

# Mix and Match: Community Organizing, Advocacy and Collaboration for Disability Inclusion in Central Japan

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## Introduction: Excluding Special

One universal dimension of human diversity is differing physical, cognitive, sensory and psychological abilities. And yet, social practices often exclude people beyond a “normal” range, eliding their existence as human beings with equal rights and value.

I became acutely aware of this when my twins were born, one with a medically recognized syndrome and one without. Contrary to national laws and the doctor’s advice, my town’s local government offered a daycare place to the twin it judged “normal,” and denied one to the twin it saw as sufficiently “special” to exclude. By refusing her social care, the town government effectively also planned to exclude me from paid labor, squeezing me into the role of “mother of a child with a disability.” On top of the isolation of baby care in Japan, and my own fears about living with impairment, the town seemed to be telling me, “This baby here can be a part of society, but that one is your private responsibility.” To make a long story short, I nabbed two places at a progressive independent daycare center and somehow returned to employment.

Loopholes aside, social exclusion remains a big issue for “ab-normal” people with disabilities (PWDs) globally and in Japan (Soldatic, Morgan and Roulstone 2014). To address exclusion, experiences from around the world support strategies of community organizing by PWDs and their families, advocacy, and collaboration with various allies (Johnson and Walmsley with Wolfe

2010; WHO 2010). In this article I touch on key concepts of disability, intersectional identity, and advocacy. I then introduce three cases of advocacy and collaboration by and with multicultural PWDs based in central Japan. Through organizing with peers and collaborating with allies, the PWDs and/or their families leveraged their “special” knowledges to promote inclusion, wellbeing and diversity.

## The Social Model of Disability

As I noted above, one of my children has medically recognized impairments and is classified as “disabled.” However, as I hope my narrative illustrates, her disability was not about her medical condition or her deficiencies as an individual, and her life is a joy, not a tragedy. Her disability was made by interaction between her impairments AND the evolving attitudes and practices of the society around her.

The above view of disability is the social model espoused by influential global institutions such as the United Nations (International Disability Alliance 2010, United Nations Department of Economic and Social Affairs). It forms the basis for the Convention on the Rights of People with Disabilities (CRPD), adopted by the UN general assembly in 2006 and since ratified by 177 nations (UN n.d.).

Thus, the CRPD sees disability as a combination of “evolving” social/ cultural/ political practices, along

with functional limitations, which tends to marginalize individuals with impairments (UN n.d.). Thus, a “person with a disability” (PWD) is shorthand for a person facing barriers to participating in community life because of his/her different abilities. In other words, one central challenge for PWDs is being treated as “special” and excluded or segregated from the rest of society.

### Campaigning for Disability Rights

In ratifying the CRPD, 177 national governments have at least nominally recognized discrimination against PWDs and committed to supporting their equal rights to participate in social life. In fact, the CRPD itself was achieved after PWDs and their families formed organizations and campaigned for decades, collaborating with local and international allies. Thus community organizing and advocacy by PWDs and their families has a long history (Sabatello and Schulze 2014).

In Japan, too, both PWDs and their families have played leading roles in campaigning for disability rights. The history of the Disabled People’s Movement in Japan has had many impressive episodes. For example, in the 1960s-1970s, a number of people with CP established the Aoi Shiba no Kai, demanding equal respect as human beings. One of their successes was calling for social support and care after a string of murder suicides of children with disabilities (Misawa 2011). Another well-known Aoi Shiba action took place in 1977, when a number of wheelchair users hijacked a city bus in protest at the company’s refusal to let them ride. The incident received media coverage, and public transport companies were forced to provide more access for wheelchair users (Misawa 2011).

For people with intellectual and multiple disabilities, campaigning by parents’ groups has been highly influential. For example, it was community organizing and advocacy by parents’ groups which pressured the national government to finally establish compulsory education for children with intellectual disabilities in the late 1970s (Murata 2010).

### Diverse Aims and Forms of Disability Advocacy

Banding together for peer support, and flexing organizational muscle to promote shared interests are common strategies for disadvantaged groups. Nonetheless, in fact PWDs are very different from one another. Their impairments are different. They come from every economic class, ethnicity, gender and age group. In other words, their particular identities and experiences are intersectional. Further, some advocacy groups, especially related to cognitive disabilities, are led by family members rather than PWDs, or are run as service organizations, including supporters as well as PWDs. So it is no surprise that the particular character, aims and actions of different advocacy groups vary.

### Collaboration for Disability Inclusion in Central Japan

Central Japan also has its fair share of great disability activists. AJU is a leading Center for Independent Living (run by wheelchair users) in Aichi. Wappan no Kai is a highly respected grassroots organization of activist service providers working with people with intellectual disabilities, also in Aichi.

The Creating Connections conference 2018 hosted three presentations on newer cases of community collaboration for disability inclusion in central Japan: a multicultural parents’ group linking up with medical doctors; a disability activist bringing together local government, service providers and the local residential community; and a service provider partnering with an ethnic minority organization. These three cases are discussed briefly below.

#### *TSC Salon Chubu*

Long term Aichi resident Naomi Epstein, an American mother of a child with TSC, a congenital condition that causes autism and seizures, used her knowledge of U.S. community organizing and medical advances to activate the existing Japanese TSC family network, creating the TSC Salon Chubu. As well as empowering and supporting one another, the Chubu (central Japan) families also linked up with medical professionals, achieving access to much improved treatment in Japan. (Personal communication. See also Naomi Epstein’s article in this issue.)

### *NPO Peace Tolerance and the Gochamaze Sports Day*

Former occupational therapist (OT), Toshie Oshitomi, a wheelchair user with severe impairments, leveraged her own professional and personal experiences to found and run a local disability advocacy organization, the NPO Peace Tolerance in Owariasahi. The organization runs various events and programs aimed at raising awareness of disability exclusion. Oshitomi observed keenly how local community events excluded PWDs by using inaccessible facilities and rules. For example, the sports day cum community picnics run by Japanese neighborhood associations every autumn are typically held on sandy school grounds – inaccessible to wheelchair users. She hit on the idea of setting up accessible races, like a traditional *pankui kyoso* (race to eat buns hung on a string without using hands), and a three-wheeled race. It seemed a hilarious way to involve children in learning about impairment in a way that showed off the skillfulness of PWDs. She roped in local PWDs, local government, and passionate service providers, including her OT colleagues to set up an annual accessible Gochamaze (“mix and match”) sports day in a local university gymnasium. The event has evolved to become not only an awareness-raising event, but also a model of disability inclusion. Rules for all races are made up as they go along, with top priority to ensuring everyone can participate and enjoy.

Oshitomi sees the main success of the sports day as the joy of the participants, particularly children. According to the exit questionnaires, 100% of participants were either “highly satisfied” or “satisfied.” In future, she aims to replace grant funding with sustainable support from local businesses, and increase involvement by local residents beyond the disability community (personal communication).

### *One Life Foundation and AAVP*

One Life Foundation runs a sports-centered daycare service for children with disabilities, and a children’s soccer club. At *Creating Connections*, founder Yuji Suzuki, a physical therapist, introduced One Life’s collaboration with a Brazilian residents’ autism parents’ group, Associacao Autismo Vencendo Preconceito (AAVP).

Aichi is home to a sizeable Brazilian population, who form a somewhat marginalized ethnic community. AAVP was established in 2014 by a small group of Brazilian parents of children with autism. As well as giving peer support, they organize information and therapies in Portuguese by Brazilian professionals (AAVP Facebook).

The collaboration between One Life and AAVP grew organically through their mutual involvement with soccer and autism support. AAVP parents and Suzuki picked up on their chance acquaintance as an opportunity to provide attractive, joyful services and fellowship for Brazilian and non-Brazilian users (personal communication). One Life started employing Brazilian physical therapists and offering fun cultural exchange through Brazilian barbecues and capoeira. As well as enriching accessible events for families with disabilities, these activities also boosted ethnic Brazilians’ place on the map as citizens of central Japan.

### Conclusion: Leveraging Special Knowledges to Create Connections

In some ways, having a disability/impairment, like having a minority ethnic background, does impart “special” needs and knowledge. This is usually grounds for exclusion from conformist norm-centered Japanese social life. However, in the three case studies above, for PWDs and their families, organizing as a community with shared interests, and collaborating with appropriate allies was a way to achieve both specific goals such as better medical treatment and the general goal of making one’s existence visible and valued. PWDs can leverage their various “special” knowledges to create connections and promote wellbeing within and beyond their particular communities.

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