



Intellectual Disabilities in Southeast Asia

Libby Cohen
Duke-NUS Graduate Medical School
Singapore



Purposes

Southeast Asia



Search Process

Search databases (limited to published research studies in English)

Examine references at end of articles

IASSID Contacts, identification of additional contacts, mass email to contacts, snowball contacts

Contacts with universities and research centers in the region

Contacts with non-governmental organizations (NGOs), World-wide organizations, Country-level policies

Studies Related to ID in SE Asia

Country	Number of Studies
Brunei	0
Cambodia	29
Indonesia	3
Laos	1
Malaysia	10
Myanmar	0
Singapore	13
Thailand	68
Vietnam	10

Disability-related Research Activities Across Levels

- World Bank/WHO Report
- Association of Southeast Asian Nations (ASEAN)
- World Bank
- Asian Development Bank
- Global Partnership for Disability and Development (GPDD)
 - <http://gpdd-online.org>
- Inclusive poverty reduction strategies
- Millennium Development Goals
- United Nations Convention on the Rights of Persons with Disabilities
- NGOs
- WHO
- UNICEF
- IASSID & other world-wide disability organizations

- Local levels
- (on ground)

- Universities
- Research Centres

- Country-level activities

Complexities

- Other reasons for lack of research:
 - the absence of a strong commitment to inclusion by the Central and State governments
 - lack of enforcement of equal rights for persons with disabilities
 - systematic exclusion, remnants of the Caste system
 - negative attitudes toward persons with disabilities
 - historical disadvantages
 - lack of employment opportunities
 - inadequate planning,
 - slow implementation of appropriate education and services
 - extreme shortages of trained personnel
 - cultural norms (Kalyanpur, 2008; Cuskelly, 2009).
- Country by country, region, village by village strategies

Thematic Analysis

- Most published research studies have been “ad hoc”
 - Researcher-led, personal interest
 - NGO-related
 - Dependent on individuals, funders’ interests
 - Local, villages
- Early intervention, children, families
- Access to services; policy and legislation
- Inclusive education
- Elderly,
- Poverty and economic instability
- Rehabilitation
- Labour market
- Culture, beliefs
- Policy documents
 - World Bank, WHO, UN Convention on the Rights of Individuals with Disabilities, Millenium Development Goals
- Absence of documents and policies
 - Country-wide
 - Universities
 - Research centers

At the Ground Level



Patterns of Research and Policy Activities in ID in SE Asia



Disability and Poverty in Southeast Asia

- For the most part, persons with intellectual disabilities (ID), their families, services, communities, policies, etc. have not been systematically studied in SE Asia.
- Kowk & Chui (2008) surveyed countries and territories in Southeast Asia.
- Many people with disabilities are also desperately poor (Groce, Kett, Lang, & Trani, 2011) and there is an inextricable link between poverty and disability.
- Individuals with disabilities and their families are more likely to live in poverty than persons without disabilities (<http://www.un.org/disabilities/documents/events/csocd49panel.pdf>).

Disability and Poverty

- Deprivation and abuse add to any other disabilities that are present as well as directly causing intellectual disability in their own right (Clarke & Clarke, 2000).
- The coupling of disability and poverty results in enormous vulnerabilities, inequities, and injustices.

Research-Policy-Practice Gap

- IASSID Academy articles (Hassiotis, Brown, Brown, Favila, McConkey, Jokinen, & Lucchino, 2011) have highlighted a gap among policymakers, practitioners and researchers which has resulted from the lack of sharing of research findings and insights as they emerge
- Contributes to a continuing cycle which deepens the research-practice-policy gap
- Some researchers may conduct research in areas that may not be relevant to practitioners
- Practitioners may not readily apply research findings that are produced
- Policies that are put in place by governmental and other organizations may not be based on solid research inputs and emerging insights from practice

Research-Policy-Practice Gap

- Changes and practices and policies are influenced infrequently as a result of research studies because there is a lack of alignment among research, practice and policy cultures
- Although individuals in these cultures may share similar goals, the cultures are distinct, creating gaps in understandings and cooperation (Emerson, Hatton, Thompson, & Parmenter, 2004; Lewig, Arney, and Scott (2006)).

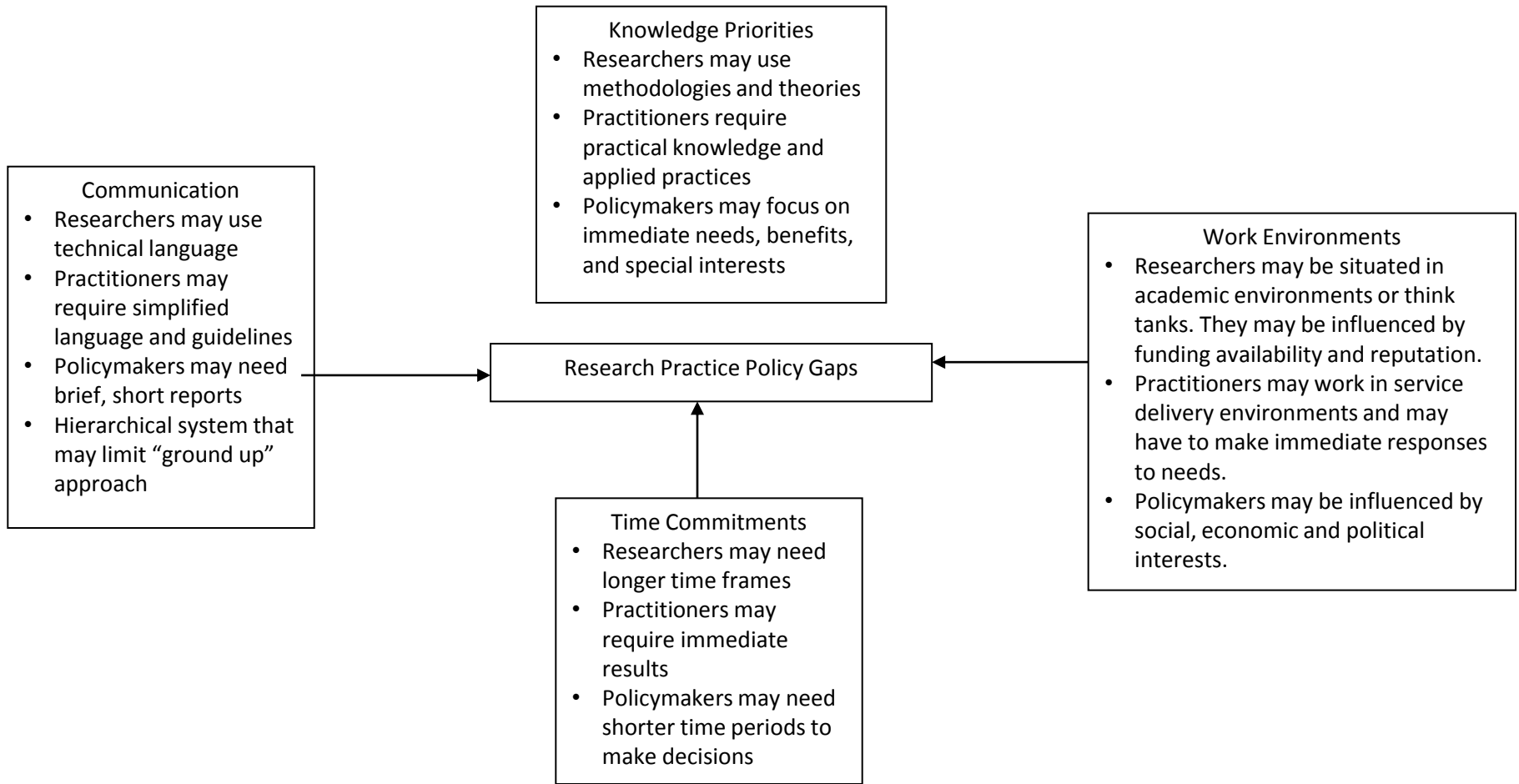


Figure 1. Gaps Among the Research Practice Policy Cultures (adapted from Lewig, Arney, & Scott, 2006).

Journal of Policy and Practice in
Intellectual Disabilities (JPPID)
Call for Submissions

WORLD REPORT ON DISABILITY



World Health
Organization



THE WORLD BANK

http://www.who.int/disabilities/world_report/2011/en

Journal of Policy and Practice in Intellectual Disabilities (JPPID) Call for Submissions

- Special issue of JPPID
 - focus on the progress and challenges regarding recommendations of the *World Report on Disability* with respect to persons with intellectual disabilities in lower and middle income regions, countries, and political entities.
- Questions
 - What progress has been made?
 - What are the barriers? What policies and legal frameworks have been or should be developed? In what ways have persons with intellectual disabilities been involved in responses to the *World Report on Disability*?

Journal of Policy and Practice in Intellectual Disabilities (JPPID) Call for Submissions (con'd)

- Policies
- Legal and political frameworks
- Research analyses
- Future directions
- Innovative practices and strategies
- Unique collaborations and partnerships among public, governmental organizations, and local initiatives
- Targeted social and economic development
- Educational participation and progress
- Inclusive employment environments
- Families and supports
- Conflict, disaster and disability
- Gender, ethnic, social, and/or cultural considerations

Journal of Policy and Practice in Intellectual Disabilities (JPPID) Call for Submissions (con'd)

- The following are the deadlines for submission:
- August 31, 2012 Submit a letter of intent to:
specialissuejppid@gmail.com
- October 31, 2012 Submit working draft to editors:
specialissuejppid@gmail.com
- December 3, 2012 Deadline for manuscript submission to Scholar One:
<http://mc.manuscriptcentral.com/jppid>

Journal of Policy and Practice in Intellectual Disabilities (JPPID) Call for Submissions

- For inquiries and suggestions, please contact one of the guest editors:
- Roy I. Brown, University of Victoria, Canada
(royibrown@shaw.ca)
- Libby Cohen, James Cook University, Singapore
(lcohen71@gmail.com)
- Keith McVilly, Deakin University, Australia
(keith.mcvilly@deakin.edu.au)

References

- Clarke, A.M. and Clarke, A.D.B. (2000). *Early Experience and the Life Path*. London: Jessica Kingsley Publishers.
- Cuskelly, M. (2009) Challenging the myths and redressing the miss-steps in family research. *Journal of Policy and Practice in Intellectual Disabilities*, 6(2), 86-88.
- Dalton, A., and McVilly, K. (2004). Ethics guidelines for international multi-centre research involving people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disability*, 1(2), 57-70. <https://www.iassid.org/pdf/ethics-guidelines.pdf>
- Emerson E., Hatton C., Thompson T. & Parmenter T. (2004) *The International Handbook of Applied Research in Intellectual Disability*. Chichester: Wiley.
- Ghosh, S., & Magana, S. (2009). A rich mosaic: Emerging research on Asian families of persons with intellectual and developmental disabilities. *International Review of Research in Mental Retardation*, 37, 179-212. doi: 10-1016/S0074-7750(09)37006-8
- Groce, N., Kett, M., Lang, R., & Trani, J.-F. (2011). Disability and poverty: the need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly*, 22, 1493-1513.
- Hassiotis, A., Brown, I., Brown, R., Favila, G., McConkey, R., Jokinen, N., & Lucchino, R. (2011). The IASSID academy on education, teaching and research and the links with low- and middle-income countries: An international partnership. *Journal of Policy and Practice in Intellectual Disabilities*, 8, 134-138.

- Kalyanpur, M. (2008). The paradox of majority underrepresentation in special education in India: Constructions of difference in a developing country. *Journal of Special Education, 42*, 55-64.
- Kwok, H. W. M., & Chui, E. M. C. (2008). A survey on mental health care for adults with intellectual disabilities in Asia. *Journal of Intellectual Disabilities Research, 52*, 996-1002. doi: 10.1111/j.1365-2788.2008.01054x
- Lewing, K., Arney, F., & Scott, D. (2006). Ideas for child and family services. *Family Matters, 74*, 12-19.
- Mahtaney, P. (2010). *India, China, and Globalization*. Singapore: Institute for Southeast Asian Studies.
- Pronylk, P. , et al. (2012). The effect of an integrated multisector model for achieving the Millennium Development Goals and improving child survival in rural sub-Saharan Africa: a non-randomised controlled assessment. *The Lancet, Early Online Publication*, 8 May 2012
- doi:10.1016/S0140-6736(12)60207-4
- United Nations. *Convention on the Rights of Persons with Disabilities*. Retrieved from <http://www.un.org/disabilities> on 20 October 2011.
- United Nations. (2010). *Disability and the millennium Development Goals: A Review of the MDG Process and Strategies for Inclusion of Disability Issues in Millennium Development Goal Efforts*. Retrieved from http://www.un.org/disabilities/documents/mdgs_review_2010_technicalpaper_advance_text.pdf on 20 October 2011.
- United Nations. (10 February 2011). *Mainstreaming Disability in Development for Poverty Eradication*. Retrieved from <http://www.un.org/disabilities/documents/events/csocd49panel.pdf> 20 October 2011.

- United Nations. *Convention on the Rights of Persons with Disabilities*. Retrieved from <http://www.un.org/disabilities> on 20 October 2011.
- United Nations. (2010). *Disability and the millennium Development Goals: A Review of the MDG Process and Strategies for Inclusion of Disability Issues in Millennium Development Goal Efforts*. Retrieved from http://www.un.org/disabilities/documents/mdgs_review_2010_technical_paper_advance_text.pdf on 20 October 2011.
- United Nations. (10 February 2011). *Mainstreaming Disability in Development for Poverty Eradication*. Retrieved from <http://www.un.org/disabilities/documents/events/csocd49panel.pdf> 20 October 2011.



Icohen71@gmail.com

Thank you!