The Effective Implementation of Rights-Based Disability Policy and Practice in Developing Countries

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Presentation Outline

• The international policy environment
  – Statistics
  – Domestic and international policies

• Empirical analysis of disability policy and practice
  – Seven African countries
  – Challenges to policy development and implementation

• Engaging with mainstream debates in development studies and public policy
  – Human rights and international development?
  – Effective user involvement and participation?
  – Utilising public policy analysis in developing a new research agenda
The International disability policy environment I
Statistics

- There are approximately 650 million disabled people than the world, 80% of whom in developing countries
  - Many disabilities could be prevented with timely and appropriate health interventions (public health and basic rehabilitation services)
  - DFID estimates that 50% of disabilities are preventable

- Disability and poverty are a cause and consequence of each other
  - 20% of the world’s poorest are disabled people

- Disabled people constitute one of the most marginalised and socially excluded groups within any society
  - Lack of access to mainstream public services, including health, education and employment
  - 98% of children with disabilities do not complete primary education (UNESCO)
The International disability policy environment II

Domestic Legislation and Policies

- Many Western and low-income countries have progressive human-rights-based legislation.
- Also, in many countries, disability discrimination is explicitly outlawed in their written constitutions.
- Therefore, from a constitutional perspective, disabled people are endowed with the same inherent rights and responsibilities as any other person, premised on the foundational principles of "citizenship".
- Disability discrimination encompasses rights to provision to appropriate health, education, employment, social protection services etc.
- Some attempts having been made to include disabled people in poverty alleviation strategies, (for example, Uganda and Tanzania), but these have met with mixed response.
The International disability policy environment III

International Instruments

- UN Convention of the Rights of Persons with Disabilities, 2008
  - First human rights treaty of the 21st century
  - Culmination of 30 year involvement of UN involvement in disability issues
    - 1981 UN International Year of the Disabled
    - 1983-1992 UN Decade of Disabled Persons
    - 1993 UN Standard Rules on the Equalisation of Opportunities of Persons with Disabilities
  - Negotiated with the full involvement of civil society institutions
  - Does not establish any new human rights
  - For the first time, disabled people have an international legally-binding instrument to hold their respective governments to account
  - To date, 71 sovereign states have ratified the Convention
Implementation modalities for disability policy

- Traditionally provided through specialist institutions
  - Segregation and social isolation
  - Small proportion of disabled people actually benefited from such services – mostly elites based in the capital cities
  - Disabled people are seen as passive recipients of charity/welfare

- 1970s – present
  - Community-based rehabilitation (CBR)
  - Compact between disabled people, their families, local communities, wider civil society institutions

- 2000s onwards
  - Increasing emphasis given to “mainstreaming” service provision within generic public services.
  - Hence, facilitates social inclusion

- DFID “twin track” approach
- ALL approaches have advantages & disadvantages
The international disability movement

- Originally arose during the 1970s after the Vietnam War
- Organisations of disabled people’s organisations (DPOs) are run and managed by disabled people themselves, and are primarily concerned with promoting disability rights
- The ideological foundations of the disability movement is the social model of disability
  - Hence, disability is the result of physical, attitudinal and institutional barriers that result in systemic oppression, discrimination and social exclusion of disabled people.
  - Therefore, disability is a socio-political construct rather than the result of physical and/or intellectual abnormalities of the disabled person.
  - The clarion call of the disability movement is “nothing without us about us”
- The disability movement played an instrumental role in the negotiation of the 2008 UN Convention
- However this, at country level, their democratic credentials are sometimes questionable
The gender dimension

- Disabled women encounter double “discrimination”
  - Social anthropological studies in South India demonstrate that disabled men are more likely to benefit from and receive health services are disabled women (Erb & Harriss-White, 2000).
  - Also, the level of impairment has a greater for disabled women for them to be exempted from undertaking household chores then disabled men

- Disabled Women are often subjected to sexual violence and abuse
  - High level of HIV/AIDS
  - In Africa, there is a myth that having sex with a disabled woman will cure a man from HIV/AIDS

- Women invariably are the principal and often sole care givers for children with disabilities
The disability-poverty nexus

- Disability is both a cause and consequence of poverty
  
  - Hence, if one is disabled
    - Less likelihood of completing primary education
    - Less likelihood of securing long-term and sustainable employment
    - Depleted levels of social capital and relational bonds
    - The majority of developing countries have no hypothecated social protection programmes
  
- Similarly, if a person is poor
  
  - Cannot afford basic healthcare – malnutrition, preventable diseases
  - Live in insanitary and poor housing
  - Lack of access of clean water
  
- The dynamics of the disability-poverty relationship remains ill-defined and under-researched
Disability & International Development: A Conceptual Framework

NGO/DPO & Government Interventions & Activities

POVERTY

- Service Provision
- Capacity building of DPOs
- Advocacy
- Legislation
- UN Convention Enforcement
- Policy Development
- Media

DISABILITY

- Social Exclusion
- Human Rights Violations
- -ve Social Attitudes

Evidence-Based Research

STRUCTURAL FACTORS
Disability Policy Research undertaken by the Leonard Cheshire Disability and Inclusive Development Centre
Disability Policy Research by the Leonard Cheshire Disability and Inclusive Development Centre

- Four DFID-funded in seven African Countries
  - June 2007: Disability Scoping Study in Zimbabwe
  - March 2008: Disability Scoping Study in Nigeria
  - June 2008: Disability Policy Audit in Namibia, Swaziland, Malawi and Mozambique
  - February 2009: Disability Policy Audit in Uganda
- All studies utilised local researchers
Common Research Objectives

• To undertake a review of existing disability policy and practice;
• To assess the extent to which each country's policy and practice were in alignment with the principles of the UN Convention on the Rights of Persons with Disabilities;
• To analyse political and policy-making environments and processes by which social and economic policy is developed within the country, with specific reference to disability issues;
• To assess to what extent disability policy had been mainstreamed in each of the seven designated countries; and
• To provide an assessment of to what extent disabled people's organisations have been effective and been engaged in the policy-making process with regard to disability issues.
Methodology Employed

- Desk-based background literature review
  - Policy documents, existing statistical surveys, ‘grey’ literature reviews, academic studies, web searches etc
- 5-10 day field visit to each country
  - Key informant interviews
    - Senior Civil Servants, Politicians, Officials from NGOs working in the disability sector,
  - Focus Group Discussions with disabled people’s organisations
    - (Not always possible to arrange)
- Stepping stool to inclusion
  - Relative roles played by the state, services, and disabled people’s organisations
- SWOT analysis of the then current policy context
Substantive Findings I

- Political and constitutional status of disabled people
  - Uganda, South Africa, Malawi and Namibia have ratified the UN Convention
  - Nigeria and Swaziland have signed the UN Convention
  - Due to the political situation, Zimbabwe has not either sign or ratified
  - All countries have ratified the other human rights based international conventions

- ALL countries have enshrined disability rights in their respective constitutions and have passed progressive disability discrimination legislation
  - In addition, other legislation, for example in education, explicitly makes reference to disability issues
  - However, these constitutional entitlements are often honoured in the breach
  - In all countries, there is evidence of systemic discrimination and human rights violations continue
Substantive Findings II

• Disability policy and poor governance
  – Invariably, notwithstanding progressive legislation and policies, there is a lack of political will by politicians and senior civil servants
    • Many governments have designated disability desks in the Office of the President/Prime Minister, but lack capacity, resources and influence (for Nigeria and Namibia)
    • Disability is seen as a “specialist” field, that requires significant public expenditure
    • Therefore, this is hard to justify in the light of other competing social and economic development challenges
    • The relationship between the disability movement and policy-makers is often characterised by each not understanding each other’s “world view”
  – There is inadequate modalities for the effective implementation of disability services
    • This is particularly the case at local and district level
    • Negative social attitudes are commonplace in local communities (for example, among school teachers and health workers)
Substantive Findings III

• The lack of robust statistical data vis-a-vis disability including prevalence rates
  – Therefore, public authorities do not have sufficiently accurate data to plan and manage services
  – Also, this results in a “democratic deficit” in as much that civil society institutions, including DPOs do not have benchmarks by which to hold their governments to account for disability rights commitments
  – This process it’s hampered by the fact that there is no universally agreed definition of what constitutes a disability
    • The UN Convention failed to agree a definition of disability
    • It is partially based on cultural factors
Challenges for development interventions

- Disability is essentially about attitudinal change
  - Changing mindsets of policy-makers, donors and the local community
  - Deeply entrenched physical, attitudinal and institutional barriers to effective social inclusion
  - Depleted levels of social capital and relational bonds, especially in conflict-affected countries
  - Many developing countries have inadequate governance infrastructure for effective implementation of services
  - Manifested by little appreciation for the rule of law, a disjuncture between policy formulation and implementation, and scant appreciation of human rights principles
  - Lack of robust statistical data on disability, which creates a “democratic deficit”
Engaging with the Development Studies Literature
The efficacy of a “rights-based approach” to policy-making

- The vast majority of governments would notionally subscribe to the notion of rights-based approaches
  - They have signed a plethora of human rights treaties and conventions, starting with the 1948 Universal Declaration of Human Rights
- Political imperatives
  - Responding to the global economic crisis
  - Both DFID’s White Paper and the Conservative Party’s Green calls for increased user involvement & accountability
  - Increased hegemony of policy networks
  - Osbourne and Gaebler - role of government is to “steer – not row”
  - Policy discourse places increasing emphasis on “stakeholder analysis” and “user involvement”
The efficacy of a “rights-based approach” to policy-making II

• **Rationale for a rights-based approach**
  
  - **Normative** – provide a moral justifications for development interventions. It provides a legal basis by which citizens in developing countries can claim no rights
  
  - **Re-politicising development** – a response to the technocratic approach propagated by the Bretton Woods organisations
  
  - **Juxtaposition with the needs-based approach**
    
    - Need-based approach focuses upon the provision of services to particular groups (charity/welfare)
    
    - Rights-based approach maintains that existing resources should be allocated more equitably and facilitate marginalised and socially excluded groups in challenging human rights violations
  
  - **Pragmatism**
    
    - Means to ensure accountability and transparency by recipient governments for international aid
    
    - Provides a means by which to reflect on the power dynamics that exist within the international aid paradigm.
    
    - “puts a spotlight on the politics of the location of the development agencies” (Cornwall and Nyami-Musembi, 2004: 1419)
The efficacy of a “rights-based approach” to policy-making

• But is human rights discourse effective in shaping the international development agenda?
  – The past 20 years have seen a movement away from defining poverty exclusively in terms of the lack of income, to a more holistic understanding that embraces a multidimensional analysis (Sen, 1990)
  – Rights discourse has provided a moral foundation for advocacy organisations
  – However, Grugel and Piper (2009) argued that there is little evidence to suggest that such debates have had a significant impact
  – Some issues are more amenable to framing human rights agendas than others, with those issues that resonate with general public opinion being the most potent
  – Increasing emphasis on rights may result in individuals and communities seeking legal redress, rather than ensuring that states provide appropriate and dignified services.
The efficacy of a “rights-based approach” to policy-making

“There is no real evidence that ratification of international charters always lead to dramatic changes in state behaviour. Even in cases where some measure of domestic legal reform follows ratification, this rarely heralds the introduction of substantive and redistributive reform. ... In the worst cases states may be able to offer legal reform as a symbolic redress to people suffering poverty and escape far more costly transformations”. (Grugel and Piper, 2009:85)

• Political and legal rights may be easier to promote and implement than the social and economic rights
• This has implications for the UN Convention
The agendas of bilateral and multilateral donors

- Poverty reduction remains the central priority, with human rights having a secondary role
- **BUT** the economic crises will result in:-
  - Donors having to demonstrate greater accountability and transparency for aid expenditure
  - An increasing role playing by the private sector and other civil society institutions in the delivery of services, as well as continuing to play a strategic role regarding advocacy
  - For example, DFID’s 2009 White Paper on International Development requires that a gender analysis for all future programmes must be undertaken, and that disabled people’s organisations “must be taken into account”.

Participation in Development? I

• The international disability movement maintains that disabled people have the inherent right to play a strategic and leading role in the development, management and evaluation of all policy and services that affect their lives — “nothing about us without us”

• But is this Utopian?

• The evidence from the development studies literature would suggest that “participation” is a ill-defined and hotly contested concept
  – Its meaning is ambiguous
  – Is it an end in itself or is it a means to achieve a greater goal?
  – Significant implications for power relations
Participation in Development? II
Contrasting definitions

“Participation is considered a voluntary contribution by the people in that one or another of the public programmes supposed to contribute to national development, but the people are not expected to take part in shaping the programme or by criticising its contents” (Economic Commission for Latin America, 1973).

“Community participation [is] an active process by which beneficiary or client groups influence the direction and execution of a development project with a view to enhancing their well-being in terms of income, personal growth, self-reliance or either values they cherish” (Paul, 1987)
Participation in Development? III

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Participation in Development?

• Critiques of participation (Mohan and Hickey, 2004)
  – Local knowledge is always deemed to be more superior
  – It is invariably the case that “local elites” are those who always participate in consultation processes etc
  – Participatory approaches often have an idealised notion of “the local community”, which does not recognise inherent local discriminatory and exclusionary practices, based on class, caste, religion or gender
  – “participation” has been hijacked and domesticated by donors and NGOs as a technocratic procedure to justify project activities – supports a neo-liberal agenda
  – Hence, the concept has lost its original “radical” transformative nature (Paulo Friere & Marx)
  – There is a tension between empowerment and a transformative agenda to development and the need to ensure that development initiatives are executed in an efficient and effective manner
  – Francis Cleaver argues that “participation” and the an act of faith – “an inherently good thing”
Proposed avenues for further Research
Will the UN Convention result in a paradigm shift in disability policy-making?

  - The advancement of “science” is perceived as a staged process
  - Hegemonic paradigms continue until a crisis fundamentally challenges the fundamental principles and axioms upon which the paradigm is founded
  - The adoption of a new paradigm occurs when new phenomena can be more rigorously interrogated
  - A paradigm is defined as “the entire constellation of beliefs, values and techniques shared by members of a given community”
Will the UN Convention result in a paradigm shift in disability policy-making? II

• The UN Convention is of historic importance because
  – It constitutes the most comprehensive delineation of disability rights
  – The unique manner in which it was negotiated, with sustained input from civil society institutions
  – It is the first legally binding instrument securing disability rights

• However, it is premature to determine whether it will result in a paradigm shift
  – Many countries that have ratified the Convention do not base the development of social and economic policy on rights
  – Inadequate implementation modalities
  – Scant respect for the principles of the rule of law, accountability and transparency
  – The UN Convention is not have an agreed definition of disability
  – The adversarial nature of disability politics

• “Global social policy” is in its infancy
  – Governance issues have yet to be determined
Policy Networks

• Disability studies has to date not really engaged with mainstream political science, to its detriment
• Policy networks would be a fruitful starting point
  – Recognition that there a multiplicity of stakeholders involved in policy making
  – Governments, donor agencies, UN agencies, national and international NGOs, disabled people’s organisations, the private sector
  – Will build on the assumption that disability is essentially a socio-political construct
  – Would identify those structural factors that either enhance or militate against the effective formulation and implementation of global and national disability policy
Advocacy Coalition Frameworks I
Paul Sabatier et al

• Principal tenets of the model
  – Policy-making is spearheaded by the fundamental beliefs held by completing advocacy coalitions, each lobbying policy-makers to adopt and implement their respective policy proposals
  – The policy-making process is comprised of policy subsystems, each of which hold strong beliefs
  – These belief systems are of a hierarchical nature which remain stable over a long period, and the constitute the basis for policy change
  – “policy participants”, comprise of legislators, civil servants, interest groups, academics and the media
  – A crucial distinction is made between “policy networks” and “policy communities”
    • Networks are adversarial, whereas communities are collegial
Advocacy Coalition Frameworks II
Paul Sabatier et al

• Hierarchal belief Systems
  – Deep core beliefs
    • Fundamental norms and beliefs (eg assumptions about human nature, the relative role of the state and the market etc)
  – Policy core beliefs
    • Eg whose welfare counts, the role of the general public in policy making
  – Secondary beliefs
    • Instrumental decisions and information regarding policy area
Advocacy Coalition Frameworks III
Paul Sabatier et al

- Potential for disability policy analysis
  - Historically, disability politics have been fundamentally driven by strong ideological beliefs
  - The introduction of the UN Convention provides an opportunity to test some of the hypotheses of the ACF in a new policy area
  - May shed light on those strategic structural factors and relationships that are of critical importance to disability policy-making
  - Is disability politics populated by “policy networks” or policy communities?