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Rethinking Children’s Disabilities through the Capability Lens: A Framework for Analysis and Policy Implications

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11.1. Introduction

This chapter has two main aims. The first is to propose a new framework for policy that complements the evolving capabilities approach (CA) developed in Chapter 2. The second is to focus specifically on children with disabilities in developing countries and to revisit current models of disability in this context. The case study of children’s well-being in Afghanistan discussed previously in this book is used to illuminate the discussion.

Children and young people with disabilities in developing countries are often very isolated and have little contact with society. A number of children with disabilities are hidden and have no access to education, be it physical access or overcoming social, cultural and religious beliefs and practices. Research shows that children with disabilities are less likely to participate in society and community affairs than their peers (Ehrmann et al., 1995), and children with mental illness and learning difficulties face more participation impediments that those with physical or sensory impairments (Longmuir and Bar-Or, 2000; Law et al., 2004). A large body of literature stresses the importance of social participation by defining it as the interaction between the individual and a disabling or enabling environment. Thus, an increased focus has been put on examining and changing the physical, social, political or institutional environment, in order to enable children with disabilities to participate (Law and Dunn, 1993; Law et al., 1999; Hammal et al., 2004; Welsh et al., 2006; Forsyth et al., 2007; Heah et al., 2007). Development programmes and policies and their underlying frameworks that aim to enhance the participation and empowerment of marginalized groups, including children with disabilities, invariably tend to over-generalize complex issues. There is overarching agreement over what these policy programmes should achieve, but often idealistic goals remain disconnected from the needs of
individuals. As a result, vulnerable groups such as children with disabilities become separated from the process and cease to be the central focus. Some studies show that the provision of support at school, for instance, may become a barrier to participation as it reduces the student’s opportunities to interact with teachers and peers and can become an obstacle to gaining autonomy (Giangreco et al., 1997; Skar and Tamm, 2001; Pivik et al., 2002; Mihaylov et al., 2004).

In this chapter, we introduce a framework based on the CA developed by Sen (1984, 1999, 2005) and others with the aim of helping policy makers to formulate policies and bridge the gap between research, policy implementation and assessment. This framework focuses on vulnerability from the perspective of increasing inclusion and strengthening empowerment. It reviews the interaction between the individual and social models of disability by giving central focus to human diversity. This framework does not segregate vulnerable groups by providing labels, but takes a more comprehensive view to address vulnerability as a multidimensional dynamic phenomenon with different types of limitations to the “capability” to achieve various “beings and doings”, or “functionings” that the vulnerable individual values (Sen, 1992, 1999). In other words, the CA can be a means of overcoming the “dilemma of differences”. It focuses on the specificity of an individual situation and needs without attempting to imprison him/her in a binding label. As Sen states, differently (dis)abled people may need different types and different amounts of capability inputs (policies, resources, changes in social norms or infrastructure) to achieve the same levels of well-being (e.g. Sen, 1999; see also Mitra, 2006).

The current impetus of looking at development with a human face invariably means expanding choices and positive freedoms. It is often stated that the CA seems to show limitations when we look at extremely vulnerable groups, such as persons with mental illness and intellectual disability. In this chapter we will argue that this framework remains relevant even for these forms of disability, if we shift the focus from the individual to the household unit and involve direct observers (carers) when considering persons with mental illness and intellectual disability. Theories of justice serve as a basis for policy action in the capability informational space: public policies are therefore responsible for providing the social and cultural (sense, perceptions, identities, etc. . . .) basis for capabilities (Nussbaum, 2000: 81). This is especially the case where impairments are preventable, or where disability is socially constructed (Baylies, 2002). Adopting the CA also changes the focus of policy goals and processes, since the effectiveness and relevance of these are gauged in terms of expansion of human capabilities and respecting people’s values. The ultimate goal thus shifts dramatically from increasing economic growth to the expanding of human capabilities, from resource-based policies to an in-depth change in the implementation process. Many policy-oriented studies use the CA to extend the informational base, adding and