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Emergence and Clashes in Disabled Service User Organisations in South Korea

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Abstract

This paper explores the development and challenges of disabled service user participation within disabled people's organisations in South Korea at a time of rapid evolution in welfare policy and practice. Since 1990s, disabled people's organisations influenced by disability activisms, especially disability Dangsajajuwei, have increased significantly in South Korea. Those changes have increased disabled service user's participation for service development, delivery, and meeting key needs such as disability rights, but many disabled people's organisations have clashed with each other in order to take initiatives of service delivery for their own organisation. This paper concludes that Korean disabled people's organisations are currently facing several challenges such as 1) defining disabled people's organisation via Dangsajajuwei, 2) creating exclusive and selective authoritarian user groups among disabled people 3) losing a collective disabled service user's voice, 4) political and service system restraints of disabled service user participation, that are major threats towards the development of service user participation.

Introduction

Over the past three decades, there is increasing internationally wide recognition about the importance of involving service users and their caregivers in the development of health and social care policy and planning processes, service delivery, monitoring and research (Omeni et al., 2014;). As Crawford et al. (2002) mentioned, service user involvement is becoming less discretionary but more compulsory (p.163). In South Korea (hereinafter Korea), citizen participation was either absent or coerced until 1987 due to the deep-rooted tradition of a state-centered society under military governments. Since the early of 1990s, social support services for the elderly, disabled and children have dramatically increased. For instance, the number of community centres in local authorities have been increased from 1836 in 2006 to 8052 in 2016 (MOHW, 2017). Although there is a growing recognition of user involvement in health and social care, there is no agreed definition of 'service users' and 'service user participation or involvement' in Korea. Rather, several terms commonly refer to user involvement including 'citizen participation', and 'consumer involvement' and refer to user organisations such as NGOs (*Mingandanche*), civil society organizations (*Simindanche*), civic movement organizations, (*Siminwoondongdanche*), and public interest corporations (*Gongickbubin*). Nevertheless, the social welfare service has been limited to socially marginalised groups in Korea. So, service user participation and voices are still largely restricted due to lack of information, low socio-economic class, limited social network and lack of political action. Service user involvement has its origins in the disabled people's movement (Beresford & Carr, 2012), especially self-advocacy movement for people with learning disabilities. In Korea, the number of disabled service user organisations have increased since 2000 under the influence of the Disability Movement (Yu & Hwang, 2018) and social interest in the rights of disabled

service users under the influence of disability Dansajajuwei¹ has increased. The importance of user participation is enshrined in Korean legislation for disabled people, notably the United Nations Convention on the Rights of People with Disabilities (UNCRPD). Nevertheless, service user involvement in social care and health is still at the nascent stage and not enough studies have been done on service user involvement. Only limited areas such as theoretical understanding of service user participation (Kim & Kim, 2007), and user-oriented services (Kang et al., 2010) have been explored. . In Korea, the term disabled people's organisations (DPOs) has been used without a clear distinction between organisations of the disabled and organisations for/with the disabled (see Oliver's typology, 1990). As a result, there are many clashes between DPOs who insist on referring to themselves as the truly 'authentic and representative' organisation 'of' or 'for' disabled people (Ableness, 2016). This paper will look closely at this issue. This paper also offers a conceptual analysis of the service user involvement in the context of Korean DPOs.

Contextualising service user movements in Korea

To begin with, it is important to briefly look at the development of service user involvement in Korea. Until 1987, user participation in social and political contexts was absent or coerced under military governments, but only selected organisations were mobilised in a range of pro-government activities to improve industrial and agriculture productivity (Kim, 2010). Those organisations were not run by user groups, and their activities did not represent genuine user involvement. In this period, military governments did not allow any opportunity for service user involvement in welfare policy. Welfare legislation and policy was used as a political instrument of the military regime to control citizens and weaken resistance of democracy and participation. As a result, welfare was largely left to the individual and their family members. In this period, there were few formal statutory support services for disabled people.

From the early 1980s, various civic organisations such as women's groups, and consumer advocacy groups, grew with the emergence of middle class and university educated groups as there was increasing awareness of the problems of the military regimes. In this period, non-disabled activist or family member of disabled people generally spoke for disabled people but disabled people's rights to speak for themselves was generally neglected.

After the nation-wide 'Democracy Movement' in June 1987, the political system in Korea had started to shift from an authoritarian state under military governments to a democratic state. After 1990s, many user-led organisations were established and grew rapidly. During the Kim Dea Jung presidency (1998-2003), for instance, the governmental agencies were encouraged and even pressured to delegate Collaborative Governance and devolve as much work as possible to market sectors and voluntary sectors, such as firms and user-led organisations. Collaborative governance was highlighted as important policy goals of the Roh Mu Hyun government (2003-2008), named itself as 'participatory government' (*Chamyeo Jeongbu*) with focus on decentralization, governmental innovation, and civic participation. In response to service users' increasing and diversifying needs, the Korean government has shifted its approach for social service to financing social services from direct funding support for service providers to the voucher system for service users since 2007 (Lee & Son, 2011). Service users are allowed to use social service vouchers to purchase services from any provider of their own

¹ This term has a very similar meaning to the disability activism slogan 'nothing about us without us', which emphasises that no decision should be made affecting disabled people without their full and active involvement. Lee (2004) defines that "a way of the disability right movement developed by disabled people to criticise and restrain unfair power relation of welfare service providing system and oppression toward disabled people in society, and to emphasise disabled people's rights, independence, self-help and decision making"(p.12)

choice. The number of individual voucher users increased from 636,093 in 2011 to 656,200 in 2014 (Kwon & Guo, 2019:670). A boom of newly established many nationwide or local user-led organisations immediately followed to raise a voice for disadvantaged users to collectively express their views and priorities.

The past five consecutive governments in Korea, albeit with varying degrees of enthusiasm, have placed emphasis on so-called ‘collaborative governance’, defined as “a governing arrangement where one or more public agencies directly engage non-state stakeholders in a collective decision-making process that is formal, consensus-oriented, and deliberative and that aims to make or implement public policy or manage public programs or assets” (Kim, 2010:166). With the continuing influence of political changes, a substantial increase in social service infrastructures and social service policy implementations in an effort to meet the increased welfare demands have been witnessed. In the past, the top-down welfare service system and provider-centred paternalist approach was allowed no room for service user participation. A decentralised social service system was introduced in 1995 and local authorities have focused on providing more social services (Kang et al., 2010). Moreover, user involvement in delivering social services were strongly demanded after several protests for introducing social security system and ensuring a stable security of social welfare budget, but it was led by academics, lawyers and few civic organisations. Since 2000s, the importance of user involvement has slowly been acknowledged by disabled people’s movement.

Emerging Disabled Service User Organisations

Before 1981, there were no appropriate support services for disabled people, and disabled people’s rights were largely ignored and neglected. There were few organisations for the disabled such as Rehabilitation Korea (1954), Korean Association for Mental Retarded (1968), the Korea Polio Association (1966), the Korean Society for the Cerebral Palsied (1978), and Korea Disabled Welfare Organisation (1981) but those organisations were led by non-disabled activists, professionals, or parents of disabled children. The main work of the organisation was mainly involving creating petitions to help certain disabled people gain access to employment and education.

Influenced by the United Nations International Year of Disabled Persons in 1981, the Korean government enacted two major disability policy for social welfare (the Act on Welfare of Persons with Disabilities in 1981) and education (the Act on Special Education for Disabled Persons in 1977). Many organisations for/with disabled people were established such as the National Union of Students with Physical Disabilities (NUSPD) (1978). The main task of these organisations was to promote a mutual friendship, or to educate and to provide support to limited disabled people who were being discriminated in education and employment. But these organisations did not work collectively to raise the voices of disabled people, rather they were merely individual efforts.

Since 1987, the democratic movements in Korea changed into social movements that evolved in the context of the military and authoritarian regimes. During this period, two key organisations were formed. First, Research Institute of the Differently Abled Person’s Right in Korea (RIDRIK) was established by university educated physically disabled people, academics, lawyers and non-disabled activists in 1987 to lobby politicians and professionals to introduce disability rights based policies and legislation. Second, disabled activists who were inspired by civil rights groups started to form their own organisations, in reaction to social attitudes and barriers, at the local and national levels. Disabled Peoples’ International Korea was formed with 20 disabled people, but this organisation was run with non-disabled professionals. NUSPD was transformed into a user-led organisation ‘Ullimteo’ (1986), that was a very small disabled user-led organisation but this organisation introduced a new rights-based paradigm for thinking about disability against capitalism (Ullimteo, 1993). In 1987, key members of Ullimteo joined

the National Organisation for People with Physical Disabilities (NOPPD) to take an initiative for disabled people's movements, but the existing members of NOPPD struggled to collaborate with the newly arrived disabled young activist's radical and direct activism. As a result, Ullimteo was dissolved in 1992 and almost all disabled young activists from Ullimteo joined the Association for Young Disabled People's Activism (AYDPA). In 1987, AYDPA discovered that the total budget for the 1988 Seoul Paralympic Games was allocated more than four times that of the total welfare budget provided for disabled people (HamkkeGulum, 2003). In 1988, a new disabled user-led organisation called Korean Differently Abled Federation (KDAF) formed and collaborated with other organisations with/for the disabled to organise a mass public protest demanding the boycotting of the Paralympic Games and to demand enacting legislation for welfare and employment for disabled people. This protest formed 'Union for Enacting Two Acts', which was not a disabled people's organisation but a group of people, including well known academics and non-disabled people in high social status, who were campaigning to achieve full human rights and equality for disabled people (Yu, 2017). From 1988, disabled organisations began to engage in mass radical, but non-violent, direct actions such as demonstrations on streets, hunger strikes and sit-in strikes at politic parties or government offices (HamkkeGulum, 1991). As a result, two key disability-related legislation (i.e. the Welfare for People with Disabilities Act 1989 and the Disability Employment Act 1990) were enacted or amended during this period.

Since 1990s, human rights, self-determination and autonomy were held as the core values for DPOs. The number of DPOs began to multiply but divided into several umbrella nationwide user-led organisations (Yun, 2012). For instance, Korea Association of People with Physical Disabilities, Korea Association of the Deaf, and Korea Association on Mental Retardation formed an umbrella organisation, entitled Korea Differently Abled Federation (KODAF) formed in 1996, and other organisations such as Korea Traffic Disabled Association, Industrial Injured Member Association, Korean Federations of Centre of Independent Living of People with Disabilities, and The Human Rights Forum for People with Disabilities in Korea formed another umbrella organisation, the Korean Federation for Organisations of the Disabled (KOFOD) in 2002. Other disabled people's activists that disagreed with the actions of the above two umbrella organisations also emerged the Solidarity Committee of the Disabled to Obtain Mobility Rights (SDOMOR) and, in 2007, SDOMOR and other disabled people's organisations merged to become the Solidarity Against Disability Discrimination (SADD), advocating the use of radical, and direct actions.

Since 2000, Consumerism and the Independent Living Movement were introduced to DPOs in Korea. Especially, self-help organisations influenced by advocacy and self-advocacy movements in Western countries have started through various organisations such as Centre for Independent Living (CIL), the Community Rehabilitation Centre for the Disabled (CRCDD) in local authorities or the Korean Parents Society for the Disabled (KPSD). CIL focused on rehabilitation services for disabled people via vocational training, cultural activities and education on disability rights and CIL support self-advocacy group in collaboration with Japan's People First. KPSD started a programme for self-advocacy based on the People First Movement's values. The National Self-Advocacy Group Convention of People with Developmental Disabilities has been held annually since 2013 and Korea's People First launched in 2016.

To summarise, disabled people's organisations influenced by activisms, especially disability Dangsajajuwei, of disability people's movements, have increased significantly. As Table-1 shows, there are currently three umbrella disabled service user organisations in Korea. The demands of each organisation vary such as citizenship issues, human rights, challenging societal attitudes and barriers and welfare rights.

Table-1 Key umbrella Disabled People’s Organisations in Korea

	Korea Differently Abled Federation	Korea Federation of Organisation of the Disabled	The Solidarity Against Disability Discrimination
Aims	Disability and human rights	<i>Disability Dangsajajuwei</i> and disability rights	Democratic movement
Key Members	Disabled people’s organisations and supporting organisations	Disabled people’s organisations (physical impairments)	Disabled people’s organisations and citizen-activist organisations
Main Activities	Making policy and legislation proposals relating to disability	CILs	Radical Public protests

Clashes between Korean Disabled People’s Organisations: Disability Dangsajajuwei

While the Independent Living Movement was introduced through Japan’s Human Care Association, the biggest change in disabled service user organisations started in the areas of health and social care from the late 1990s as a major ideological shift occurred in Korea in the name of “disability Dangsajajuwei”, which was first been introduced by the Disabled Peoples’ International (DPI) Korea in 1991 and become a key political ideology for disability activism and attempts have been made to use it to transform the disabled people’s organisations since 2002 (Yu & Hwang, 2018). However, there is no clear theoretical definition of Dangsajajuwei, but Dangsajajuwei emphasises that disabled people must make their own decisions and have control over services and policy, and strongly resists against creating/operating/managing contents, systems or facilities for disabled people by non-disabled activists or/and professionals (Yu & Hwang, 2018). Importantly, two main philosophies of Dangsajajuwei are "self-representation" and a "rights of self-determination". So, the passive role of disabled service users in welfare support and policy has been strongly challenged by Dangsajajuwei. that argues that active users involvement is imperative to make sure the needs and wishes of service users are heard.

ILM’s philosophy, which emphasises consumer control, and the idea that disabled people are the best experts on their own needs, was deeply integrated into Dangsajajuwei by the KOFOD (Lee et al, 2007) after key member organisations such as DPI Korea, Korea Association of People with Physical Disabilities (KAPPD), Korea Federation of Centers for Independence Living of People with Disabilities (KOIL) joined KOFOD since 2002.

However, there has been great debate and criticism between disabled people’s organisations. The main bone of contention is the role and function of non-disabled activists and families in operating and managing DPOs because some DPOs include family members, mostly parents, or non-disabled professionals at governance and leadership level. For instance, KOFOD criticised that KODAF was an organisation ‘for’ the disabled and they cannot truly be representative of disabled people’s organisations because Rehabilitation International (RI) Korea, RIDRIK, and KPSD, which were key member organisations of KODAF, were managed with parents and non-disabled professionals. But KODAF argues that KOFOD was a subject

interest group only to take their own initiatives and power over DPOs. These controversial debates slowly died down after the Korea Blind Union (KBU) withdrew from KOFOD and joined KODAF in 2007 (Kim, 2012). Inhee Kwon, the representative of KBU, argued to against KOFOD: “*Dangsajajuwei* has achieved many key developments for the disabled. So, the current chauvinistic and exclusive character of *Dangsajajuwei* in KOFOD, which does not allow any input from non-disabled professionals and activists needs to be changed to integrated character of *Dangsajajuwei* to accept contributions of non-disabled activists and professionals on disabled people’s organisations” (Ablenews, 2007). Finally, KOFOD’s criticism was clouded because two big disabled people’s organisations (KBU and the Korea Association of the Deaf) joined KODAF.

The second wave of clash started from debates on the functions and actions of DPOs in 2007. KODAF and KOFOD’S work were mainly limited to seminars, conference, education, public hearing, publication, establishing tie with other organisations and so on. However, many disabled people’s organisations against KODAF and KOFOD’s indirect actions, especially in relation to mobility rights for disabled people. As a result, those disabled activists and their organisations who engage in mass radical and direct actions to obtain mobility rights for disabled people gathered to form a new umbrella organisation, called Solidarity Against Disability Discrimination (SADD). DPI Korea and KFCIL disagreed with SADD’s direction actions and theycriticised SADD due to non-disabled activists or professional’s heavy involvement in their actions. Specifically, they argued a disabled people’s organisation should be ‘of’ the disabled, if it includes non-disabled people to control and manage, it cannot be called the disabled people’s organisation (Ko, 2007). However, SADD argues that conservative disabled people’s organisations such as KODAF and KOFOD are front for becoming a key partner of disability policy making and getting funds for running their organisations through *Dangsajajuwei* (Kim, 2017).

The third wave of clash started within CILs. In 1993, DPI Korea introduced the independent living movement through the Japanese version of a book entitled ‘The shock of the ADA’ to Korea. ILM’s philosophy, which emphasises consumer control, and the idea that disabled people are the best experts on their own needs, was integrated into *Dangsajajuwei* in 2002 by the Korea Federation of Organisations of the Disabled (KOFOD) (Lee et al., 2007). In 2001, Jeongnip Center for Rehabilitation and Independence started to provide independent living services, including peer counseling and personal assistance services.

10 Centres for Independent Living (CiLs) were established in Korea in 2005 with government funding, and almost 200 CiLs were in existence in 2017 (Yu, 2017:309). The Korean government revised the Welfare of Persons with Disabilities Act in 2008 to provide legal grounds for its support of CiLs.

The independent living movement had become influential in lives of disabled people, especially people with complex needs. After public demonstrations and direct actions on the street for 39 days by key members with complex needs under SADD in 2006, the Act on Activity Assistant Services for Persons with Disabilities was enacted and came into effect, which specifies to introduce personal assistants for disabled people in 2007. Those disabled people contributed to establish CILs. In 2003, 11 centres for independent living formed Korea Council of Centres for Independent Living (KCCIL). Within KCCIL, however, there has been great debate on the orientation ILM and the method by which it should be used to campaign for disabled people’s rights between CILs who led public direct actions for mobility rights and CILs who more focused support services based on disability *Dangsajajuwei* because parents of disabled people involved in the later CILs. Parents are working to receive services such as personal assistance for their disabled children. Parents and disabled people within those CILs

have insisted that priority for their CILs must be services for disabled people, not political direct actions to change policy. As a result, this clash caused CILs to split into two umbrella organisations in 2006: an advocacy-oriented CILs (i.e. Korea Federation of Centres for Independent Living of Person with Disabilities (KOIL) and a service-oriented CILs (KCCIL). KOIL has criticised KCCIL for failing to recognise disabled people's opinions; the basis of this viewpoint is that many non-disabled people and professionals function as the representatives of CILs (Yun, 2012).

As seen in the previous section, each DPO is rooted in different politics, strategies, and tactics and each DPO is led by various leading groups, including the parents of disabled people, non-disabled activists, and professionals. They have seldom worked cooperatively at a national and local level, and occasionally have even been hostile to each other to take initiatives (Yun, 2012).

Current Challenges and Future directions of DPOs

As Beresford argues (2018), the emerging DPOs in Korea has brought significant changes for disabled people in terms of factors such as public and political understandings of disability, employment, housing, education, healthcare, income, social service, and the discrimination that disabled people face and their rights. Nevertheless, it is evident that DPOs have faced several important challenges:

First, although the definition of DPOs is distinct from other disability sector organisations, the term 'DPO' has not been clearly been discussed and defined in Korea. The type, structure, role and governance of DPOs are varied, therefore there are a variety of organisations that consider themselves a DPO. In particular, the term *Dangsajajuwei* has not been defined clearly within DPOs and the Korean Disability Movement. As a result, some groups that are established primarily for the purpose of providing support services to members also claim themselves as DPO. Yun (2005) classified three DPO characters under *Dangsajajuwei*: 1) single disability group organisations who have focused only on their own interests but do not fully integrate with *Dangsajajuwei*, 2) DPOs that collaborate with non-disabled activists to achieve solidarity for disability rights, 3) DPOs that restrict non-disabled people's involvement. The debates on *Dangsajajuwei* do not clearly define who the main party of DPO that constitutes *Dangsaja* (a person/party) is and it is very difficult and subjective to judge which DPO should be included under *Dangsajajuwei*. For further development of DPOs, the identity and functions of DPOs urgently need to be debated and defined through *Dangsajajuwei*.

Second, excessively emphasising (i.e. *Dangsaja*) issue of disabled individuals under *Dangsajajuwei* led to neglect of multiplicity and plurality of DPOs (Yu, 2004). Ironically, *Dangsajajuwei* creates exclusive and selective authoritarian groups among disabled people. Kim (2012) criticises that *Dangsajajuwei* has been transformed into exclusive collective group activism that involves focusing advocacy on 'only certain' disabled groups and becoming distant from the fight against oppression and inequality for all disabled people. Those DPOs exercise power over, and are being oppressive towards, other DPOs. Dae-Sung Kim, representative of DPI Korea, concurred (2003) that *Dangsaja* cannot be same as *Dangsajajuwei* because all disabled individuals do not follow or agree with *Dangsajajuwei*. He criticised that some disabled users 'namely *Dangsaja*' were involved in decision making process but tried to exclude other disabled users' participation without any careful consideration of the individual's unique needs and circumstances. Some DPOs completely ignored the disabled service user's self-determination and participation. As a result, some disabled user groups are much more likely to be heard and listened to than others. DPOs must overcome the limitation of disability

Dangsajajuwei around the wide range of issues of diversity and equality such as gender, belief, disability and age to avoid exclusion of any disabled service users.

Third, there are approximately 347 local and regional DPOs including single-disability and cross-disability organisations in 2019. Nearly all DPOs acts as representatives and stakeholders of a single disability group (e.g. Autism Society of Korea, or The Association for People with Physical Disabilities). Each DPO must compete to obtain funding from the central and/or local government. The scarcity of available resources has also led to intense competition between the organisations. Under this environment, DPOs have hardly collaborated or allied with other user-led organisations in nationwide or local areas to provide a stronger voice for change, and occasionally have even been hostile to each other to take control of the initiative of welfare service and budgets from the central or local government, but have failed to create strong partnerships with each other (Yun, 2012). For instance, no DPOs have not been appointed on national advisory board members who monitor the implementations of UNCRPD due to hegemonic disputes between DPOs. This was particularly evident during the preparation of the report to the UNCRPD monitoring body (Ablenews, 2010). As Campbell (2009) asserts, DPOs must recognise the importance of solidarity, sharing experiences and supporting each other to bring important changes and to make a difference.

Fourth, the rights of disabled people to participate in decision making was legally guaranteed in Korea. But they are still excluded when it comes to being in positions to initiate, lead and implement the policy or service decisions that affect their lives. The Parallel Report for the UN Committee on the Rights of Persons with Disabilities written by Korean DPOs and non-governmental organisation coalition (2014) stresses that there still are many limitations to improve disabled person's rights and involvement in decision-making. Recently the Korean government pledged to collect opinions of different types of relevant DPOs, to develop policies and services for disabled people. Collaborative work with DPOs was ensured mainly through information sharing, workshops and regular consultations. For instance, the Policy Coordination Committee for Persons with Disabilities was established under the Act on Welfare of Persons with Disabilities. Half of those outside of commissioned committee members have not consisted of disabled people, having led to the participation of representatives of DPOs. Also, no official or regulatory route is in place to ensure the participation of DPOs. DPOs as the initiators of ideas for policy or service change are rarely enabled to be involved at the full procedure of policy and services that affects them. Most of the support services in social care and health areas have still largely been initiated, delivered, and managed by the provider, especially the state, and non-disabled professionals in Korea. DPOs must involve in a range of different political activities to promote the participation of disabled people or to facilitate their participation.

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