Evaluating Disability Research and Advocacy in Indonesia

Dina Afrianty, Ucca Arawindha, Alies Poetri Lintangsari
{dina.afrianty@acu.edu.au[1], uccaarawindha@ub.ac.id[2], alieslintang@aidran.org[3]}

Thomas More Law School, Australian Catholic University, Australia[1],
Universitas Brawijaya, Indonesia[2], Monash University, Australia[3]

Abstract. This article discusses the development of disability research and advocacy in Indonesia, analysing insights gathered from the process of organising the AIDRAN biennial conference. AIDRAN (Australia-Indonesia Disability Research and Advocacy Network) began organising conferences in 2017. It was designed to fostering the exchange of knowledge and experiences among disability advocates, researchers, and policy makers, mainly from Australia and Indonesia to inform policy making. This initiative aligns with the Indonesian government's commitment to promote evidence-based research to inform policy making, as outlined in Law No. 11/2019 on the National System of Science and Technology. Analysing data from the conference, this paper highlights significant progress in research interest on disability research and growing recognition of disability as a critical social identity, alongside gender and other intersecting identities.

Keywords: Disability, Research, Policy, Advocacy

1 Introduction

Indonesia has made a significant progress in advancing the rights of people with disability by introducing a number of policies and regulations. Landmark achievements include the ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2011 and the enactment of the National Law on Persons with Disabilities in 2016. These national legislations have paved the way for local authorities to adopt local regulations to implement national policies and fulfil the rights of people with disability in Indonesia. The success in policy adoption, has of course, driven by strong advocacy efforts from disability rights advocates at both at the national and local levels [1]. The emergence and growth of Disabled People's Organizations (DPOs) has further contributed to the country's movement toward disability inclusion. Despite progress in the policy framework, challenges remain, and people with disabilities continue to face discrimination and barriers in fulfilling their basic human rights. People with disability continue to face discrimination, both in policy and in social interactions because of social stigma against disability.

There is a persistent challenge in identifying accurate disability situation in Indonesia, as various reports present differing data [2], [3]. This discrepancy arises from the use of different datasets, each applying distinct definitions and methodologies. However, this should not be seen as an impediment to promoting disability inclusion. On the contrary, it highlights the need for more rigorous research to increase awareness and develop a comprehensive understanding, which can better inform policies and drive positive change for people with disabilities. Article 31 of the UNCRPD underscores the importance of reliable statistics and data collection to advance disability rights and inclusion. This is reinforced by the Human Rights Council's resolution 43/23, which requested the Office of the United Nations High Commissioner for Human Rights

ICDR 2023, November 21-23, Yogyakarta, Indonesia

DOI 10.4108/eai.21-11-2023.2352658

(OHCHR) to prepare a study on statistics and data collection under Article 31, in consultation with States and relevant stakeholders, including organizations of persons with disabilities, and to present it before the Council's forty-ninth session [4].

A report published by SMERU, an Indonesian based think tank indicated that based on the 2018 National Social Survey data (SUSENAS) about 2,92% of Indonesians aged over 2 years have disability, which is about 7,4 million of the total Indonesian population [2, p. 14]. In another account, it was reported that based on March 2019 National Socio-Economic Survey (Susenas), TNP2K,[1] reported there are about 9 per cent of Indonesia's population have disability, which is about 23,3 million [5]. However, various reports reveal that people with disability face significant barriers to access basic services including, healthcare, education, employment, social protection, financial services, and access to information. The Indonesian government, has therefore, introduced several policies to address the situation, including introducing the National Action Plan on Human Rights (2015-2019) recommending that efforts are made to ensure the fulfilment of the rights of people with disability [2, p. 9].

The obligation of the government and society to respect the rights of people with disabilities and ensure the fulfillment of these rights is also part of Indonesia's commitment to the global development agenda (SDGs). Indonesia is responsible for ensuring a better future where no citizen is denied their right to live with dignity. Therefore, the government is obligated to take steps to eliminate poverty, reduce social inequality, and provide opportunities for all citizens to participate equally in development, ensuring that no one is left behind.

In its 2017 report submitted to the UN regarding the fulfillment of the rights of people with disabilities, there were at least five elements reported to continue to be the critical problems in promoting disability inclusion. They include, 1) the lack of comprehensive, integrated, and standardized data on disabilities hinders effective policymaking, or data availability, 2) negative attitudes and cultural discrimination towards disabilities persist, 3) infrastructure challenges with inaccessible public facilities and services limit equal opportunities, 4) budgeting inefficiencies, that is insufficient understanding of diverse disability needs leads to inefficient use of resources, and 5) interagency coordination where persistent poor coordination across sectors affects disability priorities. All the five elements are interconnected, with one critical element on it being the lack of available data and disaggregated data. This report is available from the United Nations Human Rights Treaty Bodies (OHCHR.org).

2 Framework for disability research and advocacy

The Indonesian government needs to improve its data on disability to ensure inclusive policies, address inequalities, and support effective advocacy. Comprehensive, integrated data is crucial not only for allocating resources and designing inclusive public services, but also for raising awareness and driving societal change. Advocacy campaigns are needed to communicate the realities of disability, especially since people with disabilities in Indonesia are often hidden by their families, excluded from schools, and isolated from the workforce, reinforcing their invisibility.

International frameworks like the UNCRPD emphasise the need for accurate data collection to assess the living conditions of people with disabilities and identify areas where inclusion can be

---

[1] TNP2K is the National Team for the Acceleration of Poverty Reduction. It works to promote coordination across ministries/agencies to improve the implementation of poverty reduction program. More information about TNP2K can be found here: https://www.tnp2k.go.id/about/about-tnp2k

enhanced. The Sustainable Development Goals (SDGs), particularly the goal of "leaving no one behind," further underline the importance of robust data systems to track progress in disability inclusion.

To improve data collection, research can be strengthened by adopting inclusive research methodologies, fostering collaboration between government agencies, international organisations, and actively involve Disabled People's Organizations (DPOs) in data gathering. To enhance disability research, the Indonesian government has introduced Law No. 11/2019 on the National System of Science and Technology, emphasising research's role in addressing societal issues, including disability inclusion. However, challenges remain in fostering an academic culture that prioritises disability research. Efforts should include funding mechanisms for disability studies and encouraging collaborations with universities and research institutions to ensure meaningful outcomes. Additionally, the government could enhance affirmative policies to stimulate research on disability and integrate disability studies into higher education, which remains underdeveloped.

3 AIDRAN Biennial Conference

The initiative to establish Australia-Indonesia Disability Research and Advocacy Network (AIDRAN) was inaugurated by the founder, Dr Dina Afrianty in November 2017, during an international conference on Disability and Diversity in Muslim Societies in Jakarta. The initiative was officially launched in Melbourne, in October 2018, at La Trobe University, attended by Slamet Thohari, a lecturer at Brawijaya University, and Indonesia's leading disability advocate, who then served as Indonesia Chair of AIDRAN (2018-2023). AIDRAN now has a secretariat in Indonesia, with Ms Ucca Arawindha, serves as Director and Indonesia Chair of AIDRAN since 2023.

The Australia-Indonesia Disability Research and Advocacy Network (AIDRAN) is an initiative aiming to bring together Australian and Indonesian disability advocates, researchers, and practitioners. AIDRAN initiative is to promote broader disability and social inclusion through interdisciplinary research on disability inclusion to inform evidence-based disability-inclusive policy in Indonesia. Their works are centred on promoting equal engagement for people with disability in conducting research on the issues that affect their lives, engaging in policy debates on these issues, and advocating for social change. Central to AIDRAN activities is the desire to encourage mutual exchange between Australian and Indonesian disability researchers, organisations, disability advocates, and government actors.

Through a range of network activities, AIDRAN aims to create sustainable links between Australian and Indonesian counterparts in order to facilitate sharing of knowledge on effective approaches and good practices to promote disability-inclusive policy and practice, build the capacity of Indonesian researchers and disability advocates to collect quality data on disability issues, produce policy-relevant knowledge, and effectively advocate for disability-inclusive policy; and build coalitions and solidarity to advocate for social transformation. To increase disability awareness in Indonesia is part of AIDRAN broader objective in promoting disability and social inclusion. To date there are around 500 registered members in Australia and Indonesia. AIDRAN continues to collaborate with both government and non-government organisations in Indonesia at national and local level to promote better understanding and knowledge around disabilities.

Since officially launched, AIDRAN is committed to organise a biannual conference as a platform for knowledge sharing as well as part of our advocacy effort in mainstreaming disability into research in Indonesia. The design of the AIDRAN conference involves partnering with Indonesian universities. The goal is for AIDRAN to influence how universities perceive disability, ensuring they better understand the rights of people with disabilities and fulfill their obligation to provide access for students with disabilities. Before AIDRAN's establishment, its founder collaborated with Sunan Kalijaga University in Yogyakarta in 2015 and Syarif Hidayatullah State Islamic University in Jakarta (UIN Jakarta) in 2017. Both conferences were supported by the Department of Foreign Affairs and Trade (DFAT) through the Australia-Indonesia Partnership for Justice (AIPJ) and Program Peduli. The conference organized in 2017 with UIN Jakarta was considered to be the first biennial conference as it was during the opening of the conference that the initiative of AIDRAN was inaugurated.

3.1 2019 Conference

The second biennial AIDRAN conference, following its official launch in Australia, was held in 2019. Supported by the Knowledge Sector Initiative, a partnership between the governments of Indonesia and Australia, and funded by the Department of Foreign Affairs and Trade (DFAT) in collaboration with Bappenas, the first biennial conference was co-organised with Brawijaya University and La Trobe University. Slamet Thohari and Dr Dina Afrianty served as the conference convener. The theme of the conference was "Theorising Advocacy and Research for Disability Policy and Inclusion: Experiences from Asia," attracted 214 abstracts, with about 10% from international disability researchers. After rigorous assessment, 84 participants were selected, with the abstracts categorized into 12 themes: including; 1) Work and employment 2) Practices and policies on inclusive education 3) Social Inclusion for persons with disabilities 4) Accessibility and universal design 5) Health and well-being 6) Legal reform and policy of inclusion 7) Disaster and mitigation for humanitarian response 8) Women, gender, youth and identity 9) Inclusive and participatory policy making 10) Religion, ethnicity and culture 11) Communication and assistive technology 12) Researching disability and inclusive research methodology for better advocacy.

Of the 84 accepted participants, 64 abstracts were primarily from Indonesian academics, reflecting the effectiveness of the conference's outreach through social media and networks. Additionally, 12 international speakers from countries including Australia, the US, India, Bangladesh, Iraq, and Sweden. Four Plenary sessions featured government representatives and key disability advocates and researchers from Australia and Indonesia.

Apart from the abstracts submitted by individual researcher and advocate at the conference we also received interests from local DPOs and DFAT funded program partners to organise their own panels. Three special panels were organised by Program Peduli, The Australia-Indonesia Partnership for Justice, women’s disability advocates groups coordinated by Women and Children Disability Advocacy Organisation or SAPDA based in Yogyakarta, and a panel organised by Cucu Saidah, the founder of Jakarta Barrier Free Tourism. Cucu Saidah organised a panel on disaster risk management. SAPDA organised a panel on Gender, sexuality and disabilities. Individual researchers from DFAT funded partners also asked to be given the opportunity to share their work. They include KIAT and Inovasi.

The COVID-19 pandemic halted AIDRAN’s plans to host its second biennial conference, originally scheduled for 2021. While an online conference was considered, it was decided that it would not be as effective in achieving the conference’s core objectives. Holding the conference in person on university campuses allows disability advocates from across Indonesia to bring disability into visibility, fostering a tangible impact on partner institutions. The physical presence of advocates highlights accessibility issues firsthand, promoting a deeper understanding of disability inclusion, which could not be fully replicated through a virtual format.

3.2 2023 Conference

The conference in 2023, was organised in partnership with Gadjah Mada University. The Convener was Slamet Thohari, Dina Afrianty, and Fina Itriyati. The conference title was "Disability Inclusive Development." Disability Inclusive Development has been identified as an important component in creating a sustainable future. It is a twin track approach that addresses inequalities between people with disability and those who have no disability disabled and non-disabled people and supports specific initiatives to empower people with disability. Working with national and international organisations, the Indonesian government calls for all development sectors to include people with disabilities. The Indonesian government commitment is also demonstrated in The Jakarta Declaration on the Asian and Pacific Decade of Persons with Disabilities, 2023–2032. The Jakarta Declaration was adopted at the High-level Intergovernmental Meeting to guide regional efforts towards realising disability rights and inclusion in the coming Decade. The Jakarta Declaration highlights a gender-responsive life cycle approach to disability-inclusive development and underscores the importance of engaging persons with disabilities and their representative organisations and the private sector in all development efforts to build sustainable and inclusive societies

In four weeks, about 133 abstracts were received. Of these, 77 were selected for presentation, and they were divided into several topic categories including, inclusion of marginalised groups, the role of DPOs in policy making, community action for inclusive development, inclusive employment, inclusive education, social protection and well-being. In addition to the 77 selected research papers, 12 papers were chosen for keynote and plenary sessions. The selection process prioritised key factors such as the relevance of the abstract to the conference theme, the quality of the research process, and overall abstract quality. Importantly, the process also emphasized amplifying the voices and experiences of people with disabilities, ensuring writers with disabilities were given the opportunity to participate in the conference.

4 Discussion and conclusion

The conduct of the biennial conference has provided a forum where disability advocates, researchers, and policy makers shared their works and experience. Most importantly, the data gathered from authors and their research topics are valuable knowledge to see the growing interests in researching disability in Indonesia. The conduct of the conference in partnership with university also allows students and academic community to directly witness disability.

This paper is the first attempt where we aim to analyse the progress of disability research and advocacy in Indonesia. The data will be analysed further where we will look at who are doing research on disability, what are the topics that people are more interested in about, and we are also planning to see if academics and advocates continue with their research, and most importantly we would like to investigate from those who presented at our conference, the way their develop their research methodologies over the years.

The expanded research paper that will develop later will be able to answer some of the critical questions based on our key assumptions which include, first, low knowledge, interest, and concern about researching disability issues. Marginalization and absence of people with disabilities in many public spaces in Indonesia, including educational environments, result in low awareness and understanding of disability issues among the academic community. Additionally, the lack of platforms for people with disabilities to voice injustices and discriminatory treatment further distances disability issues from social concerns. Issues such as inequality, rights deprivation, neglect, accessibility, and discrimination in various aspects of daily life for people with disabilities are not yet a significant focus of researchers. Second, lack of concern for disability issues can be understood as a consequence of the weak development of disability studies in higher education in Indonesia. For instance, disability studies have not yet found a place in the production of social knowledge. This is marked by the low understanding of disability research methodologies. Third, the lack of strong affirmative policies from the government and non-governmental organizations, such as international institutions, to encourage disability research. Disability issues remain marginal. This can be attributed to the lack of concern about the welfare issues faced by people with disabilities. Additionally, disability research is often seen as requiring more time and resources than other types of research. Frequently, disability issues are merely additional or side issues without serious efforts to ensure that the entire knowledge production process—from data collection, analysis, and communication of research results—is conducted in accordance with scientific standards, namely disability research methodologies.

Finally, in the next phase our research we will also elaborate funding availability and investigate how researchers working on disability are able to generate more funding to accommodate the reasonable accommodation. This initial research findings, however, demonstrate that disability research is growing in Indonesia.

References

[1] J. Yulianto, A. Suryadini, and E. Jackson, “Securing Legal Recognition for the Rights of Persons with Disabilities in Indonesia: Navigating Successful Policy Reform,” Nov. 2023. Accessed: Oct. 04, 2024. [Online]. Available: https://asiafoundation.org/publication/securing-legal-recognition-for-the-rights-of-persons-with-disabilities-in-indonesia/

[2] Hastuti, R. K. Dewi, R. P. Pramana, and H. Sadaly, “Kendala Mewujudkan Pembangunan Inklusif Penyandang Disabilitas,” in *The SMERU Research Institute*, 2020.

[3] Lisa Cameron and Diana Contreras Suarez, “Disability in Indonesia: What Can We Learn from the Data?,” Monash, 2017. Accessed: Sep. 30, 2024. [Online]. Available: https://www.monash.edu/__data/assets/pdf_file/0003/1107138/Disability-in-Indonesia.pdf

[4] “Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities,” 2021. Accessed: Oct. 04, 2024. [Online]. Available: https://acnudh.org/load/2019/07/047-Plan-de-Acci%C3%B3n-Nacional-DPcD.pdf

[5] M. Siyaranamual and D. Larasati, “Disability Situation Analysis: Challenges and Barriers for People with Disability in Indonesia,” TNP2K. Accessed: Oct. 04, 2024. [Online]. Available: https://www.tnp2k.go.id/downloads/disability-situation-analysis:-challenges-and-barriers-for-people-with-disability-in-indonesia