independence and equal opportunities. The origins of the independent living movement reach back to a student initiative at Berkeley in 1972 and as such provide a good instance of the transnational character of international disability activism. In this year a group of disabled students moved out of the Berkeley campus to the local community and created an Independent Living Center. That the concept could take firm roots in Europe was to a large extent due to Adolf Ratzka, a German polio survivor who moved to Berkeley after he had not been able to find an accessible and affordable place to pursue his studies in his native country. The experience at Berkeley changed his life, as he put it: 'I was catapulted from the vegetable existence of a German hospital to the hotbed of flower-power activism'.[27] It was at an international conference on housing in Gothenburg

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[27] See: https://www.independentliving.org/docs5/time.html

that the Norwegian Bente Skansgard, paralyzed due to a car accident in her youth, met Ratzka in 1981 who by this time was living in Sweden. Three years later she organized the first conference on independent living in Scandinavia and the Stockholm cooperative for independent living was formed – a pilot project for personal assistance for 22 people.[28] While the concept was becoming a reality in Sweden and Norway, European-wide awareness was still lacking. In April 1989, 72 disabled persons from 20 European countries convened at a conference in Strasbourg with the intention to spread the independent living approach throughout Europe, where residential segregation of disabled people was still very much the norm. It was at this meeting that the decision was undertaken to establish an informal network and this is how ENIL came into being.

Grassroots international initiatives also proved crucial in pushing for new European legislation, and the act of 'pushing' could at times be rather spectacular. On 3 December 1993, the newly opened European Parliament building in Brussels was witness to a rather unusual scene: 440 disabled people from all over Europe entered the huge debating chamber and 72 of them took the floor and gave short talks about their experiences of segregation, discrimination and abuse. The occasion was the first Day of Disabled Persons and the unusual guests came to affirm their human rights under the European Convention. [29] As the masterminds of this event, British activist Rachel Hurt and Arthur Verney, at that time president of the British Deaf Association later recalled, the event was rather difficult to organize: on two previous occasions, Hurst's request to use the building was turned down by the Parliament's gatekeepers. So they had to turn to direct action. As she recalled:

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28 Today this is the Stockholm Independent Living Institute.
29 'Rachel Hurst: Activist/Campaigner', in Mary Wilkinson (ed.), *Defying Disability. The Lives and Legacies of Nine Disabled Leaders* (London, 2009), 58.

I got in the heavy mob from Northern France. I made contact with Disabled People's International in France and they sent half-a-dozen fierce young men in large wheelchairs, with posters. The Parliament went completely egg-shaped and refused to allow them into the building with their posters. So I said, 'Why not? This is a place of democracy and we are entitled to come in'. Faced by concerted lobbying, the questors capitulated. 'We found out later that the reason they had said no in the first place was because they thought we were going to pee on their seats! [30]

It was on the recommendation of activists from different countries to include a specific non-discrimination clause when the Maastricht Treaty of 1992 (the founding treaty of the European Union) came up for revision. This eventually happened in 1996, with the introduction of article 13 to the Amsterdam Treaty.[31] 1999 saw the establishment of the International Disability Alliance (IDA) as a network of global and, since 2007, regional organisations of persons with disabilities (DPOs) and their families. The organization has five regional sections, among them a European one which represents 350 organizations in 50 countries. The main objective of IDA is to ensure the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) worldwide.

Impairment-specific international organizations

In addition to these umbrella organizations with a European or global mandate, the number of single-impairment organizations has been greatly increasing over the last three decades. One reason for this proliferation may be that paradoxically, the more 'universal' and inclusive the definition and perception of disability has become internationally with the

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[30] *Defying Disability*, 60-61.

[31] Deborah Mabbett,'The Development of Rights-Based Social Policy in the European Union: the Example of Disability Rights, *Journal of Common Market Studies*, 33:1 (2005): 106.

adoption of the UNCRPD; the less attention can be paid to the specificities of particular types of disability in specific situations. Even within Europe, the problems that need addressing may be entirely different in Switzerland than in Serbia. In this context it is worth noting that while many of these organizations collaborate with the institutions of the European Union, their mandate typically extends to the entire continent and not merely to EU countries. Listing all of these associations would go beyond the remit of this essay; however, introducing three of them briefly may offer an insight into their dynamics. The Brussels-based Autism Europe which was set up in 1983 by parents groups and has risen to prominence because of the huge increase in the diagnosis of autism in recent decades (whether because of better diagnostic facilities or because of changing definitions of the condition): 7 million people are estimated to be affected by autism in Europe.[32] The main objective of the organization is awareness-raising and the promotion of the rights of those living with autism. In doing so, the association is compelled to navigate between divergent approaches to autism. Representatives of the neurodiversity movement believe that neurodiversity is as crucial for the human race as is biodiversity for nature. At its extreme, autism can therefore be understood as a natural human variation of the human genome and not a pathological disorder that would require cure or treatment.[33] This approach may have a ‘normalizing effect’, but the ‘romanticization’ of autism downplays the problems associated with it and it may also lead to reluctance among parents to seek treatment for their children. To a certain degree, the organization embraces the principle of neodiversity, but it simultaneously advocates for better care and educational opportunities for autistic people.

While more and more people are becoming diagnosed with autism, fewer and fewer children with Down syndrome are being born in Europe as a result of prenatal screening. The

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32 https://www.autismeurope.org/who-we-are/mission-vision-values/

33 Jim Sinclair, *Don't Mourn for Us*, 1993, See also *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*; 1:1 (2012)

European Down Syndrome Association is the continental representative of Down Syndrome International, an organization which was founded in 1993.[34] It is mainly run by parents and caregivers as a human-rights advocacy organization with the aim of spreading information and contributing to the de-stigmatization of the condition. It is operated on the principle that the capabilities of persons with Down syndrome should take precedence over their limitations. Somewhat similarly to the dilemma of autism advocates, members of the organization need to navigate between the assumption that ‘there is much richness in life with an extra chromosome’, and hence the syndrome is not a tragic divergence of proper human function, and the realization that having a family member with a Down syndrome is often experienced as a lifelong burden. The association has recently led highly successful campaigns on World Autism Day (2 April) that encouraged people to wear mismatched socks on that day to raise awareness. Yet, the case of international autism activism once again reveals that developments at the national level cannot be overlooked. Currently, abortion rates of pregnancies that test positive are around 90% in the United Kingdom, 98% in Denmark and 100% in Iceland. It is not surprising therefore that in 2017 Iceland’s president was criticized for his ‘progressive hypocrisy’ for posing with mismatched socks in social media while ‘modern eugenics’ is supported in his country.

The emergence of grassroots organizations of (former) mental health patients followed a somewhat different trajectory from that of those with physical disabilities. This group was often stigmatized even within some segments of the disability movement. Groups were initiated by survivors of psychiatry who were subject to involuntary institutionalization, forced treatment and abuse. The invention of modern psychiatric drugs provided an important impetus for de-institutionalization. Nevertheless, many people experienced the involuntary

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[34] The association’s archived newsletters can be accessed here: http://www.edsa.eu/historyarchives/

used of drugs not as a form of cure but as a form of control. Paradoxically, both those who have advocated the better accessibility of drugs and those who pointed to the misuses have accommodated their plight as a human right issue. The idea to establish a network of users and survivors of psychiatry first arose in 1991, during a conference in Mexico. In 1999 the organization was formalized with a secretariat in Denmark and continued to operate under various names. The Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) was established in the final stage of the negation of the Convention on the Rights of Persons with Disabilities (2006). The European section of the global organization, ENUSP, defines itself as a pan-Europa disease-specific organization.

The majority of these organizations, even if at their outset they were flexible and informal grassroots networks, today operate as NGO’s or INGO’s. This is also in alignment with the UN Convention on the Rights of Persons with Disabilities in 2006, the acceptance of which was hailed as an achievement ‘giving voice’ to disabled persons. However, the convention’s sole emphasis on ‘strategic leadership in human rights advocacy’ and awareness-raising has become a target of criticism: abstract claims of empowerment do not replace service provision and can hardly help people whose situation demands immediate intervention. Moreover, the formalization of status led to a high degree of bureaucratization and the imposition of straightjacket models and ‘predetermined scripts’ which often went in parallel with the need to relinquish their grassroots status. The expectation of self-sufficiency, a crucial buzzword of policy, in certain situations may amount to nothing less than the relinquishing of any collective responsibility towards the vulnerable members of society.[35]

Last but not least, cultural organizations promoting ‘disability art’ have also seen a degree of internationalization recently, although some early instances can also be observed.

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35 Stephen Meyers, Civil Society as Megaphone or Echo Chamber? Voice in the International Disability Rights Movement, *International Journal of Politics, Culture and Society* 27:4 (2014): 461.

For example, the Association of Foot and Mouth Painting Artists of the World was established in 1957 in Lichtenstein, as a self-help group, a ‘democratic cooperative’. Its first director, Arnulf Erich Stegmann was a polio victim. Members had the opportunity to exhibit their work in several museums and exhibition halls, the first two exhibitions took place in 1981 in the Town Hall of Madrid and in the UN’s Headquarters in Geneva. AMFPA grew into a global organization with regional sections and the main activity of the contributing artists is the production of Christmas cards. Operating as a for-profit organization, in recent years it attracted criticism because of the aggressive marketing strategies and because it was established that the artists themselves received only a minuscule portion of the profit. In addition to the existence of separate associations of disabled artists, another trend has been the emergence of a ‘disability scene’ within the mainstream art circuits. For example, Disability Arts International, which was created in 2013 by the British Council as part of an EU initiative, promotes disabled artists in collaboration with Greek, Dutch, Italian, German and Swedish theatres.[36]

How can the study of the internationalization of disability organizations and of disability activism complicate existing mainstream knowledge on the history of internationalism? For one thing, it encourages us to pay more attention to the multifarious spatial dimensions and patterns of internationalism both within and outside Europe. The dynamics of disability activism could follow different trajectories: at times they grew out of a single initiative, at other times from bi-or multilateral cooperation that can easily be located in time and space, but more frequently it involved a polycentric process. While initially the main ideals of of disability activism appeared to be self-evident, once the movement

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[36] http://www.disabilityartsinternational.org/creative-europe-announcement/

expanded onto the global stage it became clear that despite being a universal condition, it meant many things to many people.

In light of the pivotal role that the notion of expertise plays in histories of internationalism, the concept of disability can contribute to changing implicit assumptions about the clear delineations of expert knowledge. This essay has revealed an intriguing relationship between medical experts operating as activists or advocates, parents claiming expertise as activists or advocates and people with disabilities emphasizing their own expertise and asserting their right to speak for themselves. Put it differently, it has demonstrated that identities of experts, activists and ‘recipients’ are uniquely fluid and fraught. Last but not least, by hinting at the connections between the disability movement and other internationalisms, such as the gay and lesbian movement, the chapter has also outlined a methodological desideratum for future research: the need to pay more attention to those overlaps by putting on an intersectional lens in historical studies of internationalism.