T14P05 / Disability Inclusive Policy Development in the Asia Pacific Region

Topic : T14 / GENDER, DIVERSITY AND PUBLIC POLICY

Chair : Jennifer Smith-Merry (University of Sydney)

Second Chair : Helen Dickinson (University of New South Wales)

GENERAL OBJECTIVES, RESEARCH QUESTIONS AND SCIENTIFIC RELEVANCE

State policy is often utilised as a mechanism to implement international conventions within local contexts. 185 countries internationally have ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), including all countries in the Asia-Pacific region. The UNCRPD provides a set of principles that state parties are to adopt to ensure the rights of people with disability and the UN monitors the establishment of legislation and policies which support these rights. However, implementation often falls short of policy expectations. Both mechanistic and interpretive reasoning has been applied to understand continued policy failure and offer solutions (e.g. Steele, 2019; Verdugo et al, 2017). Disabled people and disability representative organisations have consistently noted that despite signing up to international expectations for disability inclusion, such as those expressed through the UNCRPD, local experiences do not match this. Further, in many cases the voices of people with disability are not central in policy design or implementation processes. All too often this means that the priorities for people with disability are not reflected in policy.

Disability is an under-acknowledged cause of marginalisation and poverty in developing and developed countries alike but is not always a core focus of current public policy research (Grech, 2009). This panel specifically focuses on centring discussions of disability as a case through which we can explore policy implementation for marginalised populations more broadly. This panel will focus on the ways that policies in countries in the Asia Pacific region foster the inclusion of people with disability and the barriers and enablers to implementation. We centre the discussion in the Asia Pacific region as a way of drawing attention to policy realities of countries outside of the existing Europe-North America contexts that dominate the policy research landscape.

Papers will focus on the following research questions to explore which circumstances impact disability policy implementation:

1. What strategies are most effective in creating policies that lead to effective implementation for disability inclusion?
2. How can people with disability be best included in policy implementation?
3. How can disability inclusion be prioritised in policy in low-resource settings?
4. What barriers exist to implementation of the UNCRPD goals in policy?
5. How does a focus on disability help us better understand policy design and implementation for marginalised populations?

References:

Steel, E. J. (2019). The duplicity of choice and empowerment: disability rights diluted in Australia’s policies on assistive technology. Societies, 9(2), 39.

Verdugo, M. A., Jenaro, C., Calvo, I., & Navas, P. (2017). Disability policy implementation from a cross-cultural perspective. Intellectual and Developmental Disabilities, 55(4), 234-246.

Grech, S. (2009). Disability, poverty and development: Critical reflections on the majority world debate. Disability & Society, 24(6), 771-784.

CALL FOR PAPERS

This panel aims to create a forum through which to explore factors that impact the implementation of disability policy in the Asia-Pacific region. We focus on disability because it is an area of international policy attention, with a clear international imperative to act, including through the United Nations Convention on the

Rights of Persons with Disabilities, but where most countries have not successfully enacted policies to meet these rights.

Accordingly, we welcome papers that focus on research related to any aspect of disability policy in the Asia Pacific region. Our forum centres on the Asia Pacific region to draw attention to policy realities and innovations outside of the Europe-North America contexts that dominate the much of the policy research landscape.

We are interested in how the circumstances of policy making, along with the local contexts in which policy is to be implemented impact the effectiveness of the policy. We welcome both empirical and conceptual work, including ‘blue-sky’ perspectives which rethink the way that policy should be made.

The following research questions can be used to guide thinking around the topic, but we are open to papers that focus on any area of disability policy implementation:

1. What strategies are most effective in creating policies that lead to effective implementation for disability inclusion? This
2. How can people with disability be best included in policy implementation?
3. How can disability inclusion be prioritised in policy in low-resource settings?
4. What barriers exist to implementation of the UNCRPD goals in policy?

We encourage participation from presenters who have disability and live and research in low- and middle-income countries.

T14P05 / Disability Inclusive Policy Development in the Asia Pacific Region

Chair : Jennifer Smith-Merry (University of Sydney)

Second Chair : Helen Dickinson (University of New South Wales)

Session 1Disability policy in an Asian context

Building Health Partnerships for People with Disabilities: Korea’s Response to the UN Convention on the Rights of Persons with Disabilities

HYEJIN KIM (University of Sydney)

Soong-nang Jang (Chung-Ang University)

Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) highlights the right of persons with disabilities (PWDs) to the highest attainable standard of health without discrimination, stressing the need for gender-sensitive health services, including rehabilitation. Achieving this goal requires cross-sector collaboration, as PWDs represent a diverse population spanning all ages and functional limitations, often facing various health and social determinants, such as limited social participation.

This study aims to: (1) present Korea’s Regional Health and Medical Centers (RHMCs) as a model for multisectoral collaboration, and (2) analyze local health networks in Gyeonggi-do province, which hosts the largest population of PWDs in South Korea, using Social Network Analysis (SNA). Gyeonggi-do was selected for its significant disability population, which constitutes 20% of the nation's total.

Data were collected in 2021 through a survey of 197 workers from 23 organizations across the health, social, and educational sectors. A snowball sampling approach was employed, starting with the Gyeonggi RHMC. Collaboration on referrals, information sharing, and joint service planning (both formal and informal) among these organizations was assessed using a 5-point Likert scale.

Since ratifying the CRPD in 2008, the Korean government has implemented various disability-inclusive policies. A key milestone was the enactment of the 2018 Act on Right to Health for PWDs, which supported initiatives such as a primary healthcare pilot program for PWDs, the designation of disability-friendly medical checkup facilities, and the establishment of RHMCs. Nationwide, RHMCs function as hubs within a fragmented healthcare system, integrating healthcare services and bridging gaps between community healthcare and social care systems. They are instrumental in identifying community resources, fostering partnerships, and connecting PWDs to appropriate services to address their comprehensive needs.

The results from the SNA reveal that the Gyeonggi RHMC exhibited the highest betweenness centrality, positioning it as a critical bridge between healthcare and community services. This centrality was further validated by a sociogram, which demonstrated that all 22 types of community organizations were directly connected to the Gyeonggi RHMC. This indicates that these organizations collaborate and coordinate directly with the RHMC, without relying on intermediary institutions. Additionally, rehabilitation medical institutions, the RHMC, and Community-Based Rehabilitation teams at public health centers formed a strong network of collaboration and coordination.

Hub organizations such as the RHMCs, which focus on bridging and linking networks, play a crucial role in facilitating a collaborative and multisectoral approach, despite challenges related to efficiency and the unfamiliarity of the newly implemented model. This study evaluates the Korean government’s efforts to build health partnerships for PWDs through the RHMC model. Furthermore, SNA proves to be an effective method for exploring health networks for PWDs and can guide ongoing efforts to implement and refine these initiatives.

Determinants of Ethnic Minorities Aging in Place: A Qualitative Study Using a Culturally Constructed Social-Ecological Model

Mengyuan NIU (Hong Kong University of Science and Technology)

In developed regions, most older adults prefer to age in place (AIP) within their homes and communities

rather than in institutional settings. However, research on aging choices among ethnic minority (EM) elderly yields inconsistent results. Moreover, the underlying mechanisms of the EM elderly's aging choices remain limited. This study aims to explore the ethnic minority elderly's aging choices in Hong Kong, and answer what drives their decision about AIP. We propose that cultural factors are immersed the social-ecological environment and have adapted a culturally constructed social-ecological model to examine the multifaceted reasons influencing the choice of aging in place. Using semi-structured interviews and participant observation involving 21 elderly individuals from ethnic Pakistani, Indian, and Nepalese backgrounds, our research reveals a strong inclination among EM elderly in Hong Kong towards aging in place, specifically within their own homes. We argue culture plays a dominant role in shaping the aging choices of EM elderly. When policy regulations and community resources fail to address cultural needs, AIP for EM elderly translates to aging at home without access to or benefits from community support. This contrasts with the intended goals of AIP frameworks and may diminish the quality of aging for EM individuals. Our study highlights the importance of incorporating cultural considerations into social policies and community practices to better support AIP for EM elderly populations.

From 'Viklang' (handicapped) to Enabled 'Divyang' (with divine abilities): A Socio-Legal Appraisal of the "Rights of People with Disabilities Act (RPwD), 2016" with specific reference to the UNCRPD

Anshuman Ankit (Magadh University)

Shailendra Kumar (Magadh University)

PANKAJ MISHRA (Magadh University)

The triple gems "inclusive growth, development for all, and confidence for all" are envisioned to serve as the foundation stone of the disability assessment policy in the Indian context. As per Census 2011, out of India's 1210 million population, about 26.8 million (2.21% of the total population) persons were categorised as 'disabled'. Furthermore, the National Family Health Survey-5 (2019) data vindicated the overall prevalence of disabilities in India was 4.52% of the total population, of which 44.7% were locomotor disabilities and 20.28% were mental disabilities. Disability, being an ever-evolving social phenomenon in India, has found a strong sense of destiny and a deep appreciation for the enormous potential ability in the broader Scheme for Implementation of the Rights of Persons with Disabilities Act (SIPDA).

The Government of India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 and, enduring the relevance and its commitment to inclusivity, fulfilled the obligations by passing out the ***Rights of Persons with Disabilities Act, 2016***. The act promised to strengthen the Rights and Entitlements of *Divyangjan* (PwD) while simultaneously establishing a reliable system for their empowerment and full integration into society. It also increased the existing number of types of disabilities from 7 to 21 and authorized the Central Government to add more types of disabilities in the future. The RPWD Act, 2016 makes an exceptional case of inclusivity by stipulating a 4% reservation quota for PWDs in government jobs.

Despite the Act's progressive nature in extending inclusivity in society, however, in practical application it has faced 'dismal severity of execution' which was lamented by the Supreme Court (SC) of India upon states delayed and failure to comply with provisions, leaving the promise of equal access and dignity for people with disabilities unattained. Glaring gaps in poor implementation of the act get intensified upon failure to appoint the State Commissioner for PwDs, non-creation of the State Fund for PwD, non-constitution of Special Courts & non-appointment of Special Public Prosecutors for speedy trials, and not having assessment boards for disability certificates. Notwithstanding the SC's series of orders prior to the case *Seema Girija Lal vs. Union of India* , it enforced deadlines for the Ministry to coordinate with state governments for implementation of crucial operational aspects. This prompts an important aspect to ponder upon two policy questions: *Why have states failed to implement and comply with the provisions of the RPWD Act despite consistent court orders? And what are the issues in the oversight mechanism considering that implementation is entirely within state jurisdiction?*

In the above context, the proposed study critically analyses the RPWD Act and makes a policy assessment by using a cross-sectional qualitative research approach. The purpose of this study is to make a case for issues engraved in failure to embrace disability policy to the tenets of equitable society. The policy prescriptions in the paper include the initiatives required in four vital domains: social, health, financial, and digital, that are required in terms of empowerment, service delivery, and operational execution.

Towards Disability-inclusive Policy: What Can Feminist Disability Studies Offer Martha Nussbaum’s Capabilities Approach?

Molly Saunders (Australian National University)

This paper explores the value of using Martha Nussbaum’s capabilities approach (CA) in designing and implementing disability-inclusive policies. It outlines existing critiques of the framework and considers how feminist disability studies (FDS) may strengthen the approach. The paper draws on my doctoral research involving 24 qualitative interviews with women with disability about their experiences within Australia’s National Disability Insurance Scheme (NDIS).

I begin the paper by outlining Nussbaum’s CA, noting that it comprises ten 'central capabilities' within which individuals must have access to a threshold level of opportunity to lead ‘dignified’ lives. This framework can guide policymakers on what ideals of justice public policy should support. It has been critiqued, however, for failing to consider power (due to its use as an evaluative framework which can be adopted within diverse scholarly traditions) and for privileging individual choice. These issues mean the CA may: overlook how systems of power shape people’s decisions; and; unjustly hold individuals responsible for non-conforming behaviour. This presents issues for people with disability who are often subject to oppressive systems of power that may distort their choices and aspirations.

I argue that integrating FDS into the CA has significant theoretical ramifications which help address these critiques. FDS brings together critical disability studies with feminist theory to address the complex interplay of disability and gender as distinct, yet inextricable, systems of power which shape bodily practices. Integrating FDS with the CA thus allows policymakers to consider how systems of power influence people’s aspirations and choices within distinct policy contexts. In turn, this supports policymakers to resist responsibilising non-standardised individuals.

Having employed this novel approach within my doctoral research, I explore its potential for developing disability-inclusive policies. I show how, within my qualitative interviews, it helped capture the breadth of the women's experiences of, and aspirations for, the NDIS. However, I also explore where the women’s views on what constitutes a good life differed from Nussbaum’s ideals of justice, and where the women’s perspectives showed how broader theoretical concepts within the CA required re-thinking. Drawing on the women’s interviews and FDS, however, it was possible to revise Nussbaum’s theory to ensure it resonated with the women’s own experiences. Using this revised framework, I was then able to reflect on how the NDIS was failing to support women with disability’s own ideals of ‘a good life’.

These findings show how, when contextually informed, Nussbaum’s CA can do important normative work in foregrounding people with disability’s perspectives within public policy discussions. This is valuable because paying closer attention to people with disability’s views will help policy-practitioners uncover how policies may neglect the experiences and priorities of people with disability. Moreover, when combined with feminist disability scholarship, the approach can do this whilst attending to multiple exclusionary systems of power, like gender and disability. Used in this way, Nussbaum’s CA thus offers a valuable framework for designing and implementing disability-inclusive policy in environments where people have diverse experiences of disability: environments such as those that span the Asia Pacific region.

T14P05 / Disability Inclusive Policy Development in the Asia Pacific Region

Chair : Jennifer Smith-Merry (University of Sydney)

Second Chair : Helen Dickinson (University of New South Wales)

Session 2Australian Disability Policy in an International Context

Driving inequality? Understanding the role of parental administrative capital in the operation of child disability support in Australia

Martin O'Flaherty (University of Queensland)

Jennifer Smith-Merry (University of Sydney)

Disability policy has undergone major shifts in Australia over the past decade, including most notably the advent of the landmark National Disability Insurance Scheme (NDIS). A key principle of the NDIS is to offer people with disabilities and their families choice and control over the services and supports which they receive. The primary mechanism intended to give effect to this principle is the provision of personalised budgets ('plans') that NDIS participants may employ to purchase relevant services through a system of quasi-markets. In this way, the NDIS represents an important exemplar of the international trend towards the personalisation of disability- and aged-care.

A common concern with personalised care systems is the emphasis that they place on people with disabilities and their families to undertake advocacy, navigate complex medical and bureaucratic systems, and manage multiple service providers. Indeed, critics of the NDIS suggest that this aspect of the scheme contributes to unequal outcomes as those with the skills, understanding, and resources to effectively advocate and navigate complex systems are able to obtain better support. Many qualitative studies have supported this perspective, recounting the considerable challenges faced by people with disabilities in accessing support and services.

The current study contributes to this literature by analysing a new survey of parents (N = 688) of children with disabilities aged 2-17. We propose a new measure of parents' capability to undertake advocacy, navigate systems, and effectively support their children - which we label 'administrative capital'. After preliminary investigations of the psychometric properties of the measure, we study 1) disparities in administrative capital by family background (socio-economic status, cultural background, urban/regional residence, family structure, and the presence of adult household members with disabilities), and 2) the association of parental administrative capital with disability support outcomes (child's unmet support needs, whether child has an NDIS plan, parent satisfaction with the NDIS). Our findings show inequalities in administrative capital by family socio-economic status (with families with higher income and education reporting better administrative capital) and the presence of adults with disabilities in the household. With regard to disability support outcomes, we find that administrative capital is positively associated with the child having an NDIS plan and parent satisfaction with the NDIS, and negatively associated with the child's unmet support needs. These findings suggest that administrative capital plays an important role in shaping outcomes within a system of personalised disability support, and that unequal access to administrative capital may contribute to socioeconomic- and adult disability-related inequalities in children with disabilities' access to appropriate and effective support.

The National Disability Insurance Scheme Review: the potential impact of metrocentric disability policy on rural implementation

Claire Quilliam (University of Melbourne)

Luke Wakely (University of Newcastle)

Jo Spong (La Trobe University)

Natalie Ellis (Charles Sturt University)

Project
In Australia, more than a quarter of the population resides in regional, rural, and remote communities(1).

These communities are disparate, unique, and are set among diverse geographies. People with disability in these communities experience inequitable access to services and poorer health compared to their metropolitan counterparts(2).

The National Disability Insurance Scheme, the landmark national disability policy implemented in Australia over a decade ago, has failed to address this inequity(3). This is problematic because the Australian Government is required to provide services to people with disability, no matter their location, to meet the United Nations Convention on the Rights of Persons with Disabilities signatory obligations(4). The Independent Review into the National Disability Insurance Scheme(5), known as the NDIS Review, identified NDIS implementation shortcomings and recommendations to improve the Scheme's processes and outcomes for people with disability.

This project drew on the knowledge and experiences of rural people with disability, their carers and rural academics, to explore how the circumstances of disability policymaking may impact the effectiveness of its implementation in regional, rural, and remote Australian communities.

Research questions

1. To what extent did the National Disability Insurance Scheme Review consider regional, rural, and remote contexts?

2. What are the potential impacts of the extent of consideration of regional, rural, remote contexts in the National Disability Insurance Scheme Review on disability policy implementation in regional, rural, and remote contexts and meeting UNCRPD goals?

3. How can rural people with disability be better included in policy implementation?

Methodology

We examined the NDIS Review(5) document, drawing on Nordberg's(6) distributed rural proofing policy concepts: 1) spatial justice and 2) social innovation. Through discussion and critical reflection, we identified potential impacts of poor consideration of regional, rural, and remote settings on Australian disability policy implementation in these contexts and required structural changes for including rural people with disability in policy design and implementation.

Panel's research questions

Our paper addresses questions 2 and 4 of Panel T14P05/Disability Inclusive Policy Development in the Asia Pacific Region. It identifies changes to support inclusion of rural people with disability in policy implementation (Q2) and illustrates how poor consideration of rural contexts in Australian disability policy creates barriers to UNCRPD goal implementation (Q4).

References

1 Australian Institute of Health and Welfare. Rural and remote health Australian Government; 2024. Available from: https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health.

2 Australian Institute of Health and Welfare. People with disability in Australia Australian Government; 2024. Available from: https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary#Health.

3 Smith-Merry J. The NDIS at ten years: designing an equitable scheme for the next decade. Medical Journal of Australia 2024;220:55-.

4 United Nations. Convention on the rights of persons with disabilities and optional protocol: United Nations; 2007. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. [cited 28 November 2024]

5 Commonwealth of Australia. Working together to deliver the NDIS: Independent review into the National Disability Insurance Scheme: Final report. Commonwealth of Australia, Department of the Prime Minister and Cabinet; 2023. Available from: https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis. [cited 16 June 2023]

6 Nordberg K. Distributed rural proofing–An essential tool for the future of rural development? Sociol Ruralis 2021;61(1):141-62.

Partners in Recovery: Learnings from a National Care Coordination Program for People with Psychosocial Disability

Joel Hollier (University of Sydney)

Jennifer Smith-Merry (University of Sydney)

For people with severe and persistent mental illness (SPMI), the Australian mental health system has long been characterised by fragmentation and disconnection between available services and supports. Partners in Recovery (PIR) was an Australian Commonwealth Government-funded program designed to support 35,000 people with complex needs nationwide, who experienced severe and persistent mental illness.

The PIR program was designed to foster collaborative, integrated care, providing participants with support facilitators (SFs) who could coordinate care, and partner with them on the journey to recovery. In line with global mental health system trends, the program emphasised a person-centred focus with an emphasis on integrated care.

With the rolling out of the National Disability Insurance Scheme (NDIS) from 2013, the PIR program was gradually wound up and folded by 2019 and replaced with supports within the NDIS designed to meet the needs of this population, now framed as having ‘psychosocial disability’. There has been significant concern that the structure of the NDIS does not serve this population well and that a program such as PIR is a preferable model. However, the shared elements of this model that made it successful in meeting the needs of people with psychosocial disability have not been articulated.

Built into the funding model of PIR, was an evaluative component, which resulted in a wide range of program evaluations being carried out prior to the program’s closure. This presentation draws together these evaluations, exploring factors that contributed to the program’s strengths and weaknesses along with implementation barriers and enablers.

Drawing from 30 peer reviewed studies, identified through a range of search strategies, we utilised Arksey and O’Malley’s scoping review framework to collaboratively develop a synthesis of themes and research findings.

We found that as a cornerstone of care for people with SPMI, support coordination required effective collaboration; strong communication; individualised, flexible, and recovery-oriented support; and a well-equipped workforce. The support facilitator role was an essential element of the model, as was the organisational environment around them.

Currently, Australian Governments are seeking to clarify and agree upon a system of “foundational supports” that can offer a stepped level of care across the broader population. It is apparent that PIR, as an internationally unique program, can offer vital insights into implementation and utility of care coordination practice for people with severe mental illness and inform the development of these foundational supports.

We are part of development; the implementation of disability policies in Ghana and Australia.

Hilda Agyekum (Australian National University)

There has been increased investment in the design and implementation of disability policy since the United Nations Convention on the Rights of People with Disability (CRPD) was passed in 2006. However, people with disability across the world still struggle to access the same opportunities as others in society.
This presentation is a part of my PhD thesis, which investigates why the implementation of disability policies remains consistently poor worldwide, despite the significant investments at both the national and international levels. This thesis draws on literature from critical implementation and critical disability studies to explore the complexities of implementing national disability policies in local settings, using Ghana and Australia as case sites. The thesis focuses on how implementing these policies impacts the development of people with disability. I therefore focus on implementation in the education, employment, accessible spaces and transportation sectors.
I will begin the presentation by giving an overview of the CRPD and its influence on national policies within the local context. I will describe the policy environment under which I will explore my thesis question: Why are nations finding it difficult to translate the CRPD, which is considered a universal set of norms and guidelines? I will then outline the methodology I use for this project and conclude with some findings from the fieldwork conducted in Ghana.
My initial findings highlight the impacts of contextual factors, such as culture, power dynamics and stakeholder consultation, and resource constraints on implementation levels. The findings show that the design and implementation of disability policies have improved since policymakers started involving people with disability in the process. This implies that to enhance the impacts of policies, not just disability policies on people with disability, it is essential to mainstream disability across the country. By doing so, people with disability will be better able to contribute to how the country's development sectors can more effectively address their needs.
People with disability and their organisations in the study noted that though they are consulted on policy matters, their views lack the same power and consideration as other stakeholders. They also advocated for

wider consultations that include the different associations for people with disability. The findings also revealed differing views on development for people with disability. While implementers focused on economic growth, people with disability and their organisations focused on the expansion of accessibility to spaces and services. These insights will direct researchers, policymakers and disability organisations in identifying the challenges of implementation and how to tailor implementation to align with the idea of development for people with disability in Ghana.