Social Science & Medicine 65 (2007) 1630–1641

SOCIAL
SCIENCE
&
MEDICINE

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"Nobody's just normal, you know": The social creation of developmental disability

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Abstract

This paper examines the process through which early childhood developmental disability is socially created within a US public program called Early Intervention (EI). In doing so, the paper analyses and links the social creation of early childhood disability as a category at both the macro-level level and at the micro-level. The analysis is based on qualitative interview data from 31 parents and 19 professions involved in EI programs in Massachusetts. At the macro-level, the paper addresses how federal legislation and state regulations establish the boundary between normalcy and disability. At the micro-level, it analyses adults' social creation of developmental disability, measured as impairment. The paper also investigates the impairment categories that are produced by these processes, exposing the kinds of early childhood developmental delays that have been legislated as worthy of public intervention and discusses some implications of the disability determination process.

Keywords: USA; Childhood; Developmental disability; Impairment; Normalcy; Early Intervention; Parents

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Childhood health and disability are socially constructed concepts. Child health is constructed through professionally derived physical, developmental and social criteria, with "normal" children as the goal (Mayall, 1996). Childhood disability is constructed at multiple levels. At the macro-level, public policies define eligibility criteria for programs that address childhood disability, creating the policy category of "children with disabilities". Public policy plays a fundamental role in shaping the definition of disability (Hahn, 1994; Longmore & Umansky, 2000; Oliver, 1990). Disability assessments are made on the basis of both medical grounds and political definitions (Stone, 1984). Disability is therefore an administrative concept (Marks, 1999), which is attached to both labels and remedies (Albrecht, 1992).

At the micro-level, pediatricians screen children's health and development during well-child visits, a practice that began in the 1920s (Halpern, 1988). In 2001, the American Academy of Pediatrics issued a policy statement that urged pediatricians to identify possible developmental disabilities and refer children to the Early Intervention (EI) program for additional screening and possible services. Created by Congress in 1986, the EI program provides services to children under the age of three who are identified as having developmental disabilities (American Academy of Pediatrics, Committee on Children with Disabilities, 2001).

This screening represents an application of a medical model of disability, in which disability is

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doi:10.1016/j.socscimed.2007.06.006

understood as resulting from a medical condition that results in functional limitations which in turn restrict individuals' ability to complete expected social roles (Albrecht, 1992). Adults are expected to be able to complete "activities of daily life" such as caring for their own bodies and engaging in some form of paid or unpaid labor. Older children are expected to attend school. Infants and toddlers do not have such clear-cut social activities and roles because they are expected to be dependent upon others for their needs. Instead, functioning and development are the primary activities in which they should be engaged. They are expected to be able to turn over, crawl, walk, utter words, etc. within professionally determined windows of time—that is their "job". Children, however, do not always perform those activities "on schedule", for health reasons and because human development is dynamic and variable.

Impairment in functioning therefore is not merely biological, rooted in medical conditions. It is also socially created (Hughes & Paterson, 1997) by health professionals who act as "evaluators of difference—and thus as arbiters of pathology" (Snyder & Mitchell, 2001: 369). The "disability business" focuses attention on conditions, rather than people, and in doing so it reifies impairment and disability (Albrecht, 1992), constructing disability as a problem of individual disadvantage (Oliver, 1996). Disability theorists are increasingly including impairment in analyses of disability (c.f. Barnes, Mercer, & Shakespeare, 1999) and there is an emerging interest in the "sociology of impairment" (Hughes & Paterson, 1997; Thomas, 2002), bringing the biological body into theorising about the relationship between bodies and society (Williams & Bendelow, 2003, p. 142). Medical categories are being taken apart and examined (Marks, 1999).

Contemporary surveillance of early childhood health and development provides us with an opportunity to examine how impairment is socially produced and labeled as "disability". Some recent theoretical work emphasizes how institutionalised social practices create the category of "disability" and its meaning (Oliver, 1990). The EI program in the US is one social context in which we can examine these practices.

Scholars in the EI field have produced a tremendous amount of research on developmental assessments, particularly since the creation of the EI program in 1986. This literature focuses on improving practices from a wide variety of perspectives (c.f. Meisels & Atkins-Burnett, 2000; Meisels & Fenichel, 1996), stressing interdisciplinary collaboration (Guralnick, 2000), assessment of children in natural settings (Neisworth & Bagnato, 2004), promoting family-centered practices (Crais, Roy, & Free, 2006), improved screening practices (Romanczyk et al., 2005) and the use of scientific evidence to improve clinical practice (Noyes-Grosser et al., 2005). In contrast, the current study strives to examine the assumptions regarding disability, impairment, and normalcy that are embedded in the assessment process.

The goal of this paper is to understand the process through which early childhood developmental disability is socially created in the EI program and the categories of early childhood development that are produced at a macro-level through public policy and the micro-level through clinical practice. At the macro-level, it addresses how federal legislation and state regulations establish the boundary between "normal" and "disabled" early childhood development. At the micro-level, it analyses the creation of developmental disability as a social process resulting in children being placed in disability categories. This multi-level analysis of disability assessment as a process builds upon Landsman's (2005) work on the diagnosis of early childhood disability; there she found that mothers complied initially with the medical model but developed more social understandings of disability over time. It also borrows from Blaxter's (1978) treatment of medical diagnosis as both a process and a category. As Brown notes, "Process is the set of interactions which leads to the definition of the category and to its imposition in particular cases" (Brown, 1995, p. 39). By documenting what counts as developmental disability, the paper also reveals the sources of underlying norms regarding what counts as a "normal", healthy child's body.

Method

The analyses presented here are based on qualitative interview data from parents and professionals in the context of EI, a federally legislated program in the US that provides services to children under the age of three who are identified as having developmental disabilities or delays and to their families. The children may have a specific diagnosis from physicians, such as Down syndrome, or they may have a medical history that places them