

The Meaning of Being an Activist of the Disability Rights Movement in Bali: A Phenomenological Study of the Experiences of Social Movement Activists

(Makna Menjadi Aktivis Gerakan Hak-Hak Disabilitas Di Bali: Studi Fenomenologis Tentang Pengalaman Aktivis Gerakan Sosial)

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ABSTRACT: The disability rights movement is driven by actors who are able to transform their experiences of suffering into power to bring about changes toward the fulfillment of rights of persons with disabilities. This research discusses the relationship between the reconstruction of past experiences of grievances due to stigma and discrimination, collective identity, and the capacity for involvement in the disability rights movement. Taking place in Bali, this research applied a qualitative-phenomenology methodology to reveal the meaning behind the experiences of the subjects who are disability rights movement activists, in the process of involving themselves in social movements. This study found that the social movement actors were able to reconstruct their suffering into the capacity to make changes. Their personal identity met their collective identity as actors in the disability rights movement through interaction with the community which provided space for the emergence of new awareness about rights and advocacy strategies. The UNCRPD ratification, socialized by civil society organizations, opened up opportunities for strengthening interactions and networks between disability rights activists at the national and local levels. This network has strengthened the confidence of activists in Bali to take collective action. The ratification of UNCRPD is also a momentum for mobilizing movement resources to change the old frame of charity towards a new frame of the fulfillment of rights. The change of framework was carried out by advocating Local Regulations in Bali, which are in line with the spirit of the UNCRPD. Furthermore, through their daily activities, activists can show the public that people with disabilities can be independent and actualize their self potentials if they get the chance.

ABSTRAK: Gerakan penyandang disabilitas dimotori oleh aktor-aktor gerakan yang mampu mentransformasi pengalaman negatif mereka menjadi daya untuk mewujudkan perubahan ke arah pemenuhan hak-hak penyandang disabilitas. Riset ini membahas tentang relasi antara rekonstruksi atas pengalaman negatif di masa lalu akibat stigma dan diskriminasi, identitas kolektif, dan kapasitas untuk terlibat dalam gerakan hak-hak disabilitas. Dengan mengambil lokasi di Bali, penelitian ini menggunakan metodologi kualitatif jenis fenomenologi untuk mengungkap makna pengalaman dari tujuh narasumber aktivis gerakan hak disabilitas dalam proses pelibatan diri mereka dalam gerakan sosial. Artikel ini menemukan bahwa narasumber aktor gerakan sosial mampu merekonstruksi pengalaman negatif mereka menjadi kapasitas untuk membuat perubahan. Identitas personal mereka bertemu dengan identitas kolektif sebagai pelaku gerakan hak-hak disabilitas melalui interaksi dengan komunitas yang memberikan ruang bagi munculnya kesadaran baru tentang hak dan strategi advokasi. Ratifikasi UNCRPD yang disosialisasikan oleh organisasi masyarakat sipil membuka kesempatan bagi penguatan interaksi dan jaringan antara aktivis hak-hak disabilitas di tingkat nasional dan di tingkat lokal. Jejaring tersebut menguatkan kepercayaan diri para aktivis di Bali untuk membuat aksi kolektif. Ratifikasi UNCRPD juga menjadi momentum bagi mobilisasi sumber daya gerakan untuk mengubah bingkai lama belas kasihan menuju bingkai baru pemenuhan hak. Pengubahan bingkai tersebut dilakukan melalui advokasi pada pembentukan Peraturan Daerah di Bali yang selaras dengan semangat UNCRPD. Di samping itu, para aktivis melalui kegiatan keseharian, menunjukkan kepada publik bahwa penyandang disabilitas memiliki kemampuan untuk mandiri dan mengaktualisasikan potensinya jika mereka mendapatkan kesempatan.

Keywords:

discrimination;
disability;
identity;
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Kata Kunci:

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1. Introduction

Expectations for the fulfillment of disability rights are increasing along with the advent of laws on disability rights in Indonesia, including Law number 8 of 2016 concerning Persons with Disabilities. However, a number of studies reported that discrimination and human rights violations suffered by persons with disabilities in Indonesia are still high.¹ Persons with disabilities still encounter difficulties in enforcing their rights. They still struggle their daily lives, such as securing a job, accessing public transportation, and mobility.²

In Bali, people with disabilities also face cultural hegemony that sees their disability condition as a result of bad actions in past lives.³ For persons with disabilities, this accusation is akin to a “death sentence” which undermines their will to live. Exclusion from the cultural aspect of life is also prevalent when disabled people on wheelchairs have difficulties praying at the big temples in Bali because the structure involves long and high steps.⁴

Some people with disabilities chose not to take the situation for granted and made efforts to overcome discrimination and stigma for their own personal well-being, and also for those with disabilities in general. They coordinated to mobilize resources and used the available opportunities to fight for disability rights. They were the first generation of disability rights movement in Bali. Those who entered the arena of social movement was a group of people who involved themselves in an effort to obtain or obstruct, a process of social change.⁵ This article discusses the process of interpreting personal experience into the construction of a collective identity, which then opens the way for collective actions to advocate for disability rights through the formation of local regulations and changing public views on disability rights.

Previous studies on enforcement of the rights of persons with disabilities tend to focus on three aspects: the first is discrimination experienced by persons with disabilities; the second, obstacles and achievements of disability rights movement; the third, the less optimal role of the government in enforcing the rights of persons with disabilities. Study on discrimination and stigma against persons with disabilities and their families includes the work of Nisa⁶, Fanu, Schmidt, and Virendrakumar⁷, and Trani, et al.⁸ Previous studies emphasizing the achievements and barriers of the movement of persons with disabilities include those of Prastiwi⁹, Parameswara¹⁰, van den Brink, et al.¹¹, and You and Hwang¹², and Makkasau¹³. Other studies discuss the ineffectiveness of the government, including local governments, in enforcing the rights of persons with disabilities, as seen in Tan

- 1 Disability Convention Team, “Indonesia Shadow Report: Implementation of the United Nations Convention on the Rights of Persons with Disabilities” (Indonesia, 2017); Nicola Edwards, “Disability Rights in Indonesia? Problems with Ratification of the United Nations Convention on the Rights of Persons with Disabilities,” *Australian Journal of Asian Law* 15, no. 1 (2014): 1–15; Komnas HAM, “Mendorong Pengesahan ‘Optional Protocol the Convention on the Rights of Persons with Disabilities’ (OP-CRPD) Dalam Rangka Pemenuhan Hak Asasi Manusia Penyandang Disabilitas,” 2016.
- 2 Wayan Damai, “Renungan untuk Hari Cacat Sedunia,” in *Suara Berbeda dari Pulau Dewata*, ed. Anton Muhajir and Octavia Asmarani (Denpasar: Bale Bengong, 2022), 359–62.
- 3 Berdasarkan data dari Pemda Provinsi Bali, penyandang disabilitas di Bali berjumlah 12.086 orang suaradewata.com, “12.086 Penduduk Penyandang Disabilitas Ada Di Bali,” August 21, 2021, <https://www.suaradewata.com/read/202108230020/12-086-penduduk-penyandang-disabilitas-ada-di-bali.html>.
- 4 Damai, “Renungan Untuk Hari Cacat Sedunia.”
- 5 Anthony Giddens, *Sociology* (Cambridge: Polity Press, 1993).
- 6 Uswatun Nisa, “Stigma Disabilitas di Mata Orang Tua Anak Difabel di Yogyakarta,” *Inklusi* 50, no. 1 (2021): 75–88, <https://doi.org/10.14421/Ijds.080106>.
- 7 Guy Le Fanu, Elena Schmidt, and Bhaviswa Virendrakumar, “Inclusive Education for Children with Visual Impairments in Sub-Saharan Africa: Realising the Promise of the Convention on the Rights of Persons with Disabilities,” *International Journal of Educational Development* 91 (2022): 1–9, <https://doi.org/10.1016/J.Ijeducdev.2022.102574>.
- 8 Jean-Francois Trani et al., “Stigma of Persons with Disabilities in South Africa: Uncovering Pathways from Discrimination to Depression and Low Self-Esteem,” *Stigma of Persons with Disabilities in South Africa: Uncovering Pathways from Discrimination to Depression and Low Self-Esteem* 265 (2020): 1–12, <https://doi.org/10.1016/J.Socscimed.2020.113449>.
- 9 Rani Prastiwi, “Pergerakan dan Perjuangan Difabel di Kabupaten Gunung Kidul: Studi Kasus Forum Komunikasi Disabilitas Gunung Kidul” (Skripsi, Yogyakarta, Universitas Gadjah Mada, 2009).
- 10 Ananda Vita Parameswara, “Pemenuhan Hak Politik bagi Penyandang Disabilitas (Studi Kasus Gerakan untuk Kesejahteraan Tuna Rungu Indonesia di Kota Palembang)” (Skripsi, Palembang, Universitas Islam Negeri Raden Fatah, 2019).
- 11 Amélie van Den Brink, Willem Elbers, and Aisha Ibrahim, “Fragmented yet Together: The Disability Movement in Sierra Leone,” *Disability & Society* 36, no. 7 (2021): 1035–52, <https://doi.org/10.1080/09687599.2020.1782174>.
- 12 Dong Chul You and Se Kwang Hwang, “Achievements of and Challenges Facing the Korean Disabled People’s Movement,” *Disability & Society* 33, no. 8 (2018): 1259–79, <https://doi.org/10.1080/09687599.2018.1488676>.
- 13 A. Makkasau, “Gerakan Sosial Penyandang Disabilitas di Kota Makassar” (Skripsi, Makassar, UIN Alauddin, 2020).

and Ramadhani's¹⁴ and Ndaumanu's research¹⁵. This article takes a different take on the three perspectives which dominate texts about persons with disabilities in Indonesia. Instead of only stopping at the impact of discrimination and stigma, this article goes beyond by touching on the construction of meaning from the experiences of movement actors who directly experience discrimination and stigma, and then involve themselves in the arena of social movement.

The discussion will be presented in three sub-discussions. In the first, the informants' experiences of depression, stigma, and discrimination are described in details. Afterwards, the construction of collective identity as a human rights activist is presented in the second sub-discussion. Finally, the third part describes the mobilization of movement for the rights of persons with disabilities.

2. Research Methods

This study applied a qualitative methodology, namely hermeneutic phenomenology, with the aim of understanding the meaning of daily experiences of the subjects of the disability right movement in Bali. Phenomenology offers a descriptive, reflective, and interpretive way of research that seeks to understand the essence of the subject's experience.¹⁶ This method is relevant for use in research because it emphasizes on the construction of meaning based on the subject's daily struggles, which ultimately form the basis of their actions. Phenomenology describes the meaning of life experience and hermeneutics describes the interpretation of that meaning.¹⁷ The phenomenology approach is basically hermeneutics since the researcher interprets the meaning of experience from the subject or informant themselves.¹⁸

This research involved seven informants who are activists of the disability rights movement. The informants were selected *purposively* - they are people with disabilities, with physical and sensory-visual disability variants, who become leaders in their respective communities. The informants were scattered across a number of regencies/cities in Bali, namely Denpasar, Tabanan, Gianyar, Jemberana, and Buleleng. Data was collected through in-depth interviews by exploring the depth of subjects with disabilities' life experiences, who were involved in disability rights activism. The author also examines biographies of informants, written in narrative form.

Table of Informants

No.	Subject	Domicile	Disability Variant	Education	Age (year)	Gender	Interview Time
1	NL	Denpasar	Physique	Bachelor's degree	57	Man	3 May 2022
2	SA	Gianyar	Physique	Elementary School	45	Woman	5 and 12 May 2022
3	WD	Gianyar	Physique	Junior High	44	Man	10 and 19 May 2022
4	WG	Buleleng	Blindness	Senior High	47	Man	15 May 2022
5	GS	Jemberana	Physique	Senior High	53	Man	20 and 23 May 2022
6	AY	Tabanan	Blindness	Senior High	48	Man	17 May 2022
7	MB	Buleleng	Physique	Vocational School	41	Man	22 and 25 May 2022

14 Winsherly Tan and Dyah Putri Ramadhani, "Pemenuhan Hak Bekerja bagi Penyandang Disabilitas Fisik di Kota Batam," *Jurnal HAM* 11, no. 1 (2020), <http://dx.doi.org/10.30641/ham.2020.11.27-37>.

15 Frichy Ndaumanu, "Hak Penyandang Disabilitas: Antara Tanggung Jawab dan Pelaksanaan oleh Pemerintah Daerah," *Jurnal HAM* 11, no. 1 (2020): 131–50, <http://dx.doi.org/10.30641/ham.2020.11.131-150>.

16 Clark Moustakas, *Phenomenological Research Method*. (London: Sage Publications, 1994).

17 Max van Manen, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (Albany: State University of New York Press, 1990).

18 Allen, Marion and Jensen, Louise, "Hermeneutical Inquiry Meaning and Scope," *Western Journal of Nursing Research* 12 (1990): 241–53, <https://doi.org/10.1177/019394599001200209>.

When the data was collected, the researcher carried out stages of qualitative data analysis which included: dividing the data into coding; withdrawing essential themes; looking for relationships between parts of the data; making a statement on the relationship between the themes.¹⁹ After the themes had been arranged and the relationships between themes had been identified, the researcher then interacted with the conceptual framework used in this study, namely symbolic interaction theory and social movement theory. The theory of symbolic interaction discusses the construction of meaning for subjects originating from social interaction through the use of symbols. Social movement theory provides an understanding of the cause of emergence of social movements and the process of mobilization towards collective action.

3. Discussion

3.1 Experiences of Depression, Stigma, and Discrimination

Informants with disabilities due to illness or accidents, experience depression with conditions they did not expect before, as experienced by interviewees NL, SA, WD, WG, and AY. The informant NL confined himself to his home for two years because he was ashamed of his physical condition. At home he also struggled with depression. He said, “Honestly, I admit that the family is devastated and ashamed for having a child with a disability.”²⁰

Depression in persons with disabilities reached a breaking point as experienced by the informant SA. When she entered puberty, she felt sad and disappointed in herself because her younger siblings and older siblings could freely go out and about, while she was confined at home, and felt that she was only a nuisance to her family. She regretted her disability and had plans to end her life when she entrusted her sister with buying mosquito repellent.²¹

The informant WD has a different life background from SA. They are both physically disabled as a result of being exposed to polio when they were children. Unlike SA, whose needs are met by her family, WD struggled to make ends meet for himself and his family. As a child, he sold paintings, crawling from place to place. He felt he had worked hard in order to meet his basic needs and to improve his living conditions, but not yet obtained the results he had hoped for. Even putting food on the table everyday proves difficult. He felt God had been unjust. He had once decided to end his life but couldn’t find a quick way to do it.²²

Persons with disabilities face discrimination and stigmatization in various forms. Goffman defines stigma as a phenomenon in which an individual acquires highly discredited attributes, for which he/she is then ostracized or rejected by society as a result.²³ In contrast to the stigma embedded in people’s attitudes and beliefs, discrimination is easier to identify because it manifests in actual behavior.²⁴ Discrimination refers to any form of arbitrary distinction, restriction or exclusion of a person based on certain attributes or characteristics that are deemed socially unacceptable. Discrimination is an action taken based on a pre-existing stigma.²⁵ The concepts of “stigma” and “discrimination” are interrelated in the sense that stigma causes people to act discriminatory. Discrimination, on the other hand, is the imposition of stigma and thereby encouraging and reinforcing stigma.²⁶

Negative experiences in the form of stigma and discrimination are the basis of the disability rights movement. All sources shared their experiences of discrimination from their environment, as experienced by the informant WD, a person with a physical disability who was born in a poor family of farm labourers. Since he was a child, he has helped the family earn money by selling paintings. Driven by the simple desire to write his name and signature on his paintings, WD wanted to go to school to learn to read and write. He visited a number of

19 William Gibson and Andrew Brown, *Working with Qualitative Data* (London: Sage, 2009).

20 NL, Interview oleh Penulis, Denpasar, May 3, 2022.

21 SA, Interview oleh Penulis, Gianyar, May 5, 12, 2022.

22 WD, Interview oleh Penulis, Gianyar, May 10, 19, 2022.

23 Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs NJ: Prentice Hall, 1963).

24 Bruce G. Link and Jo C. Phelan, “Stigma and Its Public Health Implications,” *Lancet* 367 (2006): 528–29, [https://doi.org/10.1016/S0140-6736\(06\)68184-1](https://doi.org/10.1016/S0140-6736(06)68184-1).

25 Peter Aggleton, Kate Wood, and Anne Malcolm, “HIV-Related Stigma, Discrimination and Human Rights Violations” (Geneva: UNAIDS, 2005), https://data.unaids.org/publications/irc-pub06/jc999-humrightsviol_en.pdf.

26 Kate Wood and Peter Aggleton, “Stigma, Discrimination and Human Rights” (London: Thomas Coram Research Unit Institute of Education, University of London, 2010).

elementary schools and expressed his wish to attend school, but became very sad when all those schools rejected him because of his disability.²⁷

Direct discrimination can also occur in the immediate environment, namely one's own family. As stated by informant WG who has visual disability (*low vision*) since he was two years old. He felt that his father was ashamed of his disability. "My father was a bit insecure about having a son like me. When we are in the crowd, my father would stay away and refuse to look after me." When his family moved to Denpasar, he was the only member not included. Lured with money, he was placed in the care of his aunt's family in Buleleng.²⁸

Rejection by schools as experienced by WD and WG is a form of direct discrimination.²⁹ Burns points out that there is another form of discrimination called structural discrimination, one dimension of which is institutional discrimination. This type of discrimination is based on certain norms, rules, regulations, procedures and positions that determine some access to resources while excluding others.³⁰ The informant, WD, said that he had experienced difficulties using public transportation facilities, and had to modify a three-wheeled motorcycle for mobility. When using a modified motorbike, he is often stopped by the traffic police and receives condescending remarks.³¹

Another dimension of structural discrimination is cultural discrimination, namely based on widely dispersed social paradigms and related categorization system which rewards a specific social group and devalue others.³² This form of discrimination was experienced by informant AY, a person with blindness. He had worked as a massager in Kuta and served hotel calls. When serving foreign guests, he often received payments in foreign currencies such as USD. He once wanted to exchange dollars at a *money changer* in Kuta, and asked the whereabouts to a driver on the side of the road. After getting directions, he rushed to the *money changer*. However, when he was about to enter, the *money changer* officer told AY that they do not donate to people. These officers are driven by a social paradigm that associates persons with visual-sensory disabilities with beggars.³³

Phelan and Link present another variant of discrimination which they call *insidious discrimination*, that works subtly and prevents persons with disabilities from actualizing themselves so that they get confirmation in accordance with the stigma attached to them, namely people with disability. The results are uncomfortable social interactions, unemployment, low self-esteem, low quality of life, and limited social networking.³⁴ This type of discrimination is found in the experience of informant SA, a person with a physical disability. Since suffering from polio at elementary school, she stopped going to school and confined herself inside her home. One time she went outside and saw people ogling at her, which she felt was a condescending gesture. She was very saddened by the treatment of her neighbors. Her family responded to the incident by restricting her from going outside, so as not to get insulted by other people. Her parents comforted her by ensuring her that they're still able to meet her needs.

A demeaning view of the surrounding environment becomes *insidious discrimination* because the act of *labeling* is degrading (perceiving as incapable), preventing SA from simply socializing with the surrounding environment.³⁵ The self-confinement at home further reinforces the pre-existing stigma. Stigma and discrimination against persons with disabilities are manifestations of the workings of structural violence. Structural violence describes socio-economic, political, legal, religious and cultural structures which hinder certain individuals, groups and societies from achieving their full potential. Structural violence makes a person's actual capacity lower than it should be.³⁶

27 WD, Interview.

28 WG, Interview oleh Penulis, Denpasar, May 15, 2022.

29 Link and Phelan, "Stigma and Its Public Health Implications."

30 Tom R. Burns, "Towards a Theory of Structural Discrimination: Cultural, Institutional and Interactional Mechanisms of the 'European Dilemma,'" in *Identity, Belonging and Migration*, ed. Gerard Delanty, Ruth Wodak, and Paul Jones (Liverpool: Liverpool University Press, 2008), 152–72.

31 WD, Interview.

32 Burns, "Towards a Theory of Structural Discrimination: Cultural, Institutional and Interactional Mechanisms of the 'European Dilemma.'"

33 AY, Interview oleh Penulis, Tabanan, May 17, 2022.

34 Link and Phelan, "Stigma and Its Public Health Implications."

35 SA, Interview.

36 Johan Galtung, "Violence, Peace, and Peace Research," *Journal of Peace Research* 6, no. 3 (1996): 167–91, <https://doi.org/10.1177/002234336900600301>.

3.2 Construction of Collective Identity as Human Rights Activist

The journey of the informant in overcoming depression and frustration is a life-defining phase in the process of becoming a human rights activist, specifically disability rights. When WD was planning to end his life, he had a dialogue with himself, “Don’t do this. Be patient, the time has not yet come. You still have a long way to go. Everything will be much better later. Let’s try even harder. Trust me!”³⁷ This dialogue gave spirit to WD. He felt guilty because he had given up hope and scorned God for his living conditions. Other informants such as GS did *self-healing* by adopting an attitude of sincerity and accepting the fact that there are people who support and those who demean persons with disabilities. When it comes to his own self, he adopts the motto, “never ask how many limbs are still there, instead ask what can be done with the existing limbs.”³⁸

The narrative on experience of rising from adversity is part of the actor’s personal identity. Personal identity or narrative identity is the internalization of the meaning of personal life experience in the form of an ever-evolving narrative. The subject draws meaning from their life experiences, that leave an impression, and experiences internalization. In late adolescence and adulthood, people begin to organize their lives into integrative narratives of the Self, reconstructing the past and imaginatively anticipating the future in such a way as to give their life a sense of wholeness and purpose.³⁹ Narrative identity provides guidelines on how ideals can be achieved, standards of value considered appropriate to uphold, and a certain way of life.

Reinterpretation of life experiences and decisions to change stigma and discrimination carries into the personal identity of the informants. This identity is the foundation for actors with disabilities to carry out social movements. Experts in social movements mention the role of collective identity as the basis for social movements.⁴⁰ Without personal identity, it is difficult for actors to open themselves up and share a collective identity with other actors of persons with disabilities movement. Collective identity is a shared definition of a group. It stems from common interests, experiences, and solidarity.⁴¹ Collective identity involves the ability to distinguish the Self as a collectivity from “other groups”, and to be recognized by these “other groups”. Actors who enter the arena of social movements do not need a complete and intact ideological similarities, interests, goals with other actors who are in the same movement organization.⁴²

When personal identity is transformed into a collective identity, the personal identity remains the personal property of the actor. As Melucci said, the construction of collective identity is a dynamic process in which actors negotiate, understand, and construct their actions through repeated interactions. Identity at individual level then becomes a collective identity when one feels connected and shares a sense of solidarity with other people. Solidarity is an *ongoing* (continuous) construction process to define a sense of “us”.⁴³

The narrative of the informant before their activity in the movement was about discrimination and sadness. The meaning then changes when they interact with other people with disabilities. There are variations in the process towards a collective identity of actors in the disability rights movement. As stated by the informant SA⁴⁴, at first meeting with fellow persons with disabilities gave rise to a feeling of shared destiny as people who are marginalized. At that time, this feeling of shared responsibility had not yet influenced collective action to fight for common interests. Initially, the feeling of togetherness was more towards solidarity to strengthen one another mentally and support each other internally within the community.

37 Imaculata Umiyati, *Aku Beda dan Aku Bisa!* (Jakarta: Gramedia Pustaka Utama, 2020).

38 GS, Interview oleh Penulis, Jemberana, May 20, 2022.

39 Jonatan Kurzweily, “Being German, Paraguayan and Germanino: Exploring the Relation between Social and Personal Identity,” *Identity: An International Journal of Theory and Research* 19, no. 2 (2019): 144–56, <https://doi.org/10.1080/15283488.2019.1604348>; Dan P. McAdams, “The Psychology of Life Stories,” *Review of General Psychology* 5, no. 2 (2001): 100–122, <https://doi.org/10.1037/1089-2680.5.2.100>.

40 Alberto Melucci, *Challenging Code* (Cambridge: Cambridge University Press, 1996); Francesca Polleta and James M. Jasper, “Collective Identity and Social Movements,” *Annual Review of Sociology* 27 (2001): (283-305, <https://doi.org/10.1146/annurev.soc.27.1.283>); David A. Snow and Robert D. Benford, “Ideology, Frame Resonance, and Participant Mobilization,” *International Social Movement Research* 1 (1988): 197–218; Verta Taylor and Nancy E. Whittier, “Collective Identity in Social Movement Communities: Lesbian Feminist Mobilization,” in *Frontiers in Social Movement Theory*, ed. Aldon D. Morris and Carol McClurg Mueller (New Haven: Yale University Press, 1992), 104–32.

41 Taylor and Whittier, “Collective Identity in Social Movement Communities: Lesbian Feminist Mobilization,” 104–32.

42 Alberto Melucci, “The Symbolic Challenge of Contemporary Movements,” *Social Research* 52, no. 4 (1985): 789–816.

43 Melucci, *Challenging Code*.

44 SA, Interview.

SA's collective identity to fight for disability rights began to grow and develop when she managed a foundation in Gianyar that works on disability issues and interacts with people who share knowledge about disability rights. Unlike SA, WD and NL are people who have interacted with persons with disabilities outside Bali (Yogyakarta) with support from the Yogyakarta YAKKUM Foundation. Their collective identity grew and developed in Yogyakarta, where they started the disability rights movement.⁴⁵

Collective identity is not solely based on common goals or interests, but also involves emotions.⁴⁶ The emotions of the informants relate to the past experiences of the actors when they experienced frustration and depression. The interviewees showed sad faces and even cried when they recalled their experiences of discrimination and stigmatization. This experience actually became an impetus for actors to carry out collective resistance, so that stigma and discrimination against persons with disabilities did not occur as they had experienced. The existence of emotional connection and the formation of collective identity can be seen from the stories of informant NL. Upon returning to Bali after several years of working at YAKKUM Yogyakarta, Informant NL bought a used car to travel around Bali looking for persons with disabilities who live isolated from the society and feel ashamed of their disability condition. He tried to provide assistance such as mobility aids for people with physical disabilities whom he visits. He remembered himself having the same feelings and conditions. NL's positive emotions have given him the solidarity and collective identity which he shares with other persons with disabilities.⁴⁷

Emotions in relation to collective identity also originate in the daily lives of actors in the disability rights movement. According to AY⁴⁸, persons with disabilities have regular meetings with fellow persons with disabilities of the same variant. Sensory-blind persons with disabilities often meet under the PERTUNI organization, which is a tiered organization found at national to local levels. Meanwhile, persons with physical disabilities are more likely to interact within the foundation that houses them. All sources stated that they have a sense of solidarity when interacting with other persons with disabilities. They shared stories about stigma and discrimination. Opposition to stigma and discrimination, is the basis of the consolidation of collective identity and solidarity, rather than common interests.⁴⁹ Positive emotions such as joy and enthusiasm make social movement activists stay in the arena of the movement even though their goals have not been achieved.⁵⁰

Collective actions carried out by persons with disabilities are a *visible* dimension of social movements, while the period in between one collective action and the next is called a latent dimension. In this latent dimension, the potential for resistance to stigma and discrimination is woven into the daily activities of movement actors both in community centers for persons with disabilities and other social spaces. Most of the important activities of social movements take place in the latent dimension. Interactions in this latent phase are a laboratory of experience. New problems and questions are asked. New answers are found and tested, and reality is perceived and named in different ways.⁵¹

The *visible* and latent dimensions of the movement of persons with disabilities have a mutually reinforcing relationship. *Visible* collective action provides energy to renew solidarity, facilitating the formation of new groups and the recruitment of new militant members.⁵² Informant MB said that while carrying out collective action in a public place, a person with a disability approached and said he wanted to join his community. This shows that collective action can attract new members.⁵³

45 WD, Interview; NL, Interview.

46 Jacqueline Adams, "The Bitter End: Emotions at a Movement's Conclusion," *Sociological Inquiry* 73, no. 1 (2003): 84–113, <https://doi.org/10.1111/1475-682X.00042>; De Volo Lorraine, "The Dynamics of Emotion and Activism: Grief, Gender, and Collective Identity in Revolutionary Nicaragua," *Mobilization* 11, no. 4 (2006): 461–74, <https://doi.org/10.17813/Maiq.11.4.Q21r3432561121t7>; Scott A. Hunt and Robert D. Benford, "Collective Identity, Solidarity, and Commitment," in *The Blackwell Companion to Social Movements*, ed. David A. Snow, Sarah A. Soule, and Hanspieter Kriesi (Malden, MA: Blackwell Publishing Ltd., 2004), 433–458.

47 NL, Interview.

48 AY, Interview.

49 Alberto Melucci, "The Process of Collective Identity," in *Social Movements and Culture*, ed. Hank Johnston and Bert Klandermans (Minneapolis: University of Minnesota Press, 1995), 41–36.

50 Cristina Flesher Fominaya, "Collective Identity in Social Movements: Central Concepts and Debates," *Sociology Compass* 4, no. 6 (2010): 393–404, <https://doi.org/10.1111/J.1751-9020.2010.00287.X>.

51 Melucci, "The Symbolic Challenge of Contemporary Movements."

52 Melucci, *Challenging Code*.

53 MB, Interview oleh Penulis, Buleleng, 22 May 2022.

In both the latent and visible dimensions, interaction in social movements is a matter of negotiating identities and roles, “Who are we and what do we do?”⁵⁴ According to symbolic interaction theory, we learn to see ourselves through the eyes of others. The way we see ourselves is largely influenced by the feedback we get about ourselves from the people around us. Mead shows the difference between I as “I” and as “Me”. “I” is the Self that we perceive as individuals. “Me” is the Self expected by society. When acting as “Me”, we do something that society expects. There are times when we also act as “I”. There is a constant conversation between “I” and “Me”.⁵⁵ There are times when we comply with society’s expectations and there are also times when we fight back. Only when resistance occurs collectively (social movement) can the society head towards social change.⁵⁶ In the disability rights movement in Bali, interaction among people with disabilities is a form of resistance against social stigma. They reject the categorization of persons with disabilities as incapacitated people who must be pitied.

3.3 Mobilization of The Movement For The Rights of Persons With Disabilities

The disability movement in Bali has experienced a shift in discourse with the advent of ratification of the *United Nations Convention on the Rights of People with Disabilities* (UNCRPD)⁵⁷ by the Government of Indonesia in 2011. Prior to the ratification of the UNCRPD, the disability rights movement in Bali was still focused on discourse and efforts to help persons with disabilities, and had not yet focused on the issue of fulfillment of disability rights by the State as well as public awareness. This can be seen, for example, from the movement patterns carried out by NL together with their organization, inviting persons with disabilities and their families to receive mobility aids so they can socialize and become more independent. NL invited colleagues from abroad to help apply for funding from international donor agencies. The financial support from the donor agency was then used by the institution to expand disability assistance services and empower the independence of persons with disabilities in NTB and NTT.⁵⁸

Discourses and movement patterns that focus on mobilizing resources to help each other with disabilities also appear in other disability movement groups such as the Bhakti Glad Hati Foundation. At the Bhakti Glad Hati Foundation, mobilization of movement resources is carried out by implementing leadership and organizational management in pioneering organizations or communities. Informant SA, with her experience in ending self-isolation at home, visits persons with disabilities in various places and invites them to do activities in her foundation. With her English language and design abilities, she made her foundation into a provider of tour services around Ubud using modified motorcycles. She and her colleagues made their foundation a place for people with disabilities to gain independence, including financial independence. The foundation has restaurants and salons managed by persons with disabilities. The effort to become independent for her is a way to fight the stigma and discrimination against persons with disabilities.⁵⁹

The ratification of the UNCRPD brought a change in the pattern of the movement for the rights of persons with disabilities in Bali. Through the dissemination of norms in the UNCRPD, people with disabilities gain an understanding that human rights are inherent in each human being. Treaties and other sources of law are intended to formally protect the rights of individuals and groups against actions or neglect by the government that interfere with the exercise of their human rights.⁶⁰

UNCRPD ratification forms the basis for the formation of other laws and regulations related to persons with disabilities. The making of these laws and regulations does not occur linearly and automatically from the international level to the district/city level, but occurs due to the contribution of the disability rights movement

54 Adamson, Kathryn Anne Grace, “The Ecology of Leadership: Examining the Relational Dynamics of Dyads through the Lens of Symbolic Interactionism” (Disertasi, Virginia Beach, Regent University, 2012).

55 Herbert G. Mead, *Mind, Self, and Society from the Standpoint of a Social Behaviourist*. (Chicago: University of Chicago Press, 1934).

56 Stacey Hannem, “Symbolic Interactionism, Social Structure, and Social Change,” in *The Routledge International Handbook of Interactionism*, ed. Dirk Vom Lehn, Natalia Ruiz-Junco, and Gibson, Will (New York: Routledge, 2021), 194–204.

57 UNCRPD diadopsi oleh PBB secara resmi pada tanggal 13 Desember 2006 dan mulai berlaku pada tanggal 3 Mei 2008. UNCRPD terdiri atas 50 artikel. Pasal 5 sampai 30 menetapkan hak substantif penyandang disabilitas, sedangkan ketentuan lainnya menetapkan mekanisme untuk implementasi dan pemantauan. Tujuan UNCRPD adalah “untuk mempromosikan, melindungi, dan memastikan perolehan penuh dan setara dari semua HAM dan kebebasan fundamental oleh semua penyandang disabilitas, dan untuk mempromosikan penghormatan terhadap martabat mereka” (Pasal 1).

58 NL, Interview.

59 SA, Interview.

60 UNOHCHR, “Human Rights: A Basic Handbook for UN Staf.,” 2020.

at both the national and local levels. In their activism, the perpetrators of this movement advocated for local regulations regarding the fulfillment of disability rights.

In Bali, the follow-up process of UNCPRD ratification was faster than at the national level. Thanks to input and pressure from the movement of persons with disabilities, the Local Government of Bali Province issued Local Regulation Number 9 of 2015 concerning the Protection and Fulfillment of the Rights of Persons with Disabilities, while at the national level the Law on Persons with Disabilities had only been implemented since 2016.⁶¹

In addition to local regulations at provincial level, disability rights activists in Bali also advocate for local regulations on the protection of disability rights at district/city level⁶², one of which is the procurement of academic papers and draft on Local Regulations (Ranperda) to the Local Government of Gianyar Regency.⁶³ They are also directly involved in providing awareness to the public and empowering people with disabilities, one of which is convoy of modified motorbikes, with gathering point on open fields. In that place they gave an explanation to the community members who were on the move or even members of the public who were interested in asking questions.⁶⁴

Advocacy for local regulations that are in favor of the rights of persons with disabilities is carried out by activists with the resources to mobilize social movements. These resources include managerial skills, strategy, communication, finance, and building networks both among and outside persons with disabilities

This capacity is formed from the experience of activists in their respective communities. Movement mobilization is not necessarily carried out by discriminated people - persons with disabilities who experience discrimination and stigmatization will not necessarily enter the arena of social movements. The choice to enter the movement arena is only one of several options.⁶⁵ Using the point of view of resource theory, strong feelings of being treated unfairly, as experienced by persons with disabilities, are the initial conditions for the rise of social movements. Groups of people who complain will establish a social movements if there are sufficient resources.⁶⁶

The attitude of the Government of Indonesia in ratifying the UNCPRD has become a political opportunity structure used by activists of the disability rights movement in Indonesia for the success of their movement. Political opportunity structures are external political conditions that provide benefits to the movement of persons with disabilities.⁶⁷ UNCPRD changed the perspective on disability from compassion to rights for persons with disabilities. Prior to UNCPRD ratification, Indonesia implemented Law no. 4 of 1997 which uses the perspective of mercy. Under this law, persons with disabilities are seen as social problems whose problems are solved by other parties, both (the government) in the form of rehabilitation, social assistance, and maintenance of social welfare levels. Unlike Law no. 4 of 1997 which defines the State as having the obligation to “work for” the realization of the rights of persons with disabilities, the UNCPRD (article 4) obliges the State to take all appropriate legislative, administrative and other steps in implementing the UNCPRD, and to amend or abolish laws, statutes, regulations, customs and practices exist that discriminate against persons with disabilities. States must also designate or establish “independent mechanisms” to “promote, protect and monitor the implementation of this Convention” (Article 33).

The consequence of this ratification is that the political regime in Indonesia is open to the emergence of new actors who make claims to the political elite or the same actors who make different political claims than before. According to informants NL and WD, after the ratification of the UNCPRD, organizations at the national and local levels often hold meetings to discuss laws and regulations on persons with disabilities as a follow-up to the ratification. In this process, there are a number of international donor agencies that also provide financial

61 NL, Interview.

62 NL, Interview; WD, Interview.

63 RedaksiBali.com, “Pemkab Gianyar Sambut Baik Naskah Akademik dan Draft Ranperda Inisiatif dari Penyandang Disabilitas,” *RedaksiBali.com*, May 18, 2021, <https://www.redaksibali.com/2021/05/pemkab-gianyar-sambut-baik-naskah-akademik-dan-draft-ranperda-inisiatif-dari-penyandang-disabilitas/>.

64 MB, Interview.

65 Craig J. Jenkins and Charles Perrow, “Insurgency of the Powerless: Farm Worker Movements,” *American Sociological Review* 42, no. 2 (1977): 249–68, <https://doi.org/10.2307/2094604>.

66 Tilly Charles, *From Mobilization to Revolution* (Reading, MA: Addison-Wesley, 1978).

67 Charles Tilly and Sydney Tarrow, *Contentious Politics* (New York: Oxford University Press, 2015); Sydney Tarrow, *Power in Movement: Social Movement: Collective Action and Politics* (Cambridge: Cambridge University Press, 1994).

assistance to facilitate these meetings.

Ratification of the UNCRPD also provides greater confidence on the part of the movement actors to communicate with other persons with disabilities, their families, and the public in general. To convince people with disabilities and their families to be more independent, activists for the disability rights movement in Bali implemented a *framing* strategy (frame). Frames are interpretive schemes that people use to identify, label, and create meaningful events in their lives.⁶⁸ Frames enable people to give meaning to their experiences and guide their actions, both in everyday life and in social movements. One of the most important tasks of being actively engaged in social movements is the production of meaning for participants, antagonists and observers.⁶⁹ That is, participants in social movements actively build collective awareness. A central part of the collective consciousness is the frame, or an overall system of interpretations that enables individuals to “find, understand, identify, and label events”.⁷⁰

Frame-stripping is a removal of inaccurate old frames that are used to see a problem or group. Once it's removed, an empty space is created where a new frame can be inserted. This doesn't necessarily mean that the new frame will be an extension of the desired frame - it can be one of a kind in its own. Stripping the frame can be done through social movements, protests or other means. This can also be aided by conscious constituencies, especially in academic or media publication areas, who insist that old frameworks should be abandoned.⁷¹

The first aspect of the old frame to be removed was the medical disorder model. In this model, persons with disabilities are seen as having medical problems, resulting in them having to take on the role of a sick person. This view assumes that, since persons with disabilities are sick people, they are unable to carry out socially-assigned tasks. They need the help of doctors and other medical personnel who specialize in a particular type of pathology. They are expected to cooperate with the medical personnel until they recover.⁷²

The second frame that needs to be changed is the view that disability is a distortion of social role. Exclusion from normal social roles means that a person is normatively deviated and, therefore, stigmatized. Majority cultures do not accept people who are stigmatized on the basis of equality. Thus, stigma must be removed before persons with disabilities can seek integration and equal opportunities, which are central to the civil rights framework.⁷³

The third frame that needs to be replaced is disability seen by society as an individual problem, with the only way to solve it being rehabilitation and individual efforts according to the old frame. The view of individual responsibility towards disability as a civil rights issue and persons with disabilities as victims of discrimination must be changed. The issue of discrimination against disabilities must be seen at its root causes in society. Discrimination can be resolved at the societal level. Discrimination should not be caused and resolved by individual effort.⁷⁴

To analyze these three old frames, actors in the disability rights movement in Bali use various methods for different segments. When they talk to government agencies, they will refer to the UNCRPD as a new perspective on disability. When dealing with people at the grassroots, disability rights movement activists in Bali use action as a form of communication to a wider audience, to show that persons with disabilities can be independent if given the opportunity. Informant NL shares his experience of meeting a three-year-old disabled person. With the permission of his family, the child was sent to school until he earned a bachelor's degree at Sampoerna University in Jakarta. Their will to fight and succeed is a story about struggle against the stigma of persons with disabilities, who are often times considered incompetent.⁷⁵ The story was spread by movement activists as part of a *framing* effort to fight stigma.

68 Erving Goffman, *Goffman, Erving. Frame Analysis: An Essay on the Organization of Experience* (New York: Harper & Row, 1974).

69 Hunt and Benford, “Collective Identity, Solidarity, and Commitment.”

70 David A. Snow et al., “Frame Alignment Processes, Micromobilization, and Movement Participation,” *American Sociological Review* 51, no. 4 (1986): 464–81, <https://doi.org/10.2307/2095581>.

71 Sharon Barnartt and Richard Scotch, *Disability Protest: Contentious Politics 1970-1999* (Washington, D.C.: Gallaudet University, 2021).

72 Barnartt and Scotch,.

73 Barnartt and Scotch,.

74 Harlan Hahn, “The Politics of Physical Differences: Disability and Discrimination,” *Journal of Social Issues* 44, no. 1 (1998): 39–47, <https://doi.org/10.1111/J.1540-4560.1988.Tb02047.X>.

75 NL, Interview.

The informant, NL, stated that the Puspadi Foundation empowers persons with disabilities who live in remote areas and who experience stigma and discrimination from their surroundings. The foundation empowers these people by providing them with skills. Once they have succeeded in becoming independent, they are made into role models by the community. For informant NL, this slowly changed old frames about disability. They indirectly become ambassadors for disability groups, sending a message to the public that persons of disability can be successful given fighting spirit and opportunities. According to NL, the frame of persons with disabilities with success stories as a result of organizational effort has succeeded in attracting the government's attention to the issue of disability rights.⁷⁶

Disability activists explore the frame that disability is the result of karma from past lives. The WG informant introduced a new frame by stating that God created humans equally. This frame is also shown through the Pertuni Bali logo which contains the slogan "*Tat Twam Asi*" which means "You are I". This is the teaching of Hinduism which states that the human soul shares the same atma. Since humans are created equal, leaders should make efforts to provide opportunities for persons with disabilities to have equality.⁷⁷

4. Conclusion

Informants with disabilities experience stigma and discrimination in various forms. This stigma and discrimination lead to feelings of hopelessness and depression when they are helpless or have no way to improve their quality of life. The opportunity to meet fellow persons with disabilities changed the point of view of the informants, ensuring them that they are not alone in facing their problems. This becomes a part of the process of constructing a collective identity as persons with disabilities, which initially involves a shared feeling as people who face problems of stigma and discrimination, and involves solidarity to support one another within their community. The construction of collective identity cannot be separated from personal identity. Personal narratives from informants who experience stigma and discrimination are connected to their collective identity as persons with disabilities who involve themselves in the arena of disability rights social movements. The connection between personal identity and collective identity allows movement actors to survive in social movements for a long time. Collective identity is not merely an instrument to achieve common goals but also an expression to gain mutual solidarity. The collective identity of the informants also experienced an expansion, from a collective identity as persons with disabilities who support each other in their community to a collective identity in social movement organizations for disability rights advocating in certain areas. The common struggle against stigma and discrimination becomes a glue that binds the actors of movement for persons with disabilities, who are of various kinds of people spread across multiple organizations and communities of persons with disabilities.

The collective identity of disability rights activists becomes an agency to fight for their rights, supported by the existence of UNCRPD, ratified by the Government of Indonesia in 2011. UNCRPD is a political opportunity for movement activists to raise awareness of the rights of persons with disabilities, which encouraged activists of the movement for persons with disabilities to actively hold meetings with persons with disabilities from various backgrounds to discuss the draft of Local Regulation in Bali concerning the fulfillment of disability rights, to be voiced and fought for at all local governments in Bali. Movement actors use resources to mobilize social movements, namely organizational management capacity, volunteers, donors, as well as the capacity of movement leader actors in designing strategies and actions to remove old frames of disability, replacing them with new ones. The old frame in question is disability as a medical problem, deviant social behavior, and individual responsibility, which then changes to a new frame, namely the fulfillment of the rights of persons with disabilities.

This research produces practical suggestions for disability rights movement organizations in preparing the regeneration and mentoring of younger movement activists, with the support from various groups, including outside groups of persons with disabilities. The continuation of this movement is highly important since conventions and legislation alone cannot fulfill disability rights, even though there are articles that claim otherwise. The implementation of these rules must be fought for collectively in order to encourage the State to take responsibility. Collective action is also needed to dismantle the hegemony in society, which tends to stigmatize and discriminate against persons with disabilities.

⁷⁶ NL.

⁷⁷ WG, Interview.

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