

REVIEWS

Self-Advocacy and Ally-Advocacy for Disability Justice: Organisational, Psychosocial, and Political Resources

Henry McCarthy*

ABSTRACT

The world of today sees more persistent, collective work of marginalised people resisting structural oppression rooted in racism and misogyny through newly-organised multinational movements like Black Lives Matter, #IamSpeaking, and Me Too. This has led to a rapid rise in public consciousness and activism about social injustices across many sectors of society. Ableism and other types of discrimination in education, employment and community-living experienced by people with a disability have both similarities to, and differences from, the indignity and impact of racism and misogyny. The activist disability community is working hard to have their advocacy agendas gain more public awareness and support. The common ground among all oppressed groups is their demand to have their human rights honoured. This requires two societal value shifts: (1) listening to voices outside the dominant culture and power structures through the involvement of insiders, based on their lived experience as members of the marginalised groups, and (2) collaborative advocacy to achieve milestones on their journey towards social justice. Applying these principles, this article aims to elevate and amplify the historical and current activities of self-advocates from the disability community to affirm and secure their human rights. The article provides explanations and examples of: (1) the complexities of disability-based discrimination; (2) political activism by the disability rights and independent living movements in the United States; (3) the psychosocial dimensions of embracing disability identity, culture, and pride; and (4) various outstanding consumer-driven artistic and organisational resources that are shaping the evolution of equal opportunity and disability justice.

Key words: *disability pride, human rights, self-help organisations*

* **Corresponding Author:** Louisiana State University Health Sciences Centre, United States of America.
Email: hmccar@LSUHSC.edu

INTRODUCTION

Traditionally, disability was perceived as a defect or deficit in the individual, signifying dependence and misfortune. Over the past half-century, persons with disabilities and their allies have collaborated to replace these disparaging attitudes with a more realistic and affirmative understanding of disability as a virtually inevitable human variation that can be transcended by environmental accommodation and social inclusion. While disability has indeed been a source of multi-dimensional social injustice, it also fosters for many a positive socio-cultural identity and can serve as a transformative experience for living a more meaningful life. For individuals with disabilities not yet experienced in self-advocacy, this article offers perspectives and resources for learning about the disability community's agendas, accomplishments, and continuing contributions to improving their quality of life and making a society more equitable and fulfilling for all. That learning can inspire and strengthen all such individuals' journey of self-discovery and justice in pursuing their potential. A sense of empowerment can be nurtured by knowing about the ingenuity and perseverance of people who have had comparable challenges and have turned around their situations, getting past entrenched barriers to social equality by fighting for their human rights and personal dreams. For people without disability from the service professions or community at large, it is hoped that this article will promote further exploration, discussion, and application of an understanding of disability issues that will allow them to become effective allies.

By way of clarification, the term "disability" is broadly used throughout this article to encompass persons with various types of physical, intellectual, or behavioural limitations or disparaged differences that have resulted in their being excluded and stigmatised. **Disability justice** is conceived as removing systemic barriers to, and providing accommodating support of, human rights, social inclusion, and self-determination of people with disabilities. At least as early as 1960, Wright (pp. 7-8) recognised the disadvantages of reductionistically equating a person with a medical condition (e.g., he is an epileptic), so person-first language was recommended when writing and speaking about persons with disabilities. This principle is now widely followed to affirm the holistic humanity of those who have been disparaged and pigeonholed by a disability label. However, not everyone endorses using person-first language, including those who assert their preference for claiming and using the term "disabled" because of their deep sense of pride in that identity and experience. In recognition of this dual validity of insiders' own

preference in self-referencing terminology, both usages are incorporated into this article. See Dunn and Andrews (2015) for a fuller discussion of this issue.

COMPLEXITIES OF DISABILITY-RELATED INDIVIDUAL DISCRIMINATION AND SYSTEMIC OPPRESSION

In many countries, of any single demographic characteristic, having a disability is the strongest predictor of living in poverty. In turn, poverty has a negative impact on one's ability to engage in activities that promote educational attainment, healthy development, and safe living. The disability experience is slowly being included within the scope of multicultural sensitivity and social justice issues that are of increasing interest in contemporary agendas of academia, business, and governments around the world. This is evidenced by the addition of competence in addressing disability issues to human service professionals' codes of ethics, corporate personnel and customer-relations practices, and public policy priorities. National legislation that prohibits discrimination against persons with disabilities in education, employment, and community participation usually parallels and sometimes precedes progressive changes voluntarily made by autonomous academic, corporate, and community organisations.

Grasping the impact of oppression requires understanding and sensitivity about the varied ways in which it operates and is expressed. **Ableism** is ingrained systemic discrimination against people with disabilities, whether the disparaged difference is functional or simply aesthetic. It is called ableism because it sets and maintains standards of acceptability based on the capabilities and preferences of the able-bodied majority, rather than thinking outside the ingrained routines to consider the real range of individual needs and workable options in any performance situation. Although created often in a taken-for-granted way, ableist assumptions nonetheless lead to the imposition of physical or procedural structures that are riddled with barriers to access and inclusion for people who cannot use their eyes, hands, legs, etc., in "normal" ways. In contrast, the concept and principles of **universal design** maximise the participation of people with a wide spectrum of functional abilities and methods, because its goal is to make the designed result as easily usable by as many potential users as possible, not to force the person to fit the design. Although the concept originated in the fields of architecture and engineering, it has also been effectively applied to behavioural disciplines like communications and education (e.g., Bowe, 2000). This quote by Montgomery (2004) capsulises the goal of universal design incisively:

"I see the situation disabled people are in as unjust, not tragic. Created and sustained by society - which is to say, by all of us - and therefore potentially changeable. I'm not interested in changing myself into the sort of person society automatically enables; I'm interested in changing society so that it enables all its members."

An awareness training manual edited by Johnson (2006) is a great resource for understanding the evidence of ableism in our everyday world and for sensitising people to ways of combating it.

Hahn (1993) developed a theory about unconscious reactions to disability as a stimulus in interpersonal situations. He cogently argued that when people without disability encounter a person who has a visible disability, two emotional reactions are often stimulated by our primitive-brain impulses. He termed these apprehensions felt by observers: (1) *aesthetic anxiety* (discomfort at being close to bodily disfigurement or deviant appearance because it reminds them that they too are vulnerable to acquiring such losses of bodily function or integrity); and (2) *existential anxiety* (unconscious threat felt to their own safety and existence by seeing disability and subconsciously associating it with traumatic or fatal accidents). Hahn suggested that these anxieties are a major contributor to negative attitudes and dysfunctional behaviours regarding disability. Thus, purely on the basis of how our minds make such implicit negative associations, people (including educated professionals) may inadvertently avoid or mishandle important interactions with people with disability. Such anxious and foreshortened interactions can easily lead professionals to underestimate the capacities or to misinterpret the intentions of a client or colleague with a disability.

There is notable within-group variability in how discriminatory behaviour is interpreted and responded to by individuals from any marginalised group. Reactions include anger, shame, internalised inferiority, self-protective strategies, and avoidance of precipitating situations or strategically responding to expressed prejudice out of a desire to understand and educate the offending person or institution. *Intersectionality* is a relevant concept that deserves mention here. It refers to the fact that many people have layered or interacting identities reflective of more than one socially marginalised group. Self-identifying or being perceived as part of such multiple groups often exacerbates or complicates persons' experience of discrimination. Although further exploration of the impact of intersectional identities is beyond the scope of this article, readers should: (1) consider intersectionality of identities in their work with students,

clients, families and colleagues; and (2) engage in further learning as needed on this topic through reading, reflection, discussion, and awareness training. Some recommended publications include: Shaw, Chan and McMahon (2012) and Goethals, De Schauwer and Van Hove (2015).

POLITICAL ACTIVISM THAT HAS ADVANCED DISABILITY JUSTICE: THE DISABILITY RIGHTS AND INDEPENDENT LIVING MOVEMENTS

It was the interwoven, persistent activities of the disability rights movement (DRM) and the independent living movement (ILM) of the 1960s and beyond that generated the powerful, concrete demonstrations of a paradigm shift in perceiving and managing disability. These movements' trailblazers deconstructed the dominant medical model's narrow definition of disability as a problem within the person that needs to be cured or corrected by changing the person. Alternatively, they explained how external factors like inaccessible environments, paternalistic attitudes, and discriminatory policies create the real and unnecessary problems of living with a disability. Accordingly, a clearer term for this conceptual perspective, known in academia as the social model of disability, is believed to be the **self-determination philosophy** of the ILM and the **human-rights platform** of the DRM.

The most extensive and impressive source of information about the ILM and DRM in the United States is by Fred Pelka (2012). It is a delightful read in one long, well-annotated volume composed mostly of his original interviews with activists or similar interviews excerpted from the Oral Histories and Archives project on Disability Rights and the Independent Living Movement (www.bancroft.berkeley.edu/collections/drilm/index.html). Other informative and interesting accounts of these movements and their leaders include: Charlton (1998); McMahon and Shaw (2000); Fleischer and Zames (2001); McCarthy (2003); and, Davis (2015). The DRM and ILM have been largely composed of people with physical disabilities such as musculoskeletal, neurological, or sensory conditions that did not affect mental functions. Corresponding activism by people whose only or primary condition is intellectual disability is usually called the **self-advocacy movement**, and Caldwell (2011) is a fine example of similar research on its leaders.

Certainly there were efforts demanding equal opportunity by small groups of self-advocates with disability throughout the world and earlier in the 20th

century. However, the Zeitgeist of activism demonstrated by the Black civil rights, women's, American Indian, and gay rights movements of the 1960s was a momentous impetus for frustrated persons with disability to organise and self-advocate. A clear example of that occurred in the hotbed of that era's liberation movements, the University of California- Berkeley (UCB). In 1962, Ed Roberts enrolled in UCB, which has competitive admission standards. Ed's acceptance involved one extra hurdle: getting the administration to admit its first resident student with a significant physical disability. As a polio survivor with a paralysed diaphragm and extremities, he required personal care assistance and ongoing use of a respirator, a portable one attached to his electric wheelchair by day and a full-body "iron lung" in which he slept at night. Despite such physical dependencies, and through his persistent self-advocacy, he convinced the administration to allow him to live on campus, in a dedicated section of the University Infirmary where staff were available to provide assistance. Given the pervasive social expectation of that time, that people with that level of disability would not pursue higher education and a career, it is a tribute to UCB that they were able to think outside the box of these accepted norms to give Ed a chance and eventually support the self-help Physically Disabled Students' Programme he organised. It became the Centre for Independent Living (CIL) (www.TheCIL.org) in 1972 and moved off-campus in 1975. There, services were provided that included wheelchair repair, referrals to accessible housing, and career-development assistance, all provided through peer-counselling and peer-teaching. It has been the model for more than 400 IL Centres in the United States as well as similar programmes in 20 other countries. Ed died in 1995, widely acknowledged as the founder of the IL movement in the U.S.

PSYCHOSOCIAL RESOURCES THAT EMPOWER SELF-ADVOCACY: DISABILITY IDENTITY, DISABILITY CULTURE AND DISABILITY PRIDE

The following excerpt is a good starting point for describing these inter-related psychosocial concepts:

"People with disabilities have forged a group identity. We share a common history of oppression, and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride, as part of our identity."

(“What We Mean by Disability Culture” link at www.instituteondisabilityculture.org) All three are multidimensional processes that evolve over time within most persons with disability. Most succinctly, the processes concern the different choices persons with disability can make regarding the degree to which they: (1) integrate that aspect of their selves, the acknowledgment of their disability, into their self-definition (disability identity); (2) develop an identification and preferential affiliation with others who offer the connections of understanding the disability experience and investing energy in both celebrating its unique opportunities and reducing its social marginalisation (disability culture); and (3) present a self-concept that embraces one’s disability experience as a source of personal strength and not shame (disability pride).

The topic of disability identity development was the most easily understandable of the three concepts, because there was an established history of related theory and research, for example on racial and feminist identity development. Interesting analyses of disability identity and activism that span three decades include: Scotch (1988); Gill (1997); and Forber-Pratt and Zape (2017). Disability culture emerged from ideological and sociological discourse in academia and the arts, starting around 1990. Some significant publications on disability culture are Linton (1998), Longmore (2003), and Riddell and Watson (2003). In the U.S., the academic discipline of disability studies and its flagship organisation, the Society for Disability Studies (www.disstudies.org), are the main engines of scholarship and mentoring that have successfully promoted both the political and psychosocial aspects of the disability experience. Putnam (2005) hypothesised that disability pride is one component of disability identity; and that it consists of four affective-cognitive elements. These are: (a) affirmatively “claiming” disability (a term chosen to contrast with the typical therapeutic goal of “accepting” one’s disability); (b) seeing impairments as a natural part of the human condition; (c) believing disability is not inherently negative, although it is frequently interpreted so; and (d) experiencing disability as a journey of developing a consciousness and identification with a cultural minority group.

At least three subpopulations of disability culture or pride can be distinguished that share fundamental commonalities but usually operate within their own networks. One is composed primarily of people with obvious physical disabilities. For them, access and accommodations for blindness and wheelchair mobility have been major issues; assertive personalities and effective communication skills have been their notable strengths. This group is predominant among the trailblazers

and current participants in the ILM and adapted competitive sports such as the Paralympics. There are several publications that reflect this community's perspectives and agendas. Prominent among them is the monthly magazine, *New Mobility*, which publishes both provocative and pragmatic articles. A second group is the Deaf culture, made up of people whose primary communication mode is sign language and who psychosocially self-identify with that culture. They do not experience the immediate reactions of being avoided, stared at, or given unwanted help that many people with visible physical disabilities have to handle. Instead, they experience significant isolation from mainstream culture because ability to communicate in sign language among the non-deaf population is very rare. People with chronic mental illness or past psychiatric histories comprise the third group. Typically, they do not encounter the physical or communication barriers just described. However, they bear the brunt of deep discrimination in the form of stigma, fearful rejection, and unreasonable or cruel treatment, even in allegedly therapeutic institutions. Schrader, Jones, and Shattell (2013) explained the evolution in self-advocacy priorities of this segment of the disability pride community, which they refer to as the mental-health consumer/survivor/ex-client movement. Its goals include: "articulate a broader culture of madness . . .the connections between madness and art, theatre, spirituality, and sensitivity to individual and collective pain . . . support interventions that target exclusion, poverty, trauma, and grief that contribute to distress and block positive adaptation".

EMERGENCE OF THE DISABILITY JUSTICE MOVEMENT

Like any group endeavours, the various movements for equity and self-determination by people with a disability have experienced their share of inter-group conflicts or dissatisfaction with some aspects of how the movements were operating. The following excerpts exemplify such a gap in groups' missions and capsulise how an evolving disability justice movement (DJM) distinguished its priorities from those of the DRM and the ILM. They are taken from the disability justice primer, 'Skin, Tooth, Bone: The Basis of Movement Is Our People' (Sins Invalid, 2019, pp. 15, 16, 18).

"While a concrete and radical move forward towards justice for disabled people, the Disability Rights Movement simultaneously invisibilised the lives of disabled people of colour...queers with disabilities, trans and gender non-conforming people with disabilities...people with disabilities who have had their ancestral lands stolen, amongst others."

“In 2005, queers with disability and activists of colour began discussing a “second wave” of disability rights. Many of these first conversations happened between Patty Berne and Mia Mingus, two queer women with disability of colour who were incubated in progressive and radical movements which had failed to address ableism in their politics...A single-issue civil rights framework is not enough to explain the full extent of ableism and how it operates in society. We can only truly understand ableism by tracing its connections to heteropatriarchy, white supremacy, colonialism, and capitalism.”

The DJM’s value-based principles include: viewing identity through a lens of intersectionality; leadership by those most impacted; commitment to cross-disability and cross-movement solidarity; and collective liberation (pp. 23-26). This 2nd edition (2019) of the disability justice primer contains chapters on diverse topics, such as Access Suggestions for Public Events, Principles of Mixed-Ability Organising, A Deeper Review into Deaf Culture, Disability Justice and Sexuality, as well as timelines of the movement’s milestones and a glossary. The text and images were collaboratively created by members of Sins Invalid, a DJ advocacy collective and “performance project that incubates and celebrates artists with disabilities, centralising artists of colour and LGBTQ / gender-variant artists as communities who have been historically marginalised” (<https://www.sinsinvalid.org/mission>).

The following roster of digital resources is representative of the creative and thoughtfully revolutionary quality of the DJM’s activities and impact:

- (1) The Disability Visibility Project is an online community founded and directed by Alice Wong that is dedicated to creating, sharing, and amplifying disability media and culture (<https://disabilityvisibilityproject.com/about/>).
- (2) Leah Lakshmi Piepzna-Samarasinha is a major activist, author and spokesperson within the DJM; her website (<https://brownstargirl.org>) is full of nurturant reflections and radical resources.
- 3) Leaving Evidence is a blog about transformative justice by Mia Mingus who explores in depth a variety of topics that provide: “Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence for each other that there are other ways to live - past survival, past isolation”. (<https://leavingevidence.wordpress.com/media/>).

- (4) Project LETS (Let's Erase The Stigma) is a grassroots organisation led by and for folks with lived experience of mental illness/madness, disability, trauma, and neurodivergence, that specialises in building just, responsive, and transformative peer-support collectives and community mental-health-care structures that do not depend on state-sanctioned systems that trap people in the medical/prison-industrial complex.

SELECTED ORGANISATIONAL RESOURCES THAT ACTUALISE AND SUSTAIN DISABILITY JUSTICE

Based on their reputations of influence, the following roster of exemplary resources was selected from among many throughout the world that are doing excellent work in advancing disability justice on personal and societal levels. An acknowledged limitation of this list is that the organisations are primarily based in the U.S., which is the author's scope of direct experience. However, many of them have had considerable experience of either working directly in various other countries or consulting with fellow self-advocates from regions around the world, to respond to the changes taking place in society. These organisations embody the combination of political and psychosocial strategies and benefits of advocating for disability justice discussed above. These examples are offered as resources, so readers can learn from, be inspired by, and perhaps partner with them. To maximise the authenticity of the summaries, they were in large part excerpted and edited from the cited websites, with some of the author's findings or observations interwoven. Each summary was sent to a senior representative of that organisation, with the invitation to revise or elaborate on the information, as desired, for accuracy and meaningful utilisation by readers.

ADAPT (<https://adapt.org>) is a grass-roots community of disability rights activists engaged in nonviolent direct action and legislative advocacy to secure the rights of persons with disability to live in freedom. When founded in 1983, their name meant American Disabled for Accessible Public Transit, and their goal was to force city bus companies to install wheelchair lifts on all public buses. ADAPT members performed civil disobedience by chaining their wheelchairs to the front and back of buses, thereby disrupting the service and the street traffic to dramatise their message, "If I can't ride the bus, then you can't ride the bus." Most often they were arrested, which created additional problems for the police and jails that did not have the accessible infrastructure or knowledge to deal with arrestees with disability needs. Their peacefully disruptive demonstrations were

successful, which led ADAPT leaders to be invited to do activist self-advocacy training in many places. In 1990, they adapted their acronym to mean American Disabled for Attendant Programmes Today, because they changed their focal mission to shift the substantial federal funding of long-term care of persons with disability from corporate-owned nursing facilities to home-based support services. Currently, this advocacy is focused on achieving passage of the proposed legislation called the Disability Integration Act. It would ensure the right of all eligible citizens who need long-term services and supports to have the choice to live in their home in the community, instead of in a conglomerate facility. Such institutions are much less preferred by consumers and more expensive for the federal budget, but very profitable for the corporate owners.

Centre for Research on Women with Disabilities or CROWD (www.bcm.edu/crowd) is based at Baylor College of Medicine in Houston, Texas. Since 1993, original research has been conducted by CROWD's founder, Margaret Nosek, Ph.D., and her colleagues. Their research focuses on six priority categories: healthcare access; health promotion; psychosocial health; secondary medical conditions; sexuality and reproductive health; and, violence against women with disabilities. In addition, CROWD analyses others' research findings, which it synopsis and disseminates as brief summaries for health practitioners and consumers. Its website has an alphabetised directory of these research briefs as well as practical guidelines and resource lists on more than 50 topics in women's health and wellness. One unusual asset that CROWD offers is a virtual reality and social network tool through a Second Life programme (www.SecondLife.com). There are several "islands" in the programme that serve as spaces to connect with other users with similar real-world disabilities or to participate in virtual activities that might be challenging in real life. Their research is exploring how this form of virtual social activity affects participants' actual health behaviours (e.g., maintaining a weight-management programme). Dr. Nosek passed away in November 2020. She was not only a highly respected scholar but also a veteran of the DRM, as a protégé and close colleague of one of its most esteemed American leaders, Justin Dart, Jr. (1930-2002). Dart was often called the "father" of the Americans with Disability Act for his long-term commitment to the various conceptual, legislative, and promotional activities that made the Act a reality.

Disability Rights Education and Defence Fund or DREDF (<https://dredf.org>) was founded in 1978 and has grown tremendously in terms of the impact and scope of practice of its legal and advocacy work in the courts of law and the court of public

opinion. Its broad scope is reflected in the variety of subsections under its main programmes, such as: School-to-Prison Pipeline; International Disability Rights; Media and Disability; Foster Youth; and, Disability and Bioethics. In addition to the usual elements, its up-to-date and user-friendly website provides archived copies of its two electronic periodical communications, eNews and Special Editions, and a powerful statement on Diversity, Equity, and Inclusion regarding its own recruitment and employment practices that are a model for human resources departments to follow. It also has a link to 'The Power of 504', a documentary that recounts the effective occupation of a federal building in San Francisco, California, by several dozen disability rights activists in April 1977. They were protesting the government's prolonged procrastination in implementing Section 504 of the Rehabilitation Act of 1973, the first American civil rights law protecting people with disability. The video depicts this successful marathon of nonviolent civil disobedience that lasted 25 days and nights. Imagine the courageous commitment, ingenuity, and personal sacrifices made by these demonstrators to manage their significant disabilities in such an inhospitable space as an office building, without their own household and hygiene resources, while working non-stop on the bureaucratic negotiations and public relations required for the protest to succeed.

Disabled in Action or DIA (<https://www.disabledinaction.org>) is a civil rights organisation committed to ending discrimination against people with all disabilities. Organised in 1970 by Judy Heumann and some fellow activists at the Brooklyn campus of Long Island University, DIA is a democratic, not-for-profit, tax-exempt membership organisation directed by people with disability. Its objectives are to: (1) Raise consciousness among people with or without disabilities concerning ableism and paternalism, as well as laws and customs that oppress people with disability; (2) Promote the passage and enforcement of effective legislation and budget initiatives that affirm and defend the rights of people with disability to independent living and equal access in all areas of life; (3) Provide the organisational basis for activists with disability to join in effective, unified political action; and (4) Educate government officials, community leaders, institutional administrators, and the general public concerning disability rights issues by organising public demonstrations, participating in speak-outs and formal hearings, and obtaining press coverage of their activities. If they are not given access to the relevant power brokers in their offices and official meetings, DIA often engages in civil disobedience to get their attention and the support of the public. After directing DIA, Judy moved on to a succession of other executive

positions related to disability rights in government, non-profit, and corporate organisations (McCarthy & Johnson, 1995). She remains active in the DRM and recently published an autobiography (Heumann, 2020). Also, an impressive documentary, 'Crip Camp' that premiered in 2020, traces the experiences of Judy and fellow activists from their meeting in a summer camp for youth with disability in 1971 to the present day.

Disabled Peoples' International or DPI (www.dpi.org) is a non-governmental, human rights organisation founded in 1981 and comprising member organisations ("national assemblies") in 130 countries. It is headquartered in Ottawa, Canada, and has the motto, "A Voice of Our Own." Its mission is expressed through consensually created advocacy agendas, written as position papers related to legal or aspirational declarations, such as the Sustainable Development Goals (SDGs) that the United Nations adopted in 2015. Such a worldwide partnership poses the complex challenge of accommodating multiple languages, cultural values, and political structures among the member organisations involved. Therefore, it is not surprising that, especially compared to the other organisations summarised in this section, DPI is much more formal in its operations and reliant on parliamentary conventions. Nonetheless, its values are rooted in the elimination of the pragmatic economic, social, and health disparities experienced by millions of people with disability throughout the world. It is known for its productive advocacy work on the SDGs and the international treaty called the United Nations' Convention on the Rights of People with Disabilities (CRPD). The well-delineated toolkits DPI developed and disseminated to promote the ratification and subsequent implementation of the CRPD are available on the DPI website.

National Alliance on Mental Illness or NAMI (www.nami.org) is America's largest grassroots organisation dedicated to improving the lives of those affected by mental illness. Its website proclaims its core values. **Hope:** We believe in the possibility of recovery, wellness and the potential in all of us. **Inclusion:** We embrace diverse backgrounds, cultures and perspectives. **Empowerment:** We promote confidence, self-efficacy and service to our mission. **Compassion:** We practice respect, kindness and empathy. **Fairness:** We fight for equity and justice. Through its widespread network of 48 State chapters and 600 local affiliates, NAMI serves a huge constituency of mental health treatment consumers, self-advocates, family members, first responders, mental health professionals, veterans, and others in the community through a host of targeted programmes. These include:

10 types of educational courses and presentations; support groups; training in advocacy strategies; policy advocacy; public awareness activities; and, a Help Line that provides resource information and support.

Not Dead Yet or NDY: The Resistance (www.notdeadyet.org) is a grass-roots disability rights group that opposes legalisation of assisted suicide and euthanasia as deadly forms of discrimination against people with disability, young and old. It demands the equal protection of the law for these targets of “mercy killing” whose lives are perceived as worthless. Its website cogently explains its ideology and grave concerns about the consequences of adding assisted suicide to the list of “medical treatment options” available to people with disabilities. To those who counter that this option is given to persons who desire to end their life, NDY argues: “...society prizes physical ability and stigmatises impairments, it is no surprise that previously able-bodied people may equate disability with loss of dignity...the prevalent but insulting societal judgment that people with incontinence and other losses in bodily function are lacking dignity.” NDY explains how outrageous it is that while society urgently promotes suicide prevention, one socially devalued group is offered death by suicide assistance. A variety of educational modalities, advocacy strategies, protest actions, and legislative efforts are employed by NDY to carry out its mission nationwide.

People First (peoplefirst.org) is a model for self-help groups of persons with developmental, intellectual, and learning differences. It dates back to 1974 when, during the planning for a self-advocacy conference in Portland, OR, one of the self-advocacy pioneers participating in the planning objected to the repeated use of the words “retarded” and “handicapped.” He spoke up and declared: “*I want to be treated like a person first.*” From that came the group’s name, People First of Oregon, and the movement’s pithy motto: “Label jars, not people.” Additional groups of self-advocates have been organised in several cities in the U.S. as well as Canada, Germany, New Zealand, and the United Kingdom. People First has a sister-network of groups with a website called www.selfadvocacy.net, which is concerned with the broader self-advocacy movement and its hundreds of groups worldwide. That branch of the movement for self-determination by and for people with cognitive disabilities had its origins in 1968 in Sweden. That first group was formed in a very similar situation when budding self-advocates, at a meeting conducted by their parents, expressed their desire to speak for themselves and specified a list of changes they wanted in the services they were using.

Wheeling Forward (<https://wheelingforward.org>) is a non-profit, consumer-driven organisation created and managed by Yannick Benjamin and Alex Elegudin. They met in 2003 when they were roommates in the spinal cord injury rehabilitation programme at Mt. Sinai Hospital in New York City. Wheeling Forward is focused on promoting active lifestyles after acquiring a physical disability. From two locations in New York City, it offers an impressive array of programmes. Many of them are adapted versions of what are offered at the most expensive health and wellness clubs, such as: acupuncture and massage, art therapy and cooking classes, boxing lessons, Pilates and yoga, spinal mobility training and weight lifting. More unique services include: wheelchair maintenance; field trips to learn to navigate the marginally accessible subway system; and, outings to cultural events or sports experiences like water skiing or sky diving (McBride, 2018). Wheeling Forward also provides other resources to members in need: college scholarships with accommodation expenses included; donations of wheelchairs; personal advocacy on managing disability services or transition from nursing home to community living; and, facilitation of systems advocacy on local disability issues. Through their own experience of disability and their vision for improving their peers' quality of life, the founders have been enormously successful in a short period of time in creating the resources to energise an active community of people with disability who demonstrate personal fulfilment and disability pride.

Whirlwind Wheelchair International (<https://whirlwindwheelchair.org/>) was founded by Ralf Hotchkiss, based on his direct-user experience and visionary enthusiasm about integrating technology with pragmatic needs of those with mobility limitations. Before receiving a prestigious MacArthur Fellowship that enabled him to expand his organisation's reach, he had established this non-profit organisation through which he seeded several consumer-run, self-sustaining wheelchair shops in high-poverty regions worldwide. Working collaboratively with fellow wheelchair-users whom he recruits from each local community, they design wheelchairs that are made from locally available materials which are especially suited to endure the region's geological terrain (e.g., mountainous or swampy). In 60 countries, these shops also provide a much-needed vocational benefit, as they train and employ local persons with a disability to fabricate and service the wheelchairs.

CONCLUSION and IMPLICATIONS

The self-advocacy struggles and successes of the disability community have certainly improved the overall level of equity and accessibility of society. The process has also shaped stronger identities and expectations among the disability community for fair treatment in dealing with the broader society. Therefore, it is critical that service providers like physicians, teachers, counsellors, and the lay community at large become educated and motivated allies to support self-actualisation and social justice. They can do this by: (1) appropriately facilitating the journey by their clients and compatriots with disabilities to participate in all their desired domains of life with dignity and equity, and (2) combatting, within their immediate spheres of influence, the misguided paternalism and ableism to which people with disability have been historically and to-date subjected by most of society. The disability community and its experiences need to be centred and equally included in education programmes for helping professionals and the public at large to learn about cultural diversity and its impact, alongside other communities who have (a) experienced marginalisation and discrimination, but have also (b) enhanced the richness and evolving equity that societies and their service systems need to cultivate.

To be truly effective and ethical in promoting disability justice, it is essential for allies to approach advocacy work with humility and to do the work collaboratively. Checking on the acceptability and validity of their perceptions and motivations regarding advocacy work is their ongoing responsibility. This is done most meaningfully by: (a) listening to the experiences and desires of the least powerful stakeholders who are most affected by discrimination; and (b) asking how best to partner with them on the journey to expand their personal sense of empowerment or to address a social-structural problem oppressing their community. Individuals and institutions with research skills and resources can strengthen advocacy awareness and strategies by conducting applied studies based in the methodology and philosophy of **participatory action research**. Examples of such research topics that emerge from merely reflecting on principles discussed in this article include exploration of: (1) the ways in which contemporary political entities are enforcing, expanding, or impeding the legislative and policy achievements by the disability rights movements over the past 50 years; (2) guidelines for optimising meaningful use of technology and social media to reduce social isolation and promote disability pride among persons with both congenital and later-acquired disabilities; (3) the factors to which leaders of

exemplary self-advocacy organisations attribute their success, the lessons they learned, and advice or encouragement they would give to informal groups of self-advocates in less-resourced countries.

In addition to improving one's advocacy work as an allied professional or citizen, it is hoped that the contents of this article have offered readers useful personal applications. As living with a disability is an inevitable part of the life cycle for most people, learning and reflecting about genuine insider experiences of disability help everyone to acquire at least two types of personal life lessons. First, it can help in understanding ourselves better by exposing our stereotyped, dysfunctional assumptions about disability and, hopefully, stimulate us to recognise our own potential for managing current challenges. Second, specific strategies and resources can be learnt from the disability community that could help people deal with the possibility of functional losses in the future, by embracing a coping perspective and a sense of pride in the worthy, ever-changing, interdependent person each one is. This is why everyone deserves and benefits from a world where disability justice and human rights are embraced and enforced.

REFERENCES

- Bowe, F. (2000). *Universal design in education: Teaching nontraditional students*. Westport, CT: Greenwood Publishing Group.
- Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, 49(5), 315-326. <https://doi.org/10.1352/1934-9556-49.5.315> PMID:21905825
- Charlton, J.I. (2000). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: Univ of California Press.
- Davis, L.J. (2016). *Enabling acts: The hidden story of how the Americans with Disabilities Act gave the largest US minority its rights*. Boston: Beacon Press.
- Dunn, D.S., & Andrews, E.E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264. <https://doi.org/10.1037/a0038636> PMID:25642702
- Fleischer, D.Z., & Zames, F. (2001). *The disability rights movement: From charity to confrontation*. Philadelphia: Temple University Press.
- Forber-Pratt, A.J., & Zape, M.P. (2017). Disability identity development model: Voices from the ADA-generation. *Disability and Health Journal*, 10(2), 350-355. <https://doi.org/10.1016/j.dhjo.2016.12.013> PMID:28065738

- Gill, C.J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9(1), 39-46. <https://doi.org/10.3233/JVR-1997-9106>
[https://doi.org/10.1016/S1052-2263\(97\)00020-2](https://doi.org/10.1016/S1052-2263(97)00020-2)
- Goethals, T., De Schauwer, E., & Van Hove, G. (2015). Weaving intersectionality into disability studies research: Inclusion, reflexivity and anti-essentialism. *DiGeSt: Journal of Diversity and Gender Studies*, 2(1-2), 75-94. <https://doi.org/10.11116/jdivegendstud.2.1-2.0075>
- Hahn, H. (1993). The political implications of disability definitions and data. *Journal of Disability Policy Studies*, 4(2), 41-52. <https://doi.org/10.1177/104420739300400203>
- Heumann, J. (2020). *Being Heumann: An unrepentant memoir of a disability rights activist.* (large print ed.). Boston: Beacon Press.
- Johnson, M. (2006). *Disability awareness-Do it right.* Louisville, KY: Advocado Press.
- Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York: NYU Press. <https://doi.org/10.1080/09687599826588>
- Longmore, P.K. (Ed.). (2003). *Why I burned my book and other essays on disability.* Philadelphia: Temple University Press.
- McBride, S. (2018). 2017 people of the year: Yannick Benjamin and Alex Elegendin. *New Mobility*, (January), pp.24-33.
- McCarthy, H. (2003). The disability rights movement: Experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counselling Bulletin*, 46(4), 209-223. <https://doi.org/10.1177/003435520304600402>
- McCarthy, H., & Johnson, P. (1995). Living independent thinking: A conversation with Judy Heumann. *Rehabilitation Education*, 9(1), 3-20.
- McMahon, B.T., & Shaw, L.R. (Eds.). (1999). *Enabling lives: Biographies of six prominent Americans with disabilities.* Boca Raton, FL: CRC Press.
- Montgomery, C. (2004, June 3). Harry Potter and the allure of separatism. *Ragged Edge*. [Online]. Retrieved Oct 5, 2020, from: <http://www.raggededgemagazine.com/focus/potter0604.html>
- Pelka, F. (2012). *What we have done: An oral history of the disability rights movement.* Amherst: Univ of Massachusetts Press.
- Putnam, M. (2005). Conceptualizing disability: Developing a framework for political disability identity. *Journal of Disability Policy Studies*, 16(3), 188-198. <https://doi.org/10.1177/10442073050160030601>
- Riddell, S., & Watson, N. (2014). *Disability, culture and identity.* New York: Routledge, Taylor & Francis. <https://doi.org/10.4324/9781315847634>
- Schrader, S., Jones, N., & Shattell, M. (2013). Mad pride: Reflections on sociopolitical identity and mental diversity in the context of culturally competent psychiatric care. *Issues in Mental Health Nursing*, 34(1), 62-64. <https://doi.org/10.3109/01612840.2012.740769>
PMid:23301572

Scotch, R.K. (1988). Disability as the basis for a social movement: Advocacy and the politics of definition. *Journal of Social Issues*, 44(1), 159-172. <https://doi.org/10.1111/j.1540-4560.1988.tb02055.x>

Shaw, L.R., Chan, F., & McMahon, B.T. (2012). Intersectionality and disability harassment: The interactive effects of disability, race, age, and gender. *Rehabilitation Counseling Bulletin*, 55(2), 82-91. <https://doi.org/10.1177/0034355211431167>

Sins Invalid. (2019). *Skin, tooth, and bone: The basis of movement is our people* (2nd ed.). Berkeley, CA: Author.

Wright, B.A. (1960). *Physical disability: A psychological approach*. New York: Harper & Row. <https://doi.org/10.1037/10038-000>