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Communicating Disability Health and Education Rights: Stories from People with Disabilities and Parents in Indonesia

Mengomunikasikan Hak Kesehatan dan Pendidikan Disabilitas: Kisah dari Penyandang Disabilitas dan Orang Tua Anak Disabilitas di Indonesia

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ABSTRACT: Indonesians with disabilities experience socio-cultural problems that result in disparities in disability rights fulfilment, particularly in accessing equal education and healthcare. In response to such problems, disability activism has been undertaken, and nowadays is increasingly mediated by social media, specifically Instagram. This study intends to shine a light on individual and parental perspectives in communicating disability rights, drawing on the co-cultural communication theory, which classifies people with disabilities as a non-dominant group in society. Diverse disability stakeholders including people with disabilities and parents of children with disabilities participated in focus group discussions and semi-structured formal and informal interviews. Using digital autoethnographic methods, qualitative content analysis was also employed to examine their Instagram content on disability topics. This study focuses on how participants raise awareness of disability inclusion and communicate disability rights within the domain of education and healthcare. This study also emphasizes the efficacy of Instagram in mediating disability rights activism in Indonesia and its impact on the participants and their disability communities. The results show that while the assertive accommodation and non-assertive assimilation strategies are applicable in offline and online settings, the non-assertive accommodation strategy is particularly prevalent in enhancing digital disability representation. These collective actions contribute to advancing the fulfilment of those rights.

ABSTRAK: *Penyandang disabilitas di Indonesia mengalami permasalahan sosial budaya yang mengakibatkan kesenjangan dalam pemenuhan hak-hak disabilitas, terutama akses terhadap pendidikan dan layanan kesehatan yang setara. Menanggapi permasalahan tersebut, aktivisme disabilitas terus berkembang, dan saat ini dimediasi oleh media sosial, khususnya Instagram. Studi ini bertujuan untuk menyoroti perspektif individu dan orang tua dalam mengomunikasikan hak-hak disabilitas, dengan mengacu pada teori komunikasi co-cultural, yang mengklasifikasikan penyandang disabilitas sebagai kelompok non-dominan dalam masyarakat. Berbagai pemangku kepentingan disabilitas, termasuk penyandang disabilitas dan orang tua dari anak penyandang disabilitas, berpartisipasi dalam focus group discussion serta wawancara formal dan informal semi-terstruktur. Dengan menggunakan metode autoetnografi digital, analisis konten kualitatif juga digunakan untuk mengkaji konten Instagram mereka tentang topik-topik disabilitas. Studi ini berfokus pada bagaimana partisipan meningkatkan kesadaran akan inklusi disabilitas dan mengomunikasikan hak-hak disabilitas pada ranah pendidikan dan layanan kesehatan. Studi ini juga menekankan efektivitas Instagram dalam memediasi aktivisme hak-hak disabilitas di Indonesia dan dampaknya terhadap para partisipan dan komunitas disabilitas mereka. Hasil penelitian menunjukkan bahwa meskipun strategi akomodasi asertif dan asimilasi non-asertif dapat diterapkan baik di lingkungan luring maupun daring, strategi akomodasi non-asertif khususnya dominan dalam meningkatkan representasi disabilitas dalam ruang digital. Tindakan kolektif ini berkontribusi dalam meningkatkan pemenuhan hak-hak disabilitas.*

Keywords:
disability; disability rights; parents of disability; Instagram

Kata Kunci:
disabilitas; hak disabilitas; orang tua penyandang disabilitas; Instagram

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1. Introduction

Disability serves as a general term for impairments, activity limitations, and participation constraints. There is no denying that the category of disability is diverse.[1] For instance, disabilities might have both visible and invisible aspects.[2] There are approximately a billion people with disabilities worldwide, according to the World Health Organization's World Report on Disability in 2020.[3] The number of disabilities is continuously increasing,[4] making it one of the biggest minority groups.[5] In the co-cultural communication theory, disability is classified as a non-dominant group.[6]

Disability is an essential component of any society globally.[7] Those born with disabilities will be affected socioculturally.[8] They are frequently vulnerable,[9] marginalized,[10] and rejected by society.[11] Disability and stigma are inextricably linked, with disabled people being stigmatized.[12] People with disabilities experience discrimination in several fields[13], as documented in the media.[14] They are often seen as incapable,[15] which limits their social engagement.[16]

The continuing disability issues contribute to inequity in the human rights fulfilment of individuals with disabilities,[17] which is frequently characterized by a lack of accessibility[18] and discrimination in healthcare services.[19] They are classified as dependents and barred from working. This also had an economic consequence, since discrimination against the rights of people with disabilities increased their likelihood of falling into poverty.[20]

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1 Jonatan Södergren and Niklas Vallström, "Disability in Influencer Marketing: A Complex Model of Disability Representation," *Journal of Marketing Management*, 2022, https://doi.org/10.1080/0267257X.2022.2144418.

2 Anthony Beudaert, Nil Özçağlar-Toulouse, and Meltem Türe, "Becoming Sensory Disabled: Exploring Self-Transformation through Rites of Passage," *Journal of Business Research* 69, no. 1 (January 2016): 57–64, https://doi.org/10.1016/j.jbusres.2015.07.020.

3 WHO, "Who Global Disability Action Plan 2014–2021: Better Health for All People with Disability" (Geneva, 2020).

4 Meliana Damayanti and Fairuz Sabiq, "Implementation of Public Facilities and Disability Treatments: A Comparison Between Indonesia and Malaysia," 2018.

5 Södergren and Vallström, "Disability in Influencer Marketing: A Complex Model of Disability Representation."

6 M. P. Orbe and T. L. Roberts, "Co-Cultural Theorizing: Foundations, Applications & Extensions," *Howard Journal of Communications* 23, no. 4 (2012): 293–311; M. P. Orbe, *Constructing Co-Cultural Theory: An Explication of Culture, Power, and Communication* (Thousand Oaks, CA: SAGE, 1998); E Griffin, A Ledbetter, and G Sparks, *A First Look at Communication Theory* (New York: McGraw-Hill, 2019).

7 W. Triwahyudi and E. Setiawan, "Disability Inclusion in WASH: 'What Has Been Achieved and How Can This Help Other Practitioners?,'" in *37th WEDC International Conference, Hanoi, Vietnam*, 2014.

8 Monica E. Madyaningrum, Christopher C. Sonn, and Adrian T. Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation," *American Journal of Community Psychology* 69, no. 3–4 (June 1, 2022): 474–83, https://doi.org/10.1002/ajcp.12560.

9 Carla Rice et al., "Project Re•Vision: Disability at the Edges of Representation," *Disability and Society* 30, no. 4 (April 21, 2015): 513–27, https://doi.org/10.1080/09687599.2015.1037950.

10 R.L. Metts, "Disability Issues, Trends and Recommendations for the World Bank" (New York, 2000).

11 Siti Nurhayati, "Social Inclusion For Persons With Disabilities Through Access To Employment In Indonesia," *Prophetic Law Review* 2, no. 1 (June 1, 2020), https://doi.org/10.20885/plr.vol2.iss1.art1.

12 Michelle R. Nario-Redmond, Jeffrey G. Noel, and Emily Fern, "Redefining Disability, Re-Imagining the Self: Disability Identification Predicts Self-Esteem and Strategic Responses to Stigma," *Self and Identity* 12, no. 5 (September 2013): 468–88, https://doi.org/10.1080/15298868.2012.681118.

13 Carli Friedman and Aleksa L. Owen, "Defining Disability: Understandings of and Attitudes Towards Ableism and Disability," *Disability Studies Quarterly* 37, no. 1 (March 7, 2017): 2–30, https://doi.org/10.18061/dsq.v37i1.5061.

14 Frichy Ndaumanu, "Hak Penyandang Disabilitas: Antara Tanggung Jawab Dan Pelaksanaan Oleh Pemerintah Daerah," *Jurnal HAM* 11, no. 1 (2020): 131–50.

15 C. Pearson, "A Blueprint for Crisis Management," *Ivey Business Journal* 66, no. 3 (2002): 63–90.

16 Mimi Lusli et al., "The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People Affected by Leprosy in Indonesia," *PLOS Neglected Tropical Diseases* 10, no. 12 (December 13, 2016): e0005088, https://doi.org/10.1371/journal.pntd.0005088.

17 Dini Widinarsih, "Disability Inclusion and Disability Awareness in Muslim Society: An Experience of Indonesians Muslim with Disability in Performing Worship," 2018.

18 Jerome Bickenbach, "The World Report on Disability," *Disability & Society* 26, no. 5 (August 2011): 655–58, https://doi.org/10.1080/09687599.2011.589198; R. Vergunst et al., "Access to Health Care for Persons with Disabilities in Rural South Africa," *BMC Health Services Research* 17, no. 1 (December 17, 2017): 741, https://doi.org/10.1186/s12913-017-2674-5.

19 Sarju Sing Rai et al., "Intersectionality and Health-Related Stigma: Insights from Experiences of People Living with Stigmatized Health Conditions in Indonesia," *International Journal for Equity in Health* 19, no. 1 (December 1, 2020), https://doi.org/10.1186/s12939-020-01318-w.

20 Rice et al., "Project Re•Vision: Disability at the Edges of Representation"; Retno Manuhoro Setyowati, Errika Dwi Setya Watie, and Ami Saptiyono, "Representation of Disability Achievements in Television Talk Show Programs," *Jurnal The Messenger* 12, no. 1 (April 10, 2020): 40, https://doi.org/10.26623/themessenger.v12i1.1587; Z. B. Husain, "Berkesan Modul Kaunseling Pemulihan Terhadap Masalah Psikososial Orang Kurang Upaya (OKU) Fizikal Akibat Kemalangan" (Malaysia Science University, 2014).

Disability activism has then emerged to fight for disability rights and awareness,[21] including in Indonesia.[22]

Indonesia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2011[23] as disability births in the country steadily rises year after year.[24] The Indonesian Law 8/2016 on People with Disabilities mandated the fulfillment of human rights and the social protection of Indonesians with disabilities. However, research has shown that disability rights in Indonesia are unfulfilled and characterised by limited public service,[25] educational discrimination,[26] and workplace exclusion[27] have all emerged as pressing challenges for Indonesians with disabilities. These socioeconomic situations hampered the participation of people with impairments. As a result, individuals with disabilities typically experience feelings of guilt and inadequacy.[28] Indonesian society must work on embracing disability as part of its diversity. Society is still unaware of disability and shows neglectful behavior. Disability is frequently associated with karma.[29] Those with disabilities are ostracized,[30] and some are even regarded as different or, even worse, invisible. The Indonesian Law 8/2016 on People with Disabilities mandated the fulfillment of human rights and the social protection of Indonesians with disabilities. However, research has shown that disability rights in Indonesia are unfulfilled and characterized by limited public service,[31] educational discrimination,[32] and workplace exclusion[33] have all emerged as pressing challenges for Indonesians with disabilities. These socioeconomic situations hampered the participation of people with impairments. As a result, individuals with disabilities typically experience feelings of guilt and inadequacy.[34] Indonesian society must work on embracing disability as part of its diversity. Society is still unaware of disability and shows neglectful behavior. Disability is frequently associated with karma.[35] Those with disabilities are ostracized,[36] and some are even regarded as different or, even worse, invisible.

Not only do people with disabilities experience sociocultural issues, but so do their families.[37] Parents of children with disabilities are frequently psychologically impacted,[38] as they have expectations for their

21 Don Kulick and Jens Rydström, *Loneliness and Its Opposite* (Duke University Press, 2015), https://doi.org/10.1215/9780822375845; E. Samuels, *Fantasies of Identification: Disability, Gender, Race* (New York City: NYU Press, 2014).

22 (Hersinta, 2020; Madyaningrum et al., 2022).

23 Nurhayati, "Social Inclusion For Persons With Disabilities Through Access To Employment In Indonesia"; Suharto Suharto, Pim Kuipers, and Pat Dorsett, "Disability Terminology and the Emergence of 'Diffability' in Indonesia," *Disability and Society* 31, no. 5 (May 27, 2016): 693–712, https://doi.org/10.1080/09687599.2016.1200014.

24 Eriando Rizky Septian and Ella Nurlaella Hadi, "Reducing Stigma of People with Disabilities: A Systematic Review," *Journal of Medical and Health Studies*, 2021, https://doi.org/10.32996/jmhs.

25 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation"; S. Thohari, Disability in Java: Contesting Conceptions of Disability in Javanese Society after the Suharto Regime (Saarbrücken : Lambert Academic Publishing, 2013).

26 Suharto, Kuipers, and Dorsett, "Disability Terminology and the Emergence of 'Diffability' in Indonesia"; Triwahyudi and Setiawan, "Disability Inclusion in WASH: 'What Has Been Achieved and How Can This Help Other Practitioners?'"

27 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation."

28 Damayanti and Sabiq, "Implementation of Public Facilities and Disability Treatments: A Comparison Between Indonesia and Malaysia."

29 Widinarsih, "Disability Inclusion and Disability Awareness in Muslim Society: An Experience of Indonesians Muslim with Disability in Performing Worship."

30 Thohari, *Disability in Java: Contesting Conceptions of Disability in Javanese Society after the Suharto Regime*; Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation."

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32 Damayanti and Sabiq, "Implementation of Public Facilities and Disability Treatments: A Comparison Between Indonesia and Malaysia."

33 Widinarsih, "Disability Inclusion and Disability Awareness in Muslim Society: An Experience of Indonesians Muslim with Disability in Performing Worship."

34 Thohari, *Disability in Java: Contesting Conceptions of Disability in Javanese Society after the Suharto Regime*; Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation."

35 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation"; S. Thohari, *Disability in Java: Contesting Conceptions of Disability in Javanese Society after the Suharto Regime* (Saarbrücken : Lambert Academic Publishing, 2013).

36 Suharto, Kuipers, and Dorsett, "Disability Terminology and the Emergence of 'Diffability' in Indonesia"; Triwahyudi and Setiawan, "Disability Inclusion in WASH: 'What Has Been Achieved and How Can This Help Other Practitioners?'"

37 Septian and Hadi, "Reducing Stigma of People with Disabilities: A Systematic Review."

38 Kim Michelle Gilson et al., "Enhancing Support for the Mental Wellbeing of Parents of Children with a Disability: Developing a Resource Based on the Perspectives of Parents and Professionals," *Journal of Intellectual and Developmental Disability* 43, no. 4 (October 2, 2018): 463–72, https://doi.org/10.3109/13668250.2017.1281386.

children.[39] Accepting their children with disabilities takes patience.[40] Parents who have children with disabilities are suffering as they receive unfavorable feedback from society and are frequently blamed when they give birth to non-normative children,[41] making their lives a misery.

The social model of disability emphasizes disability positive image[42] and acknowledges disability beyond impairment. This has driven Indonesian disability advocacy to shift from welfare to rights[43] to address the Indonesian public's lack of disability awareness,[44] which led to stigmatization.[45] This disability rights activism is in line with the concept of co-cultural communication, in which disability, as a non-dominant group, builds communicative interaction[46] to disseminate the unfulfilled disability rights.

Technology has improved in the past ten years and has fostered digital disability activism.[47] From the Indonesian perspective, more disability activists utilize social media as a platform to raise awareness of disability inclusion and advocate for disability rights.[48] Facebook has been used by parents of children with disabilities for information sharing and to enhance their children's social skills.[49] Studies[50] have found Twitter's efficacy in autism narratives through the neurodiversity movement. In addition, Instagram has also been used for disability activism.[51]

The existing literature has addressed disability rights activism from disability[52] and parental[53] perspectives. However, the literature only highlights one perspective, and this paper will include the perspectives of both disability and parents who raise children with disabilities.[54] Investigated neurodiversity activism on Twitter and[55] examined the use of Facebook among parents of disabled children. While the results are crucial, none of the literature highlights disability rights. A study by[56] has shown Instagram's efficacy in disability advocacy among disabled youths but is limited to only highlighting disability perspective.

The present study intends to shine a light on individual and parental perspectives in communicating disability rights by involving Indonesian diverse disability stakeholders. These dual perspectives offer novelty as the existing literature only focuses on one perspective of disability stakeholder. The discussion will be centered on how disability activists and parents of disabled foster disability awareness and enhance disability rights. The author also hopes to emphasize disability and parental use of Instagram in fostering inclusion and disseminating

39 Martine Dijkstra and Els Rommes, "Dealing with Disability: Challenges in Dutch Health Care of Parents with a Non-Western Migration Background and a Child with a Developmental Disability," *Disability and Rehabilitation* 44, no. 23 (2022): 7178–89, https://doi.org/10.1080/09638288.2021.1985637.

40 S. E. Green, "We're Tired, Not Sad: Benefits and Burdens of Mothering a Child with a Disability.," *Social Science & Medicine* 64, no. 1 (2007): 150–63.

41 Green; Zeynep Aydin Sünbül and Meltem Aslan Gördesli, "Self-Compassion and Resilience in Parents of Children with Special Needs: The Mediating Role of Hope," *Çukurova Üniversitesi Eğitim Fakültesi Dergisi*, 2020, https://doi.org/10.14812/cufej.749645.

42 Mónica Bonilla-Del-río, Juan C. Figuereo-Benítez, and Victoria García-Prieto, "Influencers with Physical Disabilities on Instagram: Features, Visibility and Business Collaboration," *Profesional de La Informacion* 31, no. 6 (November 1, 2022), https://doi.org/10.3145/epi.2022.nov.12.

43 T. Dibley and A. Tsaputra, "Changing Laws, Changing Attitudes: The Place of People with Disability in Indonesia," in *Contentious Belonging*, ed. Greg Fealy and Ronit Ricci (ISEAS Publishing, 2019), 77–94, https://doi.org/10.1355/9789814843478-009.

44 Widinarsih, "Disability Inclusion and Disability Awareness in Muslim Society: An Experience of Indonesians Muslim with Disability in Performing Worship."

45 (Selman et al., 2018)

46 Griffin, Ledbetter, and Sparks, *A First Look at Communication Theory*; Orbe, *Constructing Co-Cultural Theory: An Explication of Culture, Power, and Communication*; Orbe and Roberts, "Co-Cultural Theorizing: Foundations, Applications & Extensions."

47 Gerard Goggin and C. Newell, "Introduction: The Intimate Relations between Technology and Disability," *Disability Studies Quarterly* 25, no. 2 (2005).

48 Hersinta, "Communicating Autism on the Internet The Emerging of Neurodiversity Movement in Indonesia."

49 Safrina Rofasita, "Sharing Experience Dan Resiliensi: Studi Atas Facebook Group Orang Tua Anak Cerebral Palsy," *INKLUSI* 4, no. 1 (June 15, 2017): 119, https://doi.org/10.14421/ijds.040106.

50 Hersinta (2019, 2020)

51 Ani Cahyadi and Agus Setiawan, "Disability and Social Media: Exploring Utilization of Instragram Platform As a Tool for Disability Advocacy," *Al-Balagh : Jurnal Dakwah Dan Komunikasi* 5, no. 2 (2020): 223–50, https://doi.org/10.22515/al-balagh.v5i2.2746.

52 Dibley and Tsaputra, "Changing Laws, Changing Attitudes: The Place of People with Disability in Indonesia"; Hersinta, "Communicating Autism on the Internet The Emerging of Neurodiversity Movement in Indonesia."

53 Allison C Carey, Pamela Block, and Richard K Scotch, "Sometimes Allies: Parent-Led Disability Organizations and Social Movements," 2019, https://dsq-sds.org/index.php/dsq/article/view/6281/5183; Amy Conley Wright and Sarah Taylor, "Advocacy by Parents of Young Children With Special Needs: Activities, Processes, and Perceived Effectiveness," *Journal of Social Service Research* 40, no. 5 (October 1, 2014): 591–605, https://doi.org/10.1080/01488376.2014.896850.

54 Hersinta (2019, 2020)

55 Rofasita (2017)

56 Cahyadi & Setiawan (2020)

disability rights digitally. Instagram is inseparable from its visual culture; therefore, the author will highlight this social network's visuality and user connection and their impacts on disability rights. This study also aims to fill in the gap in the efficacy of Instagram in disability rights activism from an Indonesian perspective.

2. Method

This study reflected the author's lived experience as an Indonesian person with a physical disability who actively advocates for disability rights. To address the study aims, the author integrates disability research and Instagram activism, which relies on co-cultural communication theory. Digital autoethnography is chosen as a method, referring to a study by[57] which indicated that autoethnography provides co-cultural voices with a vibrant voice in addressing unequal rights, including people with disabilities.[58] Personal narratives are utilized in autoethnography to examine social, cultural, and personal experiences[59] and this study is conducted subjectively.

The author collected oral data through focus group discussions and semi-structured formal and informal interviews, which were held virtually with a 120-minute session. Two focus group discussions, one semi-structured formal interview, and two semi-structured informal interviews were video recorded and transcribed. This study merges voices from diverse disability stakeholders as participants (see Table 1) aged over 18 years old of any gender. The five participants with different disability types are members of Rumah Disabilitas – an NGO that promotes disability rights. The two latter participants are parents of children with disabilities who initiated a parent support group called Jendela Ibu to help children with special needs and their parents.

Qualitative content analysis of their Instagram profiles (see Table 1) was also carried out using digital autoethnographic methodologies.[60] Camara & Orbe found that qualitative content analysis is a valuable tool when studying strategic responses to disability prejudice. The author conducted a comprehensive visual examination of communication content using objective examination in a trustworthy and appropriate way.[61] The contents include the profile on Instagram itself, different sorts of produced content, and tagged content. The collected data serves as secondary data, complementing the oral data. Thematic analysis was performed using NVivo14 to merge both oral and visual data to then present the findings, found that qualitative content analysis is a valuable tool when studying strategic responses to disability prejudice. The author conducted a comprehensive visual examination of communication content using objective examination in a trustworthy and appropriate way.[62] Aida and Karim were chosen for content analysis as they actively share disability content. This includes Jendela Ibu's disability contents that were made by Ifta and Sandy. The contents include the profile on Instagram itself, different sorts of produced content, and tagged content. The collected data serves as secondary data, complementing the oral data. Thematic analysis, as shown in Table 2, was performed using NVivo 14 to merge both oral and visual data and then present the findings.

57 Frohlich (2012)

58 Griffin, Ledbetter, and Sparks, *A First Look at Communication Theory*.

59 C Ellis, T E Adams, and A P Bochner, "Autoethnography: An Overview," *Historical Social Research* 36, no. 4 (2011): 273–90, https://doi.org/10.12759/hsr.36.2011.4.273-290.

60 Camara, S. K., and M Orbe. "Analyzing Strategic Responses to Discriminatory Acts: A Co-Cultural Communicative Investigation." Journal of International and Intercultural Communication 3, no. 2 (2010): 83–113.

61 Camara, S. K., and M Orbe. "Analyzing Strategic Responses to Discriminatory Acts: A Co-Cultural Communicative Investigation." Journal of International and Intercultural Communication 3, no. 2 (2010): 83–113.

62 Eriyanto, *Analisis Isi: Pengantar Metodologi Untuk Penelitian Ilmu Komunikasi Dan Ilmu-Ilmu Sosial Lainnya* (Jakarta: Kencana Persada, 2013).

Table 1. Participant Demography

Category	Name	Gender	Age Group	Disability	Oral Data Collection	Instagram Profile
Disability	Aida	Female	20s	Hemiparesis	FGD, Formal Interview	@aida.mudjib
	Ana	Female	20s	Hip Dysplasia	FGD	-
	Hani	Female	20s	Deaf	FGD	-
	Imel	Female	30s	Blindness	FGD	-
	Karim	Male	30s	Wrist Deformity and Scoliosis	FGD, Informal Interview	@karim.muhamr
Parent	Ifta	Female	30s	None	FGD, Informal Interview	@jendelaibu
	Sandy	Male	40s	None	FGD	

Source: Processed by the Author

By intersecting disability research and Instagram activism on disability rights, this study was conducted in accordance with ethical considerations. Emphasizing disability inclusion is crucial in conducting disability research[63] as the voices of disabilities have historically been marginalized in research.[64] By engaging and understanding disability's lived experiences, inclusive research can empower them.[65] To collect and analyze Instagram, the author refers to the ethical criteria for internet research issued by the Association of Internet Researchers.[66] In conducting the oral and visual methodologies, the author has received oral consent from all participants by adhering to the guidelines of Human Research Ethics Committee from the University of Sydney.

3. Findings and Discussion

Before delving into the results, the author would like to briefly explore disability rights through a co-cultural communication theory perspective.[67] defines this theory as a communicative interaction between members of dominant and non-dominant groups.[68] emphasize disability in the discussion as[69] and[70] mentioned marginalized groups in this theory. Of closer relevance to disability rights is research by[71] that involved workers with physical disabilities during their first three months of working at a new workplace. They adopted an accommodating strategy, choosing not to press the dominant, while still attempting to communicate their rights to access equal workplace opportunities.

63 Christopher Blunt et al., "Editorial," *British Journal of Learning Disabilities* 40, no. 2 (June 22, 2012): 83–84, https://doi.org/10.1111/j.1468-3156.2012.00748.x; Jennifer Smith-Merry, "Inclusive Disability Research," in *Handbook of Research Methods in Health Social Sciences* (Singapore: Springer Singapore, 2019), 1935–52, https://doi.org/10.1007/978-981-10-5251-4_129.

64 Leslie Swartz, "Building Disability Research Capacity in Low-Income Contexts: Possibilities and Challenges," in *Disability and International Development: Towards Inclusive Global Health* (New York: Springer, 2009), 91–103.

65 Smith-Merry, "Inclusive Disability Research"; Jan Walmsley, Iva Strnadová, and Kelley Johnson, "The Added Value of Inclusive Research," *Journal of Applied Research in Intellectual Disabilities* 31, no. 5 (September 12, 2018): 751–59, https://doi.org/10.1111/jar.12431.

66 (Franzke et al., 2020)

67 Orbe (1998, 2005)

68 Griffin et al. (2019)

69 Orbe (1998, 2005)

70 Orbe & Roberts (2012)

71 Cohen & Avanzino (2010)

Table 2. Dominant Themes of the Analyzed and Processed Visual Data

No	Dominant Themes	Examples
1	Disability's Common Problems	• Unable to register for school • Educational discrimination • Inaccessible facilities • Negative stigma • Perceived pity by others • Social isolation
2	Parents' Common Problems	• Socially blamed due to cultural beliefs • Lack of education in health • Financial barrier • Psychological issue • Social isolation
3	Disability in Communicating Rights	• Educating surroundings first • Building connections • Need for collaborative actions
4	Parents in Communicating Rights	• Educating surroundings first • Forming Parent support group • Empowering fellow parents
5	Disability's Instagram Content	• Sharing educational achievements • Social critique • Self-representation • Visualizing disability experiences
6	Parents' Instagram Content	• Sharing information about children's health and development • Raising awareness about health • Events and educational posters • Challenging society
7	Instagram Impacts for Disability	• Self-empowerment • Empowering more individuals with disabilities • Building connection with peers
8	Instagram Impacts for Parents	• Creating program portfolios • Reaching additional parents • Strengthening parental networks

Source: Processed by the Author

Based on the overall data collection process, the author found that disability and parent participants tend to have different highlighted rights to be discussed. While the five participants with disabilities highlighted education as an unfulfilled right for persons with disabilities, the parent participants focused on the right to healthcare services for their children with disabilities. The results of this digital autoethnographic study were obtained from both oral and visual methodologies, summarized in Table 2. In presenting the results, the author structured the discussion into three parts. The first is on how the participants communicated disability rights and raised disability inclusion awareness. The discussion also examines Instagram activism and its impacts in subsequent sections.

3.1 Disability and Parents in Narrating Disability Rights

The fulfilment of disability rights in Indonesia is challenged[72] and it is rooted in the way society perceives disability as karma[73] and shame[74] to the family. These were also experienced by all participants and me. As for myself, my parents were asked to drown the one-month-old me, so I would not grow as a burden. While for Karim's parents, they were blamed and forced to confess their mistakes. This society, blaming and disregarding parents, was also experienced by Ifta and Sandy who raised two children with special needs. In fact, it is disabled people and their parent's right to live equally in society. All participants and I are lucky to have overcome such obstacles which have driven us to advocate for disability rights.

Negative stigma towards Indonesians with disabilities[75] has hampered our social participation as we are deemed invisible.[76] Aida and I have gone through a similar rejection in education due to our physical disabilities. For Aida, she was unable to register and study at her chosen boarding school owing to a lack of accessibility and she was rejected without a qualification test. Schools rejected me when I was six years old only because of my disabled hands. Despite the physical difficulties and social challenges during school, both of us achieved justice and proved that we deserved to attend a general rather than a specialized school.

Disability rights fulfilment becomes more challenging for those with special needs. The parents are challenged by their children's medical demands.[77] Their financial[78] and emotional resilience[79] was tested in raising their children. This condition is worsened by the fact that these families come from lower-income backgrounds.[80] By having two sons with special needs, Ifta and Sandy were exposed to parents from middle-income households. In addressing the issues, they built Jendela Ibu to foster support for parents of children with special needs in accessing their children's rights. According to Sandy, when parents experience financial issues, the right to healthcare for children is often unmet due to financial constraints.

Parents of children with special needs who are psychologically exhausted frequently cannot accept the fact that they must raise their disabled children,[81] which leaves them feeling lost.[82] This sense of disempowerment drives these parents to develop their knowledge of their children's situation.[83] Sandy mentioned the same situation among parents at Jendela Ibu who were initially disempowered by their children's condition and lost hope for their children to live equally. As a result, Ifta added, the children's access to healthcare services may be limited due to parents' psychological or financial constraints. Along with Jendela Ibu, she educated parents as she believes that parents' willingness is critical for the development of children with special needs.

72 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation."
73 Hersinta, "Communicating Autism on the Internet The Emerging of Neurodiversity Movement in Indonesia."
74 Septian and Hadi, "Reducing Stigma of People with Disabilities: A Systematic Review."
75 Rahayu Repindowaty Harahap and Bustanuddin, "Perlindungan Hukum Terhadap Penyandang Disabilitas Menurut Convention on the Rights of Persons with Disabilities (CRPD)," *Jurnal Inovatif* VIII, no. 1 (2015): 17–29, https://online-journal.unja.ac.id/index.php/jimih/article/view/2191; Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation"; K. Scior et al., "Intellectual Disabilities: Raising Awareness and Combating Stigma A Global Review Executive Summary & Recommendations," 2015, https://www.ucl.ac.uk/ciddr/publications; Thohari, *Disability in Java: Contesting Conceptions of Disability in Javanese Society after the Suharto Regime*.
76 Widinarsih, "Disability Inclusion and Disability Awareness in Muslim Society: An Experience of Indonesians Muslim with Disability in Performing Worship."
77 Sünbül and Gördesli, "Self-Compassion and Resilience in Parents of Children with Special Needs: The Mediating Role of Hope."
78 Sünbül and Gördesli; Tawfiq Ammari, Meredith Ringel Morris, and Sarita Yardi Schoenebeck, "Accessing Social Support and Overcoming Judgment on Social Media among Parents of Children with Special Needs," 2014, www.aaai.org.
79 B. Beresford, P. Rabiee, and P. Sloper, "Outcomes for Parents with Disabled Children," *Res. Works* 3 (2007): 1–4; Lucy Bray et al., "Parent-to-Parent Peer Support for Parents of Children with a Disability: A Mixed Method Study," *Patient Education and Counseling* 100, no. 8 (August 1, 2017): 1537–43, https://doi.org/10.1016/j.pec.2017.03.004; Gilson et al., "Enhancing Support for the Mental Wellbeing of Parents of Children with a Disability: Developing a Resource Based on the Perspectives of Parents and Professionals"; Rachel Zeutenhorst, "Parent Support Groups and Well-Being: Investigating the Benefits of Parent Support Groups for Families of Children with Special Needs," 2017, https://digitalcollections.dordt.edu/med_theses.
80 Ammari, Morris, and Schoenebeck, "Accessing Social Support and Overcoming Judgment on Social Media among Parents of Children with Special Needs."
81 Dijkstra and Rommes, "Dealing with Disability: Challenges in Dutch Health Care of Parents with a Non-Western Migration Background and a Child with a Developmental Disability."
82 Bray et al., "Parent-to-Parent Peer Support for Parents of Children with a Disability: A Mixed Method Study."
83 Dijkstra and Rommes, "Dealing with Disability: Challenges in Dutch Health Care of Parents with a Non-Western Migration Background and a Child with a Developmental Disability."

For people with disabilities, society's stigma[84] and marginalization[85] have affected their confidence in social participation. By being rejected by our prospective schools, Aida and I felt a sense of anxiety. For Aida, she became less competitive as her teachers tended to place her in a second group of students. I used to be an outstanding student, but then my achievements were perceived as mere compensation for my disability. Hani, who had limited hearing and speech abilities, was forced to isolate herself due to difficulties in communicating with other students.

The disability and parental experiences on unfulfilled disability rights have marked the significance of communicating disability rights by building communicative interactions as introduced by[86] in the co-cultural communication theory. From a disability perspective, communicating one's rights to the surrounding community is a minimal yet essential effort to assert inclusion and equality. Imel, who lost her eyesight in her adulthood, was treated as weak and incapable by her family. Following disability's less masculine stigma, my parents always considered me in need of assistance in my daily life. Our parents' stigma hampered Imel and me to pursue our degree overseas, but we constantly communicated to them our right to pursue equal education. This helped us to finally make it to study in the United Kingdom and Australia respectively.

The experience of Imel and my experience was related to parents' psychological readiness to support their children's social interactions.[87] This was also conveyed by Ifta, in which some parents did not let their disabled children socialize or even go out of their homes to prevent them from being bullied or receiving negative treatment from their surroundings. The sense of social isolation affected parents' mental health and social well-being. Some parents were also feeling too afraid and ashamed to socialize and some felt lonely and stressed. Ifta views this issue as a need for mental support for those parents, and along with Jendela Ibu, she provides multidimensional support for those parents so they can help their disabled children.

In communicating disability rights, Indonesian activists are challenged to battle society's negative view of disability.[88] Disabled activists represent themselves using their desired image.[89] As a Law lecturer, Karim has the credibility to be heard when he talks about disability educational rights. For instance, in Figure 1, he was invited onto a national radio broadcast called RRI to speak about disability rights. At that moment, he discusses digital literacy rights for people with disabilities. With her impaired mobility, Ana always tries to be an independent student and always educates her surroundings about her disability. Being the only deaf student in her school, Hani has gone through prejudices, and she tirelessly ensures that she can communicate and learn like other students. For Aida, Imel, and I, disseminating our rights in education is not easy, especially when we talk to conservative-minded people. While Imel built her inclusive school, Aida and I became a disability author. With her impaired mobility, Ana always tries to be an independent student and always educates her surroundings about her disability. Being the only deaf student in her school, Hani has gone through prejudices, and she tirelessly ensures that she can communicate and learn like other students. For Aida, Imel, and I, disseminating our rights in education is not easy, especially when we talk to conservative-minded people. While Imel built her inclusive school, Aida and I became a disability author.

84 Septian and Hadi, "Reducing Stigma of People with Disabilities: A Systematic Review."

85 S. M. Adioetomo, D. Mont, and Irwanto, "Persons with Disabilities in Indonesia: Empirical Facts and Implications for Social Protection Policies," 2014, www.tnp2k.go.id; Nicole Ditchman et al., "Stigma and Intellectual Disability: Potential Application of Mental Illness Research.," *Rehabilitation Psychology* 58, no. 2 (2013): 206–16, https://doi.org/10.1037/a0032466; Bob Edwards and John D. McCarthy, "Resources and Social Movement Mobilization," in *The Blackwell Companion to Social Movements* (Oxford, UK: Blackwell Publishing Ltd, 2007), 116–52, https://doi.org/10.1002/9780470999103.ch6; Peni Kusumastuti, Rosiana Pradanasari, and Anita Ratnawati, "The Problems of People with Disability in Indonesia and What Is Being Learned from the World Report on Disability," *American Journal of Physical Medicine & Rehabilitation* 93, no. 1 (January 2014): S63–67, https://doi.org/10.1097/PHM.0000000000000025; Faissal Malik et al., "Legal Protection for People with Disabilities in the Perspective of Human Rights in Indonesia," *International Journal of Criminology and Sociology* 10 (April 30, 2021): 538–47, https://doi.org/10.6000/1929-4409.2021.10.62; S.A. Purwanta, "Penyandang Disabilitas," in *Vulnerable Group: Kajian Dan Mekanisme Perlindungannya*, ed. E. Riyadi and S. Nurhidayat (Yogyakarta: Pusat Studi Hak Asasi Manusia Universitas Islam Indonesia (PUSHAM UII), 2012), 257–213; Suharto, Kuipers, and Dorsett, "Disability Terminology and the Emergence of 'Diffability' in Indonesia"; Filippo Trevisan, "Crowd-Sourced Advocacy: Promoting Disability Rights through Online Storytelling," *Public Relations Inquiry* 6, no. 2 (May 30, 2017): 191–208, https://doi.org/10.1177/2046147X17697785.

86 Orbe (1998, 2005) and Orbe & Roberts (2012)

87 Ammari, Morris, and Schoenebeck, "Accessing Social Support and Overcoming Judgment on Social Media among Parents of Children with Special Needs"; Bray et al., "Parent-to-Parent Peer Support for Parents of Children with a Disability: A Mixed Method Study."

88 Dibley and Tsaputra, "Changing Laws, Changing Attitudes: The Place of People with Disability in Indonesia."

89 Damayanti and Sabiq, "Implementation of Public Facilities and Disability Treatments: A Comparison Between Indonesia and Malaysia."

Figure 1. Karim Speaks for a National Radio Broadcast



Source: @karim.muhamr Instagram (https://instagram.com/karim.muhamr)

The challenge is also visible in parents' lack of expertise and understanding of their children's rights[90] which finally results in their disempowerment.[91] Therefore, they require experience-based information.[92] During their service at Jendela Ibu, Ifta and Sandy faced obstacles due to parents' lack of information about the development of their children with special needs. Some children were diagnosed late which has an impact on the delayed treatment due to their parents' pessimism of the children's impairments. Through the 'Rumah Tumbuh Kembang' program, they not only disseminated disabled children's rights to the parents but also helped the children to get proper treatment for their growth and development.

In the face of social challenges, people with disabilities demand collaborative action to raise disability awareness,[93] and to disseminate information about their right.[94] The action has been shown to be effective in fulfilling disability rights.[95] This is in accordance with the results of this study, in which Aida successfully communicated educational rights for people with disabilities like herself. For example, the university where she studied for her master's degree received input regarding disability facilities such as special rooms for disabilities in the library. She is also involved in the process of establishing special services for students with disabilities at the university.

Collective actions are also made to empower people with disabilities.[96] Karim and I are among the fortunate people with disabilities to receive government scholarships for our doctorate degree. Along with Rumah Disabilitas, we raise awareness of people with disabilities about their rights in the field of education. From this, many people approach us to follow our guidance. We also created a scholarship mentoring program in which participants with disabilities were involved. As a result, several of our mentees successfully passed the scholarship selection and they continued their graduate studies at well-known universities with scholarships. In this way, they can access their right to equal education and continue the empowerment and awareness that has been obtained.

90 Mary Law et al., "The Perceived Effects of Parent-Led Support Groups for Parents of Children with Disabilities," *Physical & Occupational Therapy In Pediatrics* 21, no. 2–3 (January 2002): 29–48, https://doi.org/10.1080/j006v21n02_03.

91 Bray et al., "Parent-to-Parent Peer Support for Parents of Children with a Disability: A Mixed Method Study."

92 Law et al., "The Perceived Effects of Parent-Led Support Groups for Parents of Children with Disabilities."

93 Widinarsih, "Disability Inclusion and Disability Awareness in Muslim Society: An Experience of Indonesians Muslim with Disability in Performing Worship."

94 Dibley and Tsaputra, "Changing Laws, Changing Attitudes: The Place of People with Disability in Indonesia."

95 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation"; Therése Mineur, Magnus Tideman, and Ove Mallander, "Self-Advocacy in Sweden—an Analysis of Impact on Daily Life and Identity of Self-Advocates with Intellectual Disability," *Cogent Social Sciences* 3, no. 1 (January 1, 2017), https://doi.org/10.1080/23311886.2017.1304513; Florian J. Seubert, "'Sanitise Your Hands with Rainbows!' Encouraging Self-Representation in Times of Crisis: Inclusive Reflections on Covid-19, Together with Women with Learning Disabilities from East London," *Research in Drama Education* 27, no. 4 (2022): 443–57, https://doi.org/10.1080/13569783.2022.2049223.

96 Nario-Redmond, Noel, and Fern, "Redefining Disability, Re-Imagining the Self: Disability Identification Predicts Self-Esteem and Strategic Responses to Stigma."

In terms of empowerment, parents who raise disabled children also require support from fellow parents[97] which is believed to be useful for ensuring the realization of children's rights as parents become more knowledgeable and skilled.[98] By assisting the parents through Jendela Ibu's programs, Ifta found that parents can help their disabled children obtain their healthcare rights. Jendela Ibu as a support group is not only communicating children's rights but also connecting the parents to medical and therapy information so they can access such services. Sandi added that empowering parents means getting them aware of their children's rights to be fulfilled. Ifta and Sandi are grateful that Jendela Ibu has helped more than a hundred children and their programs have approached more people to provide helping hands.

In a larger impact, not only children's rights are being fulfilled, but parents can build connections with their peers and foster support among them.[99] According to Ifta, Jendela Ibu's network provides parents with peer-to-peer assistance and allows parents to feel more connected. This has been shown to be beneficial in empowering parents regarding their children's condition and be more optimistic in raising their children to maximize their right to live. By having peer sharing with other parents, they can gain more knowledge that strengthens their parenting abilities and helps to optimize the children's health and development.

This sense of connection is also felt by people with disabilities who build collective actions[100] in raising awareness and campaigning for disability rights [101]. By building an inclusive school, Imel feels that she is not only fostering disability rights but also establishing connections with colleagues with disabilities. Karim, Aida, and I got to collaborate with disabled friends which allowing us to connect with and empower even more people with disabilities. Ani and Hana added that this connection provides both mutual support and fulfils their interpersonal needs to socialize. In other words, the five disabled people and I agree that the connection among us can aid in fulfilling more disability rights.

To sum up this part, the author added more insight into the co-cultural communication theory by [102] as this study highlights disability and parents as marginalized groups in communicating rights. The empowered participants with disabilities and I employed assertive accommodation in educating our surroundings on disability rights. Through this strategy, we built intragroup networking with dominant groups so we could foster an inclusive society. An assertive accommodation strategy is also used by the parent participants in providing support for the disempowered parents of children with special needs. The results show that both disability and parent participants use non-assertive assimilation to portray disability positively in line with the concept of the social model of disability.

3.2 Communicating Disability Rights on Instagram

Technology has been a driving force for the emergence of social media which improved human communication[103] and later can be utilized in communicating disability rights digitally,[104] including Indonesian disability activists.[105] Instagram's use for disability rights has been increasing in Indonesia.[106] As individual with disabilities, Aida, Karim, and I have utilized this social media platform to influence and educate regarding disability inclusion. In addition, Ifta and Sandy as parents of children with disabilities maximized Jendela Ibu's role by utilizing Instagram in raising awareness of children with special needs and their rights to healthcare. This platform is believed to be effective in reaching wider audiences across the country.

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97 Diane Behl, Janet Desgeorges, and Karl R White, "The Role of Family-Led Disability Organizations in Supporting Families with Hearing-Related Concerns," *Journal of Early Hearing Detection and Intervention* 1, no. 1 (2016), http://www.familyvoices.org.

98 Zeutenhorst, "Parent Support Groups and Well-Being: Investigating the Benefits of Parent Support Groups for Families of Children with Special Needs."

99 Behl, Desgeorges, and White, "The Role of Family-Led Disability Organizations in Supporting Families with Hearing-Related Concerns"; Law et al., "The Perceived Effects of Parent-Led Support Groups for Parents of Children with Disabilities."

100 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation"; Mineur, Tideman, and Mallander, "Self-Advocacy in Sweden—an Analysis of Impact on Daily Life and Identity of Self-Advocates with Intellectual Disability."

101 Dibley and Tsaputra, "Changing Laws, Changing Attitudes: The Place of People with Disability in Indonesia."

102 Orbe (1998)

103 Alan Roulstone, *Disability and Technology* (London: Palgrave Macmillan UK, 2016), https://doi.org/10.1057/978-1-137-45042-5; Kristen Tollan, "Exploring the Development of Identity and Community Amongst Disabled Youth on Instagram" (Brock University, 2020).

104 Amri Dunan et al., "The Right to Obtain Covid-19 Information for Those with Disabilities (Study of Government Communication on the Instagram Account of the Indonesian Ministry of Health)," 2021.

105 Hersinta, "Communicating Autism on the Internet The Emerging of Neurodiversity Movement in Indonesia."

106 Cahyadi and Setiawan, "Disability and Social Media: Exploring Utilization of Instragram Platform As a Tool for Disability Advocacy."

Figure 2. Karim's Instagram Post on Disability Educational Rights



Source: @karim.muhamr Instagram (https://instagram.com/karim.muhamr)

Instagram's visibility provides possibilities for visualizing diversity,[107] and it is beneficial for users with disabilities to visually express themselves.[108] Karim, and I utilize this visibility aspect to visualize our disabled hands in our Instagram content. With his expertise in Law, Karim often shares inclusive content. One of his contents (see Figure 2), includes himself with fellow disabled activists – Laura and Aida all of whom received graduate scholarships. The content addresses educational rights of Indonesians with disabilities and receives several comments. One of the worth noting comments (see Figure 3), filled with hope that the Instagram follower could join their footstep in pursuing the right to education and empower others.

Figure 3. A Positive Comment on Karim's Instagram Post



Source: @karim.muhamr Instagram (https://instagram.com/karim.muhamr)

Instagram has allowed its users to personalize their profiles[109] and publish their desired images , both static and dynamic.[110] Well-presented profile with appealing content can reach a wider audience.[111] This discussion follows Ifta's statement that posted content on Instagram can serve as a portfolio for Jendela Ibu's programs and services, including helping children with special needs and assisting parents, which can help them gain credibility. Jendela Ibu produces diverse content on program reports and awareness posters. Ifta believes that these ways can help Jendela Ibu gain new audiences on a greater scale in Bogor - the city where it is located.

Disability portrayal in the Indonesian media is often negative which contributes to low public awareness[112]

107 Tama Leaver, Tim Highfield, and Crystal Abidin, *Instagram: Visual Social Media Cultures* (Cambridge: Polity, 2020).
108 Coppélie Cocq and Karin Ljuslinder, "Self-Representations on Social Media. Reproducing and Challenging Discourses on Disability," *Alter* 14, no. 2 (June 1, 2020): 71–84, https://doi.org/10.1016/j.alter.2020.02.001.
109 Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.
110 Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.
111 Tri Atmoko and Dedi Rianto Rahadi, "Analisis Pemanfaatan Facebook Sebagai Media Promosi Produk Perumahan PT. Mandiri Agency Pada Masa Pandemi COVID-19" 10 (2021): 213–21.
112 Antoni Tsaputra, "Portrayals of People With Disabilities in Indonesian Newsprint Media (A Case Study on Three Indonesian Major Newspapers)," *Indonesian Journal of Disability Studies* 3, no. 1 (2016): 1–11, http://IJDS.ub.ac.id.

and the neglect of disability rights.[113] Social media including Instagram can be leveraged to promote a positive image of disability.[114] Sandy mentioned that Instagram has aided Jendela Ibu in terms of awareness. They routinely produce content that is aimed at raising disability awareness and educate audiences on disability rights. They produce educational posters as in Figure 4 which address the right to equal access for children with special needs, including access to education, employment, healthcare, and other services they need to live independently. This enables Jendela Ibu to widen its awareness and enhance children's rights fulfilment.

Figure 4. Jendela Ibu's Poster on Equal Access for Children with Special Needs



Source: @jendelaibu Instagram (https://instagram.com/jendelaibu)

Aside from its power to spread awareness, social media may be deployed to critique existing situations[115] and Instagram, with its personal use also covers this for the users.[116] Aida feels lucky to finally receive access to equal education after all the educational discrimination and rejections she has encountered. Therefore, she is driven to empower more people with disabilities to receive the same access and she used her Instagram as a platform to express critiques of discriminatory practices against people with disabilities. As shown in Figure 5, Aida tells her story when asked if she had ever wanted to commit suicide because of her disability. She criticizes society's view that limits people with disabilities from obtaining equal access to every service including education regardless of their disability.

113 Madyaningrum, Sonn, and Fisher, "Disability Organizations as Empowering Settings: Challenging Stigmatization, Promoting Emancipation."

114 Bonilla-Del-río, Figuereo-Benítez, and García-Prieto, "Influencers with Physical Disabilities on Instagram: Features, Visibility and Business Collaboration."

115 C. R. Berger, *Interpersonal Communication. In D. W. Stacks & M. B. Salwen (Eds.), An Integrated Approach to Communication Theory and Research* (New York: Routledge, 2009).

116 Cahyadi and Setiawan, "Disability and Social Media: Exploring Utilization of Instragram Platform As a Tool for Disability Advocacy."

Figure 5. Aida's Critique Content on Equal Access for Disabled People



Source: @aidamudjib Instagram (https://instagram.com/aidamudjib)

Social media allows disabled people who were previously marginalized to satisfy their interpersonal needs,[117] and this can also be felt by Instagram users[118] who represent themselves.[119] Karim and I feel empowered by receiving similar struggling stories we have encountered in gaining our right to education. For Aida, receiving positive comments as in Figure 6 has boosted her confidence to embrace her identity as a person with disability. That comment emphasizes Aida's potential to strive for future employment upon completing her master's degree. She received numerous positive comments after sharing disability-related content. For that, she feels more empowered to share more disability awareness online.

Figure 6. Positive Comment on Aida's Instagram Content

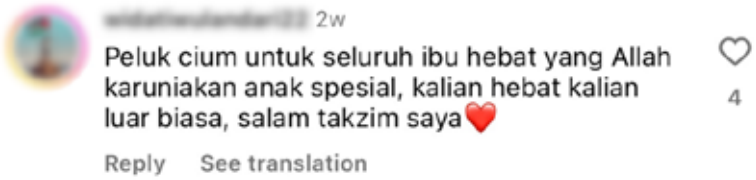


Source: @aidamudjib Instagram (https://instagram.com/aidamudjib)

These types of positive comments are also received by parents, as stated by Ifta and Sandi. Ifta mentioned that Jendela Ibu's Instagram content obtained various comments, both supportive and empowering comments, one of which is in Figure 7. She thinks that the online comments received have been a positive driving force for the parent support group in voicing disability rights and she believes that Instagram has been effectively helping her team in reaching more people digitally. This result emphasizes[120] statement on the content influence that can be fostered on Instagram and completed[121] study on the efficacy of Instagram in maintaining disability representation and communicating rights online.

117 Samira Rajabi, "Losing Someone Like Us:Memetic Logics and Coping with Brain Tumours on Social Media," in *Disability, Media, and Representations; Other Bodies*, ed. Jacob Johanssen and Diana Garrisi (New York: Routledge, 2020), 51–74.
118 Cahyadi and Setiawan, "Disability and Social Media: Exploring Utilization of Instragram Platform As a Tool for Disability Advocacy."
119 Cocq and Ljuslinder, "Self-Representations on Social Media. Reproducing and Challenging Discourses on Disability."
120 Laestadius (2018)
121 Cahyadi & Setiawan (2020)

Figure 7. Positive Comment on Jendela Ibu's Instagram Post



Source: @jendelaibu Instagram (https://instagram.com/jendelaibu)

In this part, the author has discussed disability and parental use of Instagram in increasing disability visibility and disability rights dissemination digitally. Referring to [122] co-cultural communication theory, all participants and I have yet to deploy non-assertive assimilation strategies in digitally emphasizing the positive image of disability and voicing equal rights of people with disabilities, including children with special needs. The assertive accommodation strategy is still used with a different pattern by producing educational disability rights content on Instagram. In addition, the result indicates a new communication pattern. Mediated by Instagram content, non-assertive accommodation is also used to increase disability visibility online and counter negative stigma. This strategy is shown in the produced content on disability rights.

3.3 From Visualizing Rights to Building Disability Connections

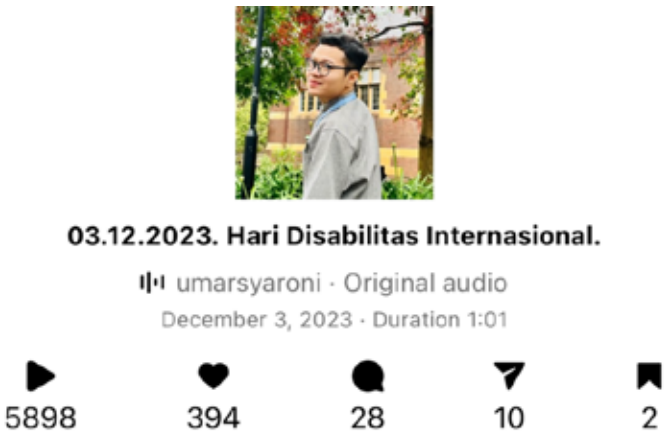
As a visual-based social media platform, Instagram allows the author to shed light on visual media cultures.[123] For users with disabilities, Instagram can mediate their self-representation to enhance disability visibility online.[124] The use of Instagram among parents has also reached an effective level.[125] However, the use of Instagram goes beyond visuality as its content can also empower other users. Most importantly, Instagram allows for a complex human connection. This connection is required by users with disabilities to build collective action in voicing disability rights.[126] This study is conducted to bridge Instagram's visuality and connection to disability rights.

Instagram users rely on the visuality of this platform.[127] and its audience preference has steadily transformed over time, which affected the effectiveness of each content piece.[128] This gradual audience shift has been experienced by Jendela Ibu as mentioned by Ifta. Her team went through difficulty in balancing in-person programs and online presence on Instagram. They still managed to produce posters on disability inclusion and finally followed the trend by producing more video content for their programs. By following the novel audience's preference, Ifta found that videos tend to be more effective in promoting disabled children's rights as they receive more positive comments and more parties who are willing to help them.

In enhancing influence, Instagram activists are forced to not only follow the trend but also be consistent in producing content.[129] As a digital disability activist, the audience's demand for visual content has urged me to adapt. In my experience, visual content helped to gain positive feedback from followers. Figure 8 shows the content coverage metrics for one video post, accessible only to the creator. As shown, the information is related to one of my video contents on the International Day of People with Disabilities that addressed my hope for disability rights in education. This awareness video content reached more audiences. The video was played by nearly six thousand audiences and received more than 20 comments which doubled other static posts.

122 Orbe's (1998)
123 Laestadius, "The SAGE Handbook of Social Media Research Methods"; Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.
124 Cocq and Ljuslinder, "Self-Representations on Social Media. Reproducing and Challenging Discourses on Disability."
125 Rani Sukma Ayu Suteja et al., "Premature Indonesia Support Group in Health Communication: Efforts to Prevent Retinopathy of Prematurity in Indonesia," *Jurnal Komunikasi Profesional* 7, no. 3 (2023): 427–39, http://ejournal.unitomo.ac.id/index.php/jkp.
126 Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.
127 Laestadius, "The SAGE Handbook of Social Media Research Methods"; Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.
128 Suteja et al., "Premature Indonesia Support Group in Health Communication: Efforts to Prevent Retinopathy of Prematurity in Indonesia."
129 Laestadius, "The SAGE Handbook of Social Media Research Methods."

Figure 8. Coverage Information of Umar's Instagram Content



Source: @umarsyaroni Instagram (https://instagram.com/umarsyaroni)

Following the audience's preference shift, Instagram users and content creators are required to construct attractive profiles to gain more influence on wider audiences.[130] For Aida, producing awareness and critique content often left her a challenge. She always has various considerations before creating and sharing content, considering that the topic of disability is still sensitive in Indonesia. With that, she aims to ensure her content is culturally and socially appropriate and achieves the goal of raising disability awareness. Not only sensitive, but disability content in Indonesia is also overlooked[131] Therefore, Karim, Aida, and I rely on Instagram's visuality by visualizing our physical disability as part of our digital self-representation and in producing such content, we refer to our lived-experiences.

From a parental perspective, social media is viewed as a medium for societal change.[132] Sandi mentioned that Jendela Ibu is following Aida in having consideration before the content production. As shown in Figure 9, Jendela Ibu produces content regarding a festival for children with special needs. In producing this content, according to Sandi, it is not only about highlighting the implementation of the program itself. The team also ensures disability representation and their parents in the content through a positive portrayal. This visual content has received substantial views and various positive comments as in Figure 6.

130 Brittany Ferdinands, "The Exposure Economy Model: Navigating Visibility on Instagram," 2022; Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.

131 Fadhlizha Izzati Rinanda Firamadhina and Hetty Krisnani, "Perilaku Generasi Z Terhadap Penggunaan Media Sosial TikTok: TikTok Sebagai Media Edukasi Dan Aktivisme," *Share : Social Work Journal* 10, no. 2 (February 12, 2021): 199, https://doi.org/10.24198/share.v10i2.31443; Rika Veronika and Sisca Aulia, "Pengaruh Daya Tarik Konten Media Sosial @akutahu Terhadap Minat Baca Generasi Milenial," *Koneksi* 6, no. 2 (November 2, 2022): 295–304, https://doi.org/10.24912/kn.v6i2.15677.

132 Marina Krcmar, David R. Ewoldsen, and Ascan Koerner, *Communication Science Theory and Research: An Advanced Introduction* (New York: Routledge, 2016); Rofasita, "Sharing Experience Dan Resiliensi: Studi Atas Facebook Group Orang Tua Anak Cerebral Palsy."

Figure 9. Jendela Ibu's Instagram Video Post



Source: @jendelaibu Instagram (https://instagram.com/jendelaibu)

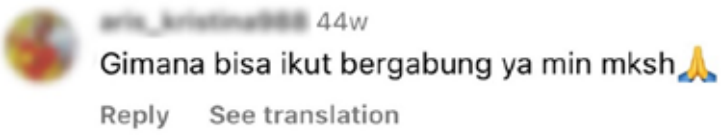
Social media facilitates engagement for its users and allows disability activists to interact with.[133] Aside from visualizing diversity, Instagram allows its users to engage with other users using direct messages.[134] Although it is not a main communication platform, Aida and I use Instagram's direct message for good. Both of us receive positive direct messages every time we post Instagram content on disability rights and awareness. We are grateful that some direct messages come from fellow friends with disabilities who are motivated by our struggles in obtaining access to equal education and have used us as their example to seek higher education, specifically by governmental disability scholarship.

Social media interactions are also built by parents who share similar parental challenges in raising their children with special needs.[135] Related to this study, Instagram has been used by parents of disabled children for informational purposes as it can foster parent support groups online.[136] According to Ifta, Jendela Ibu's content has reached audiences across Indonesia, who have provided diverse feedback, including such parental interaction. Therefore, they have demonstrated openness by responding to parents of disabled children who contacted them through Instagram's direct messages. Ifta and her team used this interaction to empower those parents and educate them on their children's rights to equal healthcare.

For parents, social media use is beyond interaction as it can mediate their connection with other parents[137] and Instagram enables users to establish virtual connections.[138] Sandy added that upon Jendela Ibu's Instagram presence, they can build a support group for parents of children with special needs. Figure 10 shows a comment from a parent who requests to be included as a Jendela Ibu member. Sandy mentioned that the parents who get connected will feel empowered as they can share their parental challenges with fellow parents. With that, Jendela Ibu can provide both interpersonal support for parents and address challenges through parental workshop programs. The program's posters are posted on Instagram to reach more parents and video content for more awareness.

133 Ellis and Kent, *Disability and Social Media*.
134 Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.
135 Wright and Taylor, "Advocacy by Parents of Young Children With Special Needs: Activities, Processes, and Perceived Effectiveness."
136 Suteja et al., "Premature Indonesia Support Group in Health Communication: Efforts to Prevent Retinopathy of Prematurity in Indonesia."
137 F. Köbler et al., "Social Connected Ness on Facebook—An Explorative Study on Status Message Usage," in *AMCIS 2010 Proceedings*, 2010, www.aisel.aisnet.org/amcis2010/247; C. Riedl et al., "Tweeting to Feel Connected: A Model for Social Connectedness in Online Social Networks," *International Journal of Human–Computer Interaction* 29 (2013): 670–87.
138 Laestadius, "The SAGE Handbook of Social Media Research Methods"; Leaver, Highfield, and Abidin, *Instagram: Visual Social Media Cultures*.

Figure 10. Positive Comment on Jendela Ibu's Instagram Post



Source: @jendelaibu Instagram (https://instagram.com/jendelaibu)

Dual social media platforms can mediate parents' connection. WhatsApp becomes a follow-up medium after Instagram to foster communication for connected parents. This was Jendela Ibu's way of connecting the parents by making an official WhatsApp group for its members. Sandy mentioned that the group was requested by Jendela Ibu's members and it has been an open room for the parents to interact and share their stories, allowing them to feel more connected. By December 2023, Jendela Ibu had connected more than 130 parents of children with special needs, and the number continues to grow. Ifta and Sandy believe that the more parents are connected, the more children with special needs receive their right to healthcare by obtaining a medical diagnosis from doctors and medical treatment from therapists.

Social media's possibility for human connection also affects disabled users who get connected through virtual communities[139] which enables users with disabilities to represent their disabled selves.[140] For Karim, Aida, and I who produce content on disability rights, we can self-represent ourselves by visualizing our disabilities and voicing the educational rights of people with disabilities. By producing such content, we can empower and feel empowered at the same time as we can get connected to more diverse disability stakeholders. While Ana and Hani feel a sense of virtual connection with fellow users with disabilities and by getting connected, they can feel empowered and have a broader insight into disability types and disability rights.

In concluding this part, the author will address Instagram's visuality and connection in communicating disability rights through the lens of co-cultural communication.[141] As discussed in the previous part, the visuality of Instagram required participants, including myself, to adapt to audience preference which then led us to employ assertive accommodation strategies by producing visual content on disability rights. This strategy is also beneficial in spreading awareness to wider audiences as it enables us to connect with diverse disability stakeholders. In addition, all participants and I can increase the digital representation of disability by deploying non-assertive accommodation strategies. By maximizing visuality and connection, more audiences are educated, and more disability rights are fulfilled.

4. Conclusion

This study highlights the role of communication in disability rights fulfilment by dual disability stakeholders with a focus on equal access to education and healthcare. The results showed that individual and parental activism is critical in disseminating disability rights. These collective actions have increased the visibility of people with disabilities who are presented. The five disabled participants indicated that disability self-acceptance also relies on how they communicate their rights with their surroundings. The parent participants believe that by having parents' social and mental welfare fulfilled, they can bridge the fulfilment of their disabled children's right to healthcare. This fact highlights the relevance of inclusion movements. Not only does this contribute to a more inclusive society, but it also helps to fulfil disability rights.

Along with technological advancements, Instagram has proven to be effective in mediating disability and parental activists in disseminating disability rights online and reaching more diverse audiences in Indonesia. However, they should rely on Instagram's visuality as the audience trend has shifted and the demand for visual communication. With that, activists are required to adjust their communication patterns through more attractive content to gain more views and influence. A compelling finding of this study is that Instagram's role is beyond visualizing disability in digital content but rather being a source of networking for people with disabilities and parents of children with special needs to feel empowered. All participants and I believe that Instagram content can increase awareness of disability rights and ultimately help fulfil those rights.

139 Rajabi, "Losing Someone Like Us:Memetic Logics and Coping with Brain Tumours on Social Media."
140 Mineur, Tideman, and Mallander, "Self-Advocacy in Sweden—an Analysis of Impact on Daily Life and Identity of Self-Advocates with Intellectual Disability."
141 Orbe, *Constructing Co-Cultural Theory: An Explication of Culture, Power, and Communication*.

By involving the theory of co-cultural communication, this study shed light on both in-person and online activism from disability and parental perspectives. The results highlight the use of assertive accommodation and non-assertive assimilation strategies by participants to promote disability rights in offline settings and through digital visual content on Instagram. By leveraging these strategies, the participants were able to educate and connect with a wider audience, ultimately fostering a more inclusive society and challenging negative stigmas surrounding disabilities. While the latter two strategies are applicable in all settings, the non-assertive accommodation strategy is prevalent in enhancing digital disability representation. In conclusion, communicating rights leads to bringing people with disabilities' rights closer to fulfilment regardless of their setting.

This study offers practical recommendations for disability activists and organizations to broaden their digital strategies beyond a sole emphasis on visual content. By enhancing interaction, they can create safe online spaces for individuals with disabilities and their families. It is anticipated that policymakers will leverage digital platforms to engage a larger audience of people with disabilities whose rights are still unfulfilled. While this study focuses exclusively on individuals with disabilities and their parents, future research should incorporate perspectives from those without disabilities regarding disability rights. Additionally, this study is limited to examining educational and health rights; thus, future research could explore a wider range of rights. The current research employs only qualitative methodology, suggesting that future studies could benefit from a larger participant pool through quantitative methods. Furthermore, future research could investigate other social media platforms or analyze their roles in comparison to Instagram in facilitating disability activism.

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