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4 **Disability and development: different models, different places**

5 **Introduction**

6 While people in the rich world are talking about Independent Living and
7 improved services, we are talking about survival (Joshua Malinga, leading
8 Zimbabwean disabled activist, in Stone 1999, 1)

9 Debates about disability within geography, as well as in disability studies more generally,
10 have been largely urban, Anglophone and western-centric. Not only have industrialised
11 societies remained the predominant focus of attention (Power 2001), but the debates
12 themselves are rooted within an often unacknowledged western context. In addition, it is
13 only relatively recently that the issue of disability has emerged within the development
14 literature. This is perhaps surprising given the impact that human development
15 approaches – which place emphasis on human beings as ends rather than means and on
16 broader notions of social well-being and justice than development as material prosperity
17 – have had on studies of development. Indeed, some commentators suggest that while
18 there ought to be clear links between human development and disability issues, the latter
19 have been relatively neglected in comparison with issues such as gender justice and
20 sustainability (Harriss-Whyte 1996; Baylies 2002). Attitudes towards disability in
21 developing countries have undoubtedly played a part in this lack of visibility, since there

22 is still the notion in some places (Latin American countries are prime examples) that
23 issues regarding disability are a private or at least a family matter (Gatjens 2004).¹

24 The relative neglect of disability within studies of development is even more
25 surprising given its prevalence in developing countries and its mutually constitutive
26 relationship with poverty. According to the United Nations, three quarters the world's
27 disabled people live in developing countries (Helander 1992). Impairment and, in turn,
28 disability are both causes and consequence of poverty; disabled people in developing
29 countries are often among the poorest of the poor and measures to tackle poverty are
30 unlikely to be successful unless the rights and needs of disabled people are taken into
31 account (DfID 2000). While it might be assumed that achieving international
32 development targets for social, economic and human development will reduce prevalence
33 in many poor countries, it is only recently that development agencies and government
34 departments (e.g. the UK's Department for International Development) have recognised
35 that specific steps are required to prevent disability, and to ensure that disabled people are
36 able to participate fully in the development process and claim their rights as full and
37 equal members of society.

38 In the light of this, the aims of this paper are two-fold. Firstly, the paper aims to
39 bring together debates about disability and development and to trace some of the most
40 salient issues concerning disability in developing countries. Secondly, it aims to further
41 debates about the significance of geography in disability studies, to highlight some of the
42 problems with the western-centric focus of disability models and to extend understanding
43 of the shifting and complex landscapes of disability in developing countries. The paper

¹ Indeed research in Britain has shown that such attitudes amongst members of some minority ethnic groups mean that they do not take up services aimed at disabled people to the same extent as white British people (Priestley 1995).

44 begins by recapitulating some of the difficulties involved in defining disability, especially
45 cross-culturally, and examines some of the major criticisms within development
46 literatures about western-centric definitions. It then examines various approaches to
47 disability in the context of developing countries, drawing on literatures that have explored
48 and critiqued issues of prevention, social models of disability, the significance of
49 government policy and rights-based approaches in developing countries and debates
50 about community rehabilitation. The paper points to a series of challenges that remain in,
51 and lessons that might be learnt from, developing countries and concludes by reiterating
52 the significance of geography to the creation of more appropriate policies and practice
53 with regard to disability issues in developing countries.

54

55 **The problem of defining disability**

56 It is axiomatic that defining disability is fraught with problems, which are compounded in
57 cross-cultural analyses of disability issues. As Whyte and Ingstad (1995, 5) argue, “any
58 attempt to universalize the category ‘disabled’ runs into conceptual problems of the most
59 fundamental sort”. Not only does the category refer to a broad range of physical, mental
60 and sensory impairments, some more manifest than others, but disability is also a socio-
61 cultural construction. Clearly, disability does not mean the same thing across cultures and
62 over time. For example, it has been widely acknowledged that the place of disabled
63 people in industrialised societies has changed as social, cultural, economic and political
64 environments have developed (Oliver 1990, Barnes 1991, Gleeson 1999). However,
65 definitions of disability are required to shape policy and there is a general tension
66 between the need, on the one hand, for internationally shared meanings that enable cross-

67 cultural information exchange and, on the other hand, the need to recognise cultural
68 differences (Stone 1999, 2). In the recent context of development, disability has been
69 defined as “Long-term impairment leading to social and economic disadvantages, denial
70 of rights, and limited opportunities to play an equal part in the life of the community”
71 (DfID 2000, 2). This definition counters the reduction of disability to medically-defined
72 impairment by recognising the social dimensions of disability, a topic to which we return
73 to subsequently.

74 As Power (2001) argues, what partly defines disability in developing countries is
75 the ‘voicelessness’ and institutional neglect of disabled people who are often forced to
76 take positions on the peripheries of their societies. This is both a product of prevailing
77 attitudes within these societies but can also be attributed to ways in which disability was
78 institutionalised under colonialism. In many pre-colonial societies, disabled people were
79 pragmatically accommodated by what they were able to contribute to the life and welfare
80 of communities. In pre-colonial southern Africa, for example, disabled children
81 participated to varying degrees in community life by carrying water, herding cattle or
82 assisting with domestic chores (Kisanji, 1995). Family and kinship ties, competence in
83 doing tasks considered useful for the household and the ability to behave in a socially
84 acceptable manner determined the status and inclusion of a person within a community
85 (Ingstad, 1999; Kabzems and Chimedza, 2002). Obviously, the degree and type of
86 impairment determined levels of inclusion and this is not to say that marginalisation and
87 persecution did not take place, but the treatment of disabled people was often very
88 different in pre-colonial and colonial contexts.

89 Under colonialism, humanitarian models were imposed, with disabled children
90 attending special schools run by a church or charitable NGOs. The charitable link
91 provided communities with personnel, funding and equipment that served as an
92 alternative source of attitudes towards disabled people. Churches and charities very often
93 filled, and continue to fill, gaps in provision for disabled people. However, they also
94 imported attitudes that emphasised medical/charitable models of disability, development
95 and service delivery; aid was usually contingent upon the adoption of the philosophy of
96 the donor or service provider and this is still very often the case (Kabzems and Chimedza,
97 2002). As with ‘development’ more broadly, historically the power to define disability
98 has resided with professionals – mostly western, mostly medical, educational or
99 administrative. Recent decades have seen new and challenging definitions coming from
100 disabled people themselves but, as discussed subsequently, from mostly western, white
101 and educated disabled people (Stone 1999). However, greater recognition is currently
102 being given to the socio-cultural dimensions of disability as a means of mitigating some
103 of the more problematic and often western-centric approaches. Raising the complex
104 issues of socio-cultural dimensions of disability is not new (see Goffman 1963, for
105 example). However, the fact that disability is socio-culturally constructed and also
106 constitutive of social, economic, political and psychological relations between both
107 individuals and/or institutions has considerable significance for conceptualising disability
108 and development in a range of different contexts. In what follows, we explore critically a
109 number of different approaches to disability as they relate to development more broadly,
110 focusing on what we perceive to be the central issues for rethinking disability and
111 development policy and practice.

112

113 **Prevention of impairment and disability**

114 The most frequently made connection between disability and development in developing
115 countries is the link between poverty and impairment (Stone 1999). The root causes of
116 impairment in poor countries are malnutrition, poverty, landmines and lack of services
117 and these hit the poorest hardest (Chambers 1983). A considerable proportion of
118 impairments in developing countries are a direct result of poverty, injustice and
119 geopolitical interventions in which industrialised countries are often deeply implicated.

120 One example of the link between poverty and disability is childhood impairment.
121 As Bartlett (2002) argues, extraordinary numbers of children around the world are
122 impaired every year as a result of preventable injuries that occur within homes and
123 neighbourhoods; the percentage of injuries per capita is much higher in the poorest
124 countries. Impairments are often a consequence of injuries caused by open fires and
125 exposed kerosene heaters, unprotected stairways and heights, poor quality construction,
126 lack of safe storage of chemicals and poisons, piles of debris and poor waste disposal,
127 heavy traffic and a scarcity of safe play areas for children. The lack of access to
128 affordable emergency health services increases the number of long-term impairments. It
129 is generally acknowledged that the problem of injury-related impairment is growing in
130 absolute terms in poorer countries (see Forjuoh and Gyebi-Ofusu 1993; Sharma *et al.*
131 1993; Zwi *et al* 1996; Meyer 1998; Deen *et al.* 1999; Guastello 1999; Krug *et al.* 2000;
132 Bartlett 2002). Evidence suggests that children living in poverty are disproportionately
133 affected by injuries (Berger and Mohan 1996; Butchart *et al.* 2000; Laflamme and
134 Diderichsen 2000). Not only are physical environments more hazardous but families are

135 also vulnerable to psychosocial stress that accompanies childhood injury; financial
136 problems, poor health and challenging living conditions also result in lower levels of
137 supervision of children. While figures are often unavailable, anecdotal evidence suggests
138 that accidents are especially common amongst working children in developing countries.
139 An ILO survey of the Philippines, for example, found that more than 60% of working
140 children were exposed to hazards at work and, of these, 40% had suffered serious injury
141 (ILO 1996 in Bartlett 2002, 3).

142 It would seem, therefore, that a large amount of disability is preventable, often
143 through relatively simple and low-cost interventions. Measures to improve general living
144 conditions and standards can have a positive effect in reducing the incidence of disability;
145 improvements in health services reduce risks and mitigate the effects of impairment when
146 it occurs. Efforts to eradicate specific diseases can also have widespread and significant
147 effects. The commitment by the World Health Organisation to eradicate polio, for
148 example, has had a significant impact in reducing the number of cases around the world
149 from 350,000 in 1988 to only 5,000 in 1999 (DfID 2000). Similar health programmes
150 have been rolled out by international development agencies (e.g. the UN) to combat other
151 diseases such as leprosy, river blindness and HIV-AIDS, all of which can have severe
152 disabling effects, but it is important that these programmes do not separate issues of
153 disease eradication from underlying causes relating to poverty. Access to improved health
154 care systems that better serve the needs of the poor is critical, which includes enabling
155 even the most marginalised of people to access sexual and reproductive health services.
156 That disabled people often face the greatest difficulties in accessing health care needs to
157 be considered when measures are taken to improve provision.

158 Of course, impoverished people still have the greatest difficulties in accessing
159 clean water supplies and sanitation; they encounter greater risks of exposure to
160 environmental hazards and have poorer nutrition, all of which contribute to the incidence
161 of impairment and long-term disability. They are often the most vulnerable to the worst
162 effects of conflict and reliant on the least safe forms of transport. Any attempt to prevent
163 disability in developing countries, therefore, must deal with underlying poverty and its
164 associated risks.

165

166 **Social models of disability**

167 In addition to a greater focus on development policies aimed at prevention of disability,
168 recent years have witnessed a shift from medical models of disability to ones that
169 acknowledge the social dimensions of disability (see, for example, Butler and Bowlby
170 1997; Tregaskis 2002). For example, the International Labour Office formerly drew a
171 distinction between three concepts of disability (physical, occupational and general) (ILO
172 1989, 74). This was a medical/occupational method of assessing disability and the effect
173 on earning capacity and was criticised because its point of departure was a non-disabled,
174 employed person who became disabled through accident, injury or disease; it made no
175 provision for a person born disabled or becoming disabled before having an opportunity
176 to enter the labour market. Equally, this model of disability centralised western medical
177 knowledge and thus reflected the “postcolonial paternalism” (Lee 1997) of many
178 international debates about disability. More recently, the ILO Code of Practice on
179 Managing Disability in the Workplace, adopted in 2001 by experts from developing and
180 industrialized countries, recognizes the “need for definitions to reflect the social

181 dimensions of disability, be in harmony with human rights principles” and allows for
182 “variation in national interpretations of disability”

183 (<http://www.ilo.org/public/english/employment/skills/disability/download/adhoc.doc>).

184 These shifts in international definitions reflect the success of disability activism,
185 primarily in industrialised countries. Social models of disability, which see the problem
186 not as located in the individual, but in a society, economy, political system and culture
187 that fails to meet the needs of disabled people, was developed primarily by British
188 disabled people and activist allies. Disability, in this sense, is social disadvantage and
189 discrimination and in order to make a change in disabled people’s lives there is a need to
190 change society and the way society treats people who have impairments. Whilst the term
191 ‘the social model’ has become “a gloss for a range of theoretical and methodological
192 commitments”(Dewsbury *et al* 2004: 145), these commitments are rooted in specific
193 notions of civil rights, the need for inclusion and the removal of disabling barriers to full
194 participation. It is significant that the recent ILO statement acknowledges that while
195 social models are appropriate for politicised disabled people in industrialised countries,
196 they might be inappropriate elsewhere. As critics have argued, imposing western-centric
197 social models of disability in developing countries without consideration of local
198 historical and cultural practice would be more like imperialism than empowerment (Miles
199 1992; Stone 1997).

200 Most, if not all social models are based on the assumption of the availability of
201 technical and environmental solutions, in addition to cultural shifts, which have resource
202 implications. Even in relatively wealthy industrialised countries where such models have
203 been developed and embraced, disabled people do not have full entitlement because of

204 costs to individuals, institutions and arenas of government (Oliver 1990). Caution is thus
205 required when exploring the wider relevance of disability debates grounded in particular
206 cultural values and geographical spaces. For example, Komardjaja (2001a; 2001b) argues
207 (primarily in the context of Indonesia) that western-centric debates about accessibility
208 and barrier-free environments are less relevant than the need to enhance the general
209 quality of life for disabled people, including reducing illiteracy, increasing access to
210 information, and participation in economic and political decision-making. Clearly, issues
211 for disabled people in developing countries are profoundly different to those in
212 industrialised societies. In developing countries, it is rare to see ambulant disabled people
213 using mobility aids such as leg braces, crutches, walking canes and wheelchairs. As
214 Komardjaja (2001b) argues, for impoverished disabled people the streets are the places
215 most suitable for begging. Generally, disabled people in such contexts are not
216 pedestrians; rather, they are on the streets for specific purposes, often related to
217 survivalist strategies. Sidewalks along main roads and thoroughfares are strategic sites for
218 economic activities of low-income and informal traders who hardly leave space for
219 pedestrians (Ballard and Popke, 2003). Therefore, concerns with access are not always
220 appropriate in such contexts, where disabled people are preoccupied with coping and
221 surviving. These debates bring international classifications and universalising models of
222 disability under scrutiny, particularly if they inform policies that might be ignorant of
223 geographical and cultural differences.

224 There are questions, therefore, about whether current social models that have been
225 formulated in industrialised countries are appropriate in developing countries, where
226 resource constraints are extreme and where issues of prioritising are urgent. Social,

227 economic and political structures may be common concerns, but the forms, causes and
228 the resulting salient issues for disabled people differ. The issue of poverty is again
229 significant. There are greater disabling barriers that prevent disabled people in poorer
230 countries from acquiring education, employment and access to appropriate support and
231 services. Some barriers are rooted in local attitudes to disability; others are rooted in
232 broader structural processes of poverty and injustice, but it has only recently been
233 recognized that “local and global factors impact on perceptions of and responses to
234 impairment and disability” (Stone 1999, 6).

235 Reflecting some of these concerns, a number of authors (for example, Butler and
236 Bowlby 1997, Hughes and Patterson 1997, Imrie 2004) have argued that both medical
237 and social models, while capturing aspects of disabled people’s lives, are problematical
238 for failing to recognise that biology and society (including its culture, economy and
239 politics) are entwined in a dialectical relationship. This implies that:

240 physical and mental impairment, in contributing to functional limitations of
241 bodies, cannot be discounted as ephemeral in the construction of disability and
242 disabled people’s lives. Rather, a focus on interactions between functionally
243 impaired bodies and socio-cultural relations and processes is seen, by some, as
244 crucial in the development of a non-reductive and non-essentialised understanding
245 of disability (Imrie 2004: 288).

246 As Imrie argues, these ideas are gaining ascendancy in a range of important
247 developmental contexts, most notably in the World Health Organisation’s (WHO 2001)
248 *International Classification of Functioning, Disability and Health*. This seeks to develop
249 the conception that “mind, body, and environment are not easily separable but rather

250 mutually constitute each other in complex ways” (Marks 1999, 25) and conceives of
251 disability as “a compound phenomenon to which individual and social elements are both
252 integral” (Bickenbach *et al.* 1999, 1177). This is clearly an important development in
253 international understandings of disability. However, as Imrie suggests, there is still a lack
254 of clarification on the definition of impairment and the principle of universalisation as the
255 basis for disability health and social programmes remains questionable. The shifting and
256 complex terrain of disability in developing countries brings these issues into sharp focus.

257

258 **Rights-based approaches**

259 One positive aspect of social models of disability is that they provide an opportunity for
260 cross-cultural differences in the interpretation of disability to be accommodated in our
261 understanding. This has helped raise the significance of how societies interpret and react
262 to disability and the importance of tackling discrimination towards disabled people.

263 Considerable gains have been made by activists in some developing countries in the field
264 of civil rights, which in turn also places emphasis on the significance of government
265 policy within developing countries. Two well-documented examples are South Africa and
266 Uganda.

267 Disability issues came to prominence in South Africa during the political
268 transformation in the early 1990s, when minority groups were quick to organise and seize
269 the opportunity to shape new state institutions and the nature of democracy being
270 constructed. Disability activists were among these minority groups lobbying hard for
271 recognition and guarantees of rights and equality within the new dispensation. As a
272 consequence of high visibility and activism, the Office of the Status of Disabled Persons

273 was established in the Office of the President and is thus located at the heart of
274 government. The National Co-ordinating Committee on Disability (NCCD) played a key
275 role in the establishment of the Disability Program and the drafting of the 1997 White
276 Paper on Integrated National Disability Strategy, which aims to create an enabling
277 environment that will lead to the full participation and equalisation of opportunities for
278 persons with disabilities. The OSDP has also developed mechanisms and capacities to
279 facilitate the integration of disability issues into government development strategies,
280 planning and programmes, as well as the coordination, monitoring and evaluations of
281 these at national, provincial and local government levels. One of its main activities has
282 been to train previously marginalised disability groups in effective advocacy skills.

283 Protection against the contingency of disability is provided through the
284 Constitution, primarily via the anti-discrimination clause, which protects *all* people
285 against direct and indirect discrimination. Disability is mentioned as one of the arbitrary
286 grounds, undoubtedly a product of disability activism, which presented itself as a
287 movement for full citizenship rights. Despite this, disabled people in South Africa face
288 high levels of inequality and discrimination and labour and social security laws continue
289 to define disability with reference to a particular medical model (Truter 2001). For
290 example, Section 1 of the Employment Equity Act (1998) defines disabled people as
291 “people who have long-term or recurring physical and mental impairments which
292 substantially limit their entry into or advancement in employment”. Despite this, the
293 legislation has been significant in allowing disabled people to claim their rights as
294 citizens.

295 The 1998 Employment Equity Act is important in prohibiting unfair
296 discrimination against disabled people and providing for affirmative action measures.
297 These include modifying or adjusting jobs and working environments to accommodate
298 disabled people and numerical goals to address under-representation in the workplace.
299 The public sector was required to achieve a 2% level of employment of disabled persons
300 by 2005, while bigger employers have to register employment equity and skills
301 development plans setting numerical targets in terms of race, gender and disability
302 (Rowland 2002). The 1999 Skills Development Levies Act aims to improve the
303 employability of those who find it difficult to enter the labour market, particularly people
304 from previously disadvantaged groups, including disabled people. However, the
305 Department of Labour has set equity targets for skills development initiatives at only 4%
306 of disabled people (Cape Business News 2001), which does not equate with lowest
307 estimates of disability within South Africa.

308 The South African government has attempted to reform other laws to counter
309 persistent inequalities. Both the White Paper for Social Welfare (1997) and the White
310 Paper on an Integrated National Disability Strategy (1997) acknowledge that South
311 Africa's security system has in the past not operated in the interest of disabled people.
312 The former foresees the formulation of a policy on social security for disabled people and
313 the government has endorsed the World Programme of Action concerning Disabled
314 Persons, the UN Standard Rules and the UN Charter on Rights for People with Mental
315 Handicaps (White Paper 1997, 22). This represents a major change in government
316 thinking on disability issues in accordance with international developments. A wide range
317 of issues, such as public transport, employment, accessible communication, integrated

318 education and the restructuring of social security benefits are addressed. It acknowledges
319 that social security legislation tends to be discriminatory towards disabled people and sets
320 as the objective a social security system that meets their needs. This includes an
321 appropriate assessment method, accessible information and payout facilities, proper
322 administration, effective feedback mechanisms and a co-ordinated social security safety
323 net (White Paper, Ch 2). In addition, a National Environmental Accessibility Programme
324 is underway, focusing on rural areas, education and employment (Power 2001).

325 The case of Uganda is also notable in that disabled people have achieved a higher
326 level of political representation than in any other country (Ashton 1999, cited in DfID
327 2000). Like South Africa, Uganda has a relatively new constitution that provides for the
328 representation of the disability movement at all levels of political administration. At
329 parliamentary level, five seats are reserved for disabled people, one for each of the four
330 regions of Uganda and one representing the interests of women with disabilities.
331 Moreover, in local elections, at all levels of government, there has to be at least one
332 representative with a disability. This prominence within government is seen as essential
333 to ensuring that the needs of disabled people are fully articulated within government
334 policy.

335 Whilst the rights-based social model adopted on paper in some developing
336 countries appears to be progressive, there are still significant questions over the
337 possibilities of delivering what is promised. These questions to some extent revolve
338 around the limitations of social models discussed previously, particularly in terms of
339 poverty, access to resources and a profound rural-urban divide in many developing
340 countries. Even in relatively resource-rich countries like South Africa, it is difficult to see

341 how disabled people living in impoverished rural communities, where there are
342 significant technology and service provision gaps, will be able to claim their rights under
343 recent legislation or to improve the circumstances in which they live. Many Latin
344 American and Caribbean countries have only recently approved disability legislation, but
345 there is still very little effective compliance (Gatjens 2004).

346 The macro-economic context in which developing countries have to operate also
347 raises doubts about the possibilities of translating progressive legislation into reality for
348 disabled people. South Africa, for example, has undergone what various critics have
349 described as a self-imposed structural adjustment (Bond 2000; Marais 1998; Hart 2005),
350 with the effect that the progressive welfarist and redistributive policies have been
351 superseded by a neo-liberal macro-economic policy. This raises questions about the
352 effects of a restricted social welfare budget on populations dependent on social welfare,
353 especially those with disabilities. In many developing countries where progressive
354 legislation has been adopted the biggest obstacle to change appears to be the private
355 sector, which has been slow to include, promote and address the legacy of discrimination
356 against disabled people.

357 The key issue for developing countries is whether, in a neo-liberal macro-
358 economic context, the guarantees to equality within constitutional and progressive
359 legislation can be translated into *de facto* improvements in the lives of disabled people. If
360 social models are seen as the solution, which imply a level of state spending on
361 improving technology and access to resources, there are questions about whether this will
362 be possible given enormous budgetary constraints. In sub-Saharan African countries, in
363 particular, the effects of HIV/AIDS and economic globalisation have the potential for

364 negative impacts on the welfare of disabled people. Kabzems and Chimedza (2002) point
365 out that in South Africa, for example, there is already less talk of world class facilities for
366 disabled people and more talk of the “common good” – trying to prevent disabilities
367 through providing access to clean drinking water, immunisation programmes and injury
368 prevention.

369 Social models also recognise that further constraints are created by existing
370 cultural barriers, which are not likely to be overcome by legislation and policy alone.
371 Social acceptance and attitudes are both reflected and constantly reinforced by the
372 vocabulary employed to refer to individuals with disabilities. Many southern African
373 languages, for example, use prefixes designated for noun classes referring to objects of
374 animals when referring to individuals with disabilities (Devlieger, 1998) – spoken and
375 written language reinforces their marginalisation within society. In many sub-Saharan
376 African countries negative cultural attitudes persist, where disability in children continues
377 to be associated with maternal wrongdoing, witchcraft, evil spirits, or divine punishment
378 (Kabzems and Chimedza, 2002). A family might be accused of “sacrificing” the child in
379 exchange for good crops or a father will accuse his wife of promiscuity in order to deny
380 his part in the “creation” of disabled child (*ibid.* 151). And in many developing countries
381 around the world, international aid agencies have perpetuated the public perception that
382 disabled people are a burden in need of support from charitable organisations and
383 external agencies; it is not surprising, therefore, that negative attitudes exist within
384 communities where resources are scarce. Thus, although the civil rights of disabled
385 people in some developing countries are increasingly protected, cultural barriers still
386 remain and are continually reinforced. One remaining positive factor, however, is that in

387 countries where progressive policies have been adopted civil society structures have also
388 been put in place and can play a major role in lobbying and advocacy. Awareness
389 campaigns, which receive some state support, have some potential in empowering
390 disabled people (Gleeson 1999) and advocacy is important in changing attitudes (Parker
391 2001).

392

393 **Community-based rehabilitation**

394 In some ways related to debates about cultural barriers, community-based rehabilitation is
395 an approach that has grown out of the debate between social and medical models of
396 disability. It attempts to combine physical rehabilitation through medical intervention and
397 care with empowerment and social inclusion through the participation of disabled people,
398 as well as their communities, in the process of rehabilitation. This has often been claimed,
399 particularly by aid agencies and development organisations, to be the most effective way
400 of making use of scarce resources and of socially integrating disabled people. Emphasis
401 is placed on participation, active community support, specialist medical inputs and
402 indigenous knowledge and practices. Advocates believe it empowers individuals to take
403 action to improve their own lives, but critics are numerous.

404 Perhaps most obviously, concerns have been raised that negative institutional
405 practices and attitudes have, in many cases, simply been relocated into communities
406 (DfID 2000). In addition, aid agencies advocating these approaches are often unaware of
407 earlier, imperialist attempts to rehabilitate disabled people. As Miles (2001) argues, they
408 often accept the conventional mythology that “nothing was done for disabled people”
409 before a phase of “institution-building” in the 1960s, which they now wish to replace

410 with “community-based” rehabilitation and “inclusion”. They thus ignore the fact that
411 community-based rehabilitation, very much the fashion since the 1980s, is simply an
412 updated, less obviously imperialistic version of missionary responses in the 1890s (Stone
413 1999). They might be well-meaning, but they are often insensitive and inappropriate to
414 local practices and perceptions. Most importantly, these schemes often under-estimate the
415 support of families and communities already in existence for disabled people (Rao,
416 2001). Disability service developments are often dominated by the disparate trends of
417 European countries funding them. For example, Scandinavian countries have been active
418 internationally in promoting disability issues in southern Africa starting with
419 normalisation, integration and community-based services and inclusion. Policy affirms
420 the need to include persons with disabilities at all levels and stages of projects. Yet, as
421 Kabzems and Chimedza (2002, 149) point out: “It remains rare for a person with a
422 disability to be on the project payroll, whether in the capacity of consultant, accountant or
423 tea lady”.

424 This lack of user involvement in planning in disability and development appears
425 to be widespread despite stated policies to the contrary. A study by Flower and Wirz
426 (2000) explores how selected European-based international non-governmental
427 organizations (INGOs) facilitate the participation of disabled people in their planning
428 process. While INGOs involve disabled people’s organizations (DPOs) in their planning
429 of services and projects this is most commonly through sharing information rather than
430 through consulting with them, including them in decision-making or supporting action
431 initiated by them. The study found that if there is no assurance that ideas raised will be
432 implemented, then there is no guarantee of the participation of DPOs in the planning

433 process of INGOs. Yet despite failing in facilitating participation, INGOs have helped to
434 strengthen DPOs, encouraging their formation and making disability an issue that cuts
435 across sectoral boundaries. This might facilitate the participation of disabled people in the
436 planning process of INGOs in the future, but there is still a long way to go.

437 Many critics argue that models of community-based rehabilitation and inclusion,
438 imported from countries with much stronger economies and longer histories of universal
439 primary education, child-centred education, and educational research, have seldom been
440 culturally or conceptually appropriate to the countries in which they have taken place (see
441 Miles 1996; Lorenzo 2003; Metts and Metts 2003; Millward *et al.* 2005). Rao (2001)
442 argues that the status of disabled people in the majority world is complex and there is
443 great variability in the ways in which they are treated. Thus:

444 it is worthwhile to understand the indigenous ways in which disabled people have
445 been accommodated. Recognising the differences in social, cultural and historical
446 contexts may be critical in implementing inclusion initiatives, which are culturally
447 appropriate (*ibid.*, 533).

448 It remains the case, however, that external ideologies are often imposed that do not
449 necessarily match local practices and attitudes towards disabled people. As Kabzems and
450 Chimedza (2002, 150) point out, “the years of bilateral support do not seem to have
451 elicited contemporary, locally rooted, competing conceptualisations of disability”.

452

453 **Remaining challenges: lessons from developing countries**

454 A number of challenges remain in developing countries concerning the social and
455 economic inclusion of disabled people. How disability activists, governments, aid

456 agencies and society at large respond to these will continue to be instructive. As this
457 paper has demonstrated, one major concern is that models aimed at incorporating
458 disability into development policy and practice are often devised in advanced economic
459 contexts and, consequently, are too tightly focused on urban-based populations and
460 environments. For example, the initial work of United Nations Economic and Social
461 Commission for Asia and the Pacific region (UNESCAP) has been to empower urban-
462 based persons with disabilities in mainstream facilities (Parker, 2001). In recognizing the
463 problems with this in developing countries, a long-term strategic intention is to work to
464 raise disability issues in rural areas; this will be a more holistic approach and will include
465 other social and developmental issues such as child labour, exploitation and poverty
466 alleviation. In this sense, then, UNESCAP is responding to the need to include *all*
467 disabled persons in the development process (see also Turmusani (2003) on participatory
468 research with disabled people and Jordan and Parker (2001) on efforts towards
469 participation and inclusion in the more developed Asian economies). A further challenge
470 is ensuring that debates within poorer countries can inform development strategies, but
471 first there needs to be an understanding of what these debates are and an assessment of
472 their potential to inform broader policy and practice. The legislative changes in South
473 Africa and Uganda, and the positive effects these have had in driving the disability rights
474 agenda and energising civil society organisations are instructive in this regard.

475 Importantly, formal citizenship in South Africa incorporates a notion of cultural
476 citizenship (Stevenson, 2001), in which cultural rights are added to civil, political and
477 social rights. Cultural rights are related to identity and are based on “the right to be
478 different while enjoying full membership of a democratic and participatory community”

479 (*ibid.* 2); they “herald a new breed of rights claims for unhindered representation,
480 recognition without marginalisation, acceptance and integration without ‘normalising’
481 distortion” (*ibid.* 3). For disabled people, this is of significance since against this
482 backdrop, legislation does not simply seek to ‘normalise’ them as productive contributors
483 in the formal economy (*cf.* Erevelles’ case study of South India (2001) and Shang’s
484 discussion of employment policies for disabled people in urban China (2000), but to
485 create conditions for acceptance and integration on their terms as disabled people).

486 Challenges also remain concerning acknowledgement within policy and practice
487 of the interconnections between gender and disability (Lorenzo 2003). Until recently,
488 there has been little consideration by theorists of disability of the ways in which gender
489 might structure the experience of disability (Morris 1994; 1996). Equally:

490 It is quite absurd that international development programs rarely address the needs
491 of disabled women. Women with disabilities are harassed sexually, exploited by
492 men, suffer abject poverty and social disrespect, malnutrition, disease and
493 ignorance (Safia Nalule in Mobility International USA 2002).

494 In spite of critical need, women with disabilities are under-represented and under-served
495 in every aspect of the international development field: as partners, staff and beneficiaries
496 of development schemes. In addition, in much of southern Africa, Latin America and the
497 Caribbean, disability has been the concern of a voiceless minority “cared for” largely by
498 women (Miles 2001); in South Asia women in most settings are more likely than men to
499 experience as well as report poor health and functional impairments but little is known
500 about the association between gender, marital status, co-residence with sons, and
501 disability (Sengupta and Agree, 2002).

502 Women with disabilities traditionally have not had access to economic
503 development initiatives, even those targeting women. Micro-credit programmes use
504 selection criteria, lending procedures and training facilities that discriminate against
505 women, primarily because of a lack of accessibility, and disabled women often do not
506 have access to vital health information, particularly HIV/AIDS prevention. Coping with
507 disability is a much tougher proposition for women because of unequal access to income-
508 generation opportunities, through male bias in planning and the way that providing care
509 for disabled people is constructed as an exclusively female concern (Snyder 1995). As
510 Power (2001) points out, there are important links between the assumed passivity of
511 disabled people and the assumed passivity of women; the struggle against social stigma is
512 thus more complex for women. The South African legislative and policy context,
513 however, recognises these links and, at least on paper, is progressive; both international
514 development programmes and debates within industrialised countries could learn from
515 this approach.

516 Similarly, Uganda has adopted a Universal Primary Education policy to provide
517 all children with access to basic education (DfID 2000). The policy provides free
518 education for four children per family, two of which must be girls (where there are girls)
519 and any children with a disability. This represents considerable progress in a context
520 where the education of disabled children might previously have been considered a waste
521 of resources. India also has a District Primary Education Programme in place that seeks
522 to include disabled children in mainstream schools. This is aimed at providing an
523 education for disabled children while challenging the stigma and negative stereotypes
524 often associated with such children (*ibid.*). While significant challenges still remain

525 concerning policy, infrastructure, issues of empowerment, cultural attitudes, visibility,
526 and the effects of conflict on disability, positive steps are being taken in many developing
527 countries, incorporating the lessons learned from other contexts, but combining these
528 with an understanding of local difference, and having the potential to effect more
529 appropriate policies.

530

531 **Conclusions**

532 The need to prioritise disability issues in development policy is increasingly recognised.
533 For example, the UK government Department for International Development recently
534 launched a Disability Knowledge and Research Programme and has collated a directory
535 of key information resources entitled “Disability, development and inclusion”. This is
536 aimed at organisations working with disabled people in developing countries and covers a
537 wide range of themes including human rights, gender, poverty and mainstreaming, as
538 well as planning and management of disability programmes and service delivery relating
539 to children, community-based rehabilitation, mental health and HIV/AIDS (see
540 www.asksource.info/res_library/disability.htm). However, in planning and practice by
541 development organisations disability remains relatively neglected. South Africa, Uganda
542 and India are examples where relatively poor countries have attempted to tackle head on
543 issues of disability rights and human development, drawing primarily on social models
544 that are now embedded in international frameworks but increasingly recognising the
545 impacts of local factors that limit practical implementation of these. They are also noting
546 the importance of local-level understandings and needs. Each context is, of course,
547 unique and this needs to be acknowledged when attempting to draw lessons from their

548 progression of disability issues. However, they suggest that prioritising the meeting of
549 basic human needs and assuring social justice and equity need to precede addressing
550 issues of access for disabled people. This is particularly relevant, as Komardjaja (2001b,
551 101) argues, in cultures of coping, tolerance and survival where marginalization is less of
552 an issue than it might be in industrialised countries.

553 What sets disability issues in developing countries apart is that it is difficult to
554 encounter them without conceptualising disability as a product of both the traumatic
555 processes of colonialism and the often problematic construction of postcolonial national
556 identities. This is particularly the case in Africa, where, as Quayson (2002, 228) argues:

557 [W]ars and rumours of war succeed in proliferating disability on the streets
558 daily. Angola, Mozambique, Liberia, Rwanda, Sierra Leone. In all these countries
559 reckless wars have ensured that the disabled are part of everyday life. In any
560 attempt to create a civil imagining in these countries, the problem will always be
561 how to confront a traumatic history of disability at the personal as well as the
562 social level.

563 There is thus a need for a more holistic and flexible approach to understanding disability,
564 with a greater focus on local and individual experience and on recognising the importance
565 of geopolitical, social and cultural as well as economic contexts. This is one welcome
566 lesson from social models of disability. However, individual experience is constituted by
567 biology (being a body of flesh and blood), social discourse (including ideas about
568 ‘normal’ bodies), interactions with social constructs, other people and institutions (Butler
569 and Bowlby 1997). The fact that these factors differ spatially suggest that models of
570 disability also need to be flexible.

571 Finally, what is striking about much international debate is a failure to recognise
572 ‘development’ itself as potentially disabling. As Power (2001) argues, to do so is to begin
573 to open up quite profound questions about the margins of ‘development’ and its impulse
574 to objectify the marginal. Indeed, “To add disability to a development agenda as if it was
575 some kind of cumulative list of needs means that the underlying ableist assumptions of
576 development remain unchallenged” (*ibid.* 95). Related to this is a need to theorise
577 development and disability in both local and global contexts, for both a deeper
578 understanding of disability issues by those involved in the development field and of
579 developing world issues by those involved in the disability field (Stone 1999). There is
580 also a need for greater networking between those involved in disability and development
581 in poorer countries (Hurst 1999), which would greatly enhance the possibilities of
582 theorising from these contexts and producing more locally appropriate policies and
583 practice.

584

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