Diversity in Disability Studies: A Malaysian Perspective

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Malaysia: A country of diversity

- People from different ethnicity, cultures, and religions.
- Located in Southeast Asia, comprises 2 regions, Peninsula Malaysia and Sabah and Sarawak located in the Borneo Island.
- Population of 28.25 million people (www.statistics.gov.my) - Malays, Chinese, Indian, the indigenous groups Iban, Bidayuh & some 26 other groups in Sarawak, the Kadazan-Dusuns & Bajaus and many other smaller groups in Sabah.
- In Peninsula Malaysia, indigenous groups in smaller number collectively referred to as *Orang Asli*.

Rural-Urban Divide, Different stages of 'development'

Twin tower – capital city Kuala Lumpur

Remote region in the interior of Sarawak where health care comes in the form of flying doctor services

VS

Diversity in experiences of disability

- Disabilities conceptualized and understood differently among cultural groups.

- What does this mean for disability studies in Malaysia?

- Is the official definition of disability stated in government policy and as stipulated in the Persons with Disabilities Act (2008) adequate in capturing the varied experiences of people with disabilities?

- Can or to what extent the theories of disability studies in the North inform disability studies in a culturally diverse context in Malaysia?

Exploring Disability

- Explore various concepts of disability in Malaysia

- Case studies and narratives of experiences of care, education and employment

- Lessons learned from the recent collaborative research project between Manchester Metropolitan University, UK and Universiti Malaysia Sarawak (**http://www.rihsc.mmu.ac.uk/malaysiaukdisability**)

Towards Culturally Sensitive Disability Studies: MMU, UK/ UNIMAS, Malaysia (funded by PMI 2)

- develop understandings of the barriers facing disabled people in the UK and in Malaysia;
- explore different national perspectives on disability and to see how they can be applied in the other's country;
- develop our international perspectives through the sharing of theory, research findings, practice and policy in relation to the promotion of disabled people in mainstream society
- Researchers from Sarawak and Manchester : to cast our gaze on the other's culture as well as learn from each other

'Global' Models of Disabilities used in Malaysia

Charity model

- prevalent approach in many quarters

Medical model

- Disabilities to be categorised, classified, certified by medical personnel

Social Model

- (Disabled People's Organisations, Disability Rights movement since 1970s – Physically disabled; visually Impaired – more recently United Voice-Self Advocacy for people with learning disabilities

2 other models…

1. International Classification of Functioning, Disability and Health (ICF) - WHO.

- Conceptually, ICF is presented as an integration of the medical and the social models (WHO, 2001). This model starts with a health condition that gives rise to impairments, and then activity limitations and participation restrictions.

➢ learning and applying knowledge, mobility, self-care, education, remunerative employment, and economic self-sufficiency.

2. Amatyr Sen's capability approach

- Disability is understood as a deprivation of capabilities where capabilities refer to practical opportunities.

- Disability occurs when an individual with an impairment is deprived of practical opportunities and results from the interaction between the resources available to the person, personal characteristics (e.g., type of impairment, age, gender) and the environment which encompass physical, social, cultural, political, economic environment (Kuno, 2010).

Disabilities in Malaysia

- Following global trend of changing the term of

- Handicapped (*cacat*) (80s)

- → Disabled Persons/Persons with Disability (persons come first) (*Orang Kurang Upaya*)(90s)

- → recently Persons with Different Abilities (*Orang Kelainan Upaya*).

Legal and official definitions

- **Persons with Disabilities Act 2008, Malaysia**

  "…disability is an evolving concept…."(Preamble)

  The preamble of the Convention of the Rights of People with Disabilities 2006(CRPD)

- **'Persons with disabilities' include those who have long term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinders their full and effective participation in society**

Social Welfare Department:
New categories of PwDs

Passed in Parliament on 27 May 2009; Enforce on January 2010

- 1. Visually Impaired
- 2. Hearing Impaired
- 3. Physically Disabled
- 4. Learning Disabilities
- 5. Speech Impairment
- 6. Mental Disabilities
- 7. Multiple Disabilities

Meanings of Disabilities

Cultural meanings of impairment

- 'cacat' (in Malay / Iban)

- chan chiek'残疾人in Chinese

- implied diseased 'spoilt/broken and lacking' in Chinese

The meanings of disability varied and diverse

' This child is a God's gift' (Malay families)

'Could this be bad feng shui ?'

'May be something I did wrong in my past lives (Chinese families) (Ling, 2007)

This person is handicapped because her parents had broken certain taboo when her mother is pregnant with her. It is a curse!

(Iban villagers/Terence Mamba, 2010)

'This is God's testing for me' (both Muslim and Christian/Chan, 2011)

However, much heterogeneity ;different religions, rural urban backgrounds within and across different groups; Need to be careful about generalisation

Positive stories

- Someone having an impairment, but accepted by the community, having a social role no different from the non-disabled.

- Some in rural setting – able to do small farm work

- A man who has never been to school, cant count, like money but don't know the value of it, but able to speak 3 languages!

- Persons with impairments holding good jobs, in high positions, well integrated in the community

- Married, having own families

Other stories:

- Disabled children hidden away because of shame and stigma attached.

- The disabled persons confined in their own home because of inaccessibility to the outside world (school, education, work, social-economic participation, built environment)

- 'stories' of people who are being tied to their bed because of being 'uncontrollable', 'anti-social behaviour' who are never seen by people outside the family.

WHAT ARE THE ISSUES AND CHALLENGES FOR DISABILITY STUDIES IN MALAYSIA ?

The Relative Invisibility of Disabled persons

UNIMAS/MMU project:

Difficulties in locating Disabled persons in rural Sarawak; PwDs less visible in town

- In UK: disabled persons seen out in public places much more

- No. of disabled persons registered with Social Welfare Dept : 283,204 (Dec 2009) – 1 % of population

- According to WHO estimate, greater proportion of disabled people are found in developing countries than in developed countries; estimate 10 % of population

DPs unseen? Hidden? Reluctance to report?

'Parents reluctant to register their children with disabilities' (Social Welfare Offciers)

Questions :

➢ Are they in the know of services available?

➢ What are the incentives for them to register?

➢ Can they be sure that benefit will be provided?

➢ *Do they have access?*

Government promote early detection and correct labeling of categories of disabilities. However, waiting for a medical doctor to certify especially in a rural area can take months or even years...

'We have registered my child with the Social Welfare Department...we waited months after months, nothing come about...'

(3 single mothers in a rural town/Lucy Sebli, 2010)

Adopting the medical model become disabling, at the expenses of providing the needed services and assistance

A more provocative question

Or Is it possible that certain impairment may not be considered a disability in Sarawak ?

Disabilities in one context such as UK may not be disabilities in Sarawak.

An even disabilities in an urban setting may not a disability in a rural village, and vice versa.

Example, someone who may have a learning disabilities and is engaged in farm work in a rural setting will not be able to hold down a job if in a urban setting

However, cash economy gives rise to new form of disability

Some 'experiences' from UK

"In our day, we have remedial class, we don't have anything. I only found out about my disabilities when I was 49 or 50"

"I am a dyslexic and I work as a project manager here. I discovered that I have dyslexia only when I was in my 40's. I went back to education when I am an adult."

"I didn't walk till I am five. I didn't see anything wrong. But when I went shopping with mum, someone asked what's wrong with her?? It was then only I asked "what's wrong with me?"

- Disability is socially constructed

Stigmatisation and Isolation

Mothers as caregivers experience isolation

' I avoid seeing my friends when they are pregnant'

(Chinese Mother of a 10 year old Down's Syndrown child/Chaitaka, 2009)

'In my community, when there is someone pregnant, I will not dare go near her…I will try to avoid her…'

(Mother with a DS child from a rural Iban community/Chan, 2010)

Gender dimension – women bear the burden of care, and more isolated because of this belief.

Gendered Impact

Some case examples

- A woman in her 50s was denied the opportunity of marriage when she was young because she has a sibling who is deaf; and there was supposedly an arranged marriage but when the man's family got to know about the presence of a deaf sister, the wedding was called off.

- Another woman who did not get to marry the man of her love as the relationship was opposed by the man's parents simply because she has a brother who has severe learning disabilities.

- A 26 year old woman with learning disabilities was found pregnant. Community leader reported to the welfare office. 2 days later the community leader returned and said her problem has been resolved as they have found her a husband, a much older man, 60 over year, who has never married. 'Although he is old and a poor farmer, he can have a wife who could do basic housework and perhaps cooked for him and looked after him in his old age, as well as giving him a child. She, on the other hand, escaped the stigma of an unmarried mother!

- The multiple disabling environment a rural woman from a minority ethnic group has had to endure in her life (Bidayuh woman from a rural region / Imelda Jipos, 2008).

Work and employment

- As in industrial capitalism, work is tied to employment - wage labour and paid work
- In 1989 the government announced that 1% of jobs in the public sector will be reserved for the people with disabilities. In 1990 the private sector was encouraged to do likewise. The Ministry of Human Resources has since helped out in the placement of people with disabilities in suitable jobs. However, in spite of the incentives provided such as double tax deduction for the employment of disabled workers in the private sector, the quota is far from being filled.
- Launching grant; Allowance for disabled worker (below RM 1200 – top up Rm 300/)
- Job Coach
- UK – 'work' may mean losing the benefits

- 'It is important to look behind the meaning of work, support and activism to explore those processes by which disabled people can assess the prospect of employment from an informed, supported and empowered position'.

- How would 'work' be conceptualised as part of a wider enabling vision of society?

  (Goodley, 2005)

Education and School

- Special Schools; Integrated system
- The Department of Special Education established in 1995 looks into the needs of students who are blind, deaf and those with learning disabilities
- However, no special provision for those who are physically handicapped with the mental ability to follow the normal curriculum and those with multiple disabilities, with "profound physical handicap or with severe mental retardation".

Education in UK

UK: debate on inclusive education; or segregation in an inclusive system?

'It was a good impact for me in the mainstream school' (Woman in her 50s)

Diverse Disability Studies (Goodley, 2010)

1. It follows then that we need to develop many ways of knowing and understanding disabilities taking into consideration class, culture and gender as well as rural and urban divides.

2. Social inclusion of people with disabilities within the multiplicity and diversity of socio-economic and cultural contexts in Sarawak and Malaysia.

Final remark

As we, esp. the non-disabled, engage in disability studies, we can take heed from

Maori anthropologist   Linda Tuhiwai Smith (1999) who has criticised the way Maori has been subjected to research in the same way as a scientist looking at an insect under a microscope

Damaging : 'the ones doing the looking are giving themselves the power to define'

Research must engage people with disabilities.

NOTHING ABOUT US, WITHOUT US

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TERIMA KASIH

Thank You