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## **Abstract**

Personal, idiosyncratic, geographical, and social-economic parameters are presented as a framework for understanding parental perceptions of mental retardation in Cali, Colombia. Three stages of special education development are described that define the history of the Colombian case: from a history of neglecting children with disabilities, to crossing a diagnosis-planning stage of institutional reassuring, to an emergent humanitarian acknowledgment of individuals with disabilities. Finally, a case is presented for the need to understand parental perceptions of disability in planning for the future of special education in that country.

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As I was growing up in Colombia, three events drew my attention to parents' perceptions of their children's disability. First, when I was a young child, I saw a child with macrocephaly in Palmira City, where I was born. He was about five years old. I still remember my mother talking with his mother in order to understand the child's disability and then my mother trying to answer my pressing questions. My childhood questioning resides in my memory almost as a satiric, caricatural painting by Botero.

Second, there was a popular anecdote about Buga, a neighboring city of Cali. It was said that parents would stop a visitor from entering their house while they "tied or locked up" the family member who had a disability; then the parents would return to attend to the visitor.

Third, two close relatives of mine were born with different disabilities, spina bifida and microcephaly. Their parents made "una peregrinación al Señor de los Milagros de Buga"; that is, they visited a well-known church in Buga called the Lord of Miracles. I still remember the mother of the child with spina bifida trying to comprehend and explain the disability. I also have a vivid memory of her maternal verbalizations about her hope for a cure. Three years later, her second child was born, with microcephaly.

Since I immigrated to the United States, my own difficulties in dealing with a different culture, a different language, and many other obstacles have, I believe, given me an additional perspective on the experience of disability. Moreover, my first job in the U.S. was as a teacher in a facility for children with disabilities sponsored by the Association for Children with Retarded Mental Development.

Later, I taught students with learning disabilities for the New York City Board of Education. In both of these settings, I found parents' observations and perceptions to be invaluable in deciding what would most likely further their child's development. Furthermore, it seemed to me that empowering parents in their roles as natural educators was crucial in helping many children navigate the transitional stages of life, society, and education. Yet as significant as I found parental perceptions to be, I have encountered few studies that deal with the nature and range of these perceptions or with the differences that there may be—to the child, to the parents, or to the professionals who seek to help them—when parents adopt one view of their child's disability rather than another.

### **Promising Research**

It is surprising that there has not been more research into parental perceptions of children with disability, since such perceptions constitute a variable that is likely to affect many aspects of the development and education of these children. For example, do parents who accept the medical explanation that has been provided treat their child differently from parents who believe that the disability is part of God's plan or that it is a punishment for past transgressions? And if there are differences in treatment, how do children respond to them? Another issue is the fit between the perceptions of parents and those of the professionals whom they encounter in seeking help for their child. Are professionals and parents aware of discrepancies in their views, and if they are, how do they react? Do professionals take into account parental beliefs when they make recommendations for intervention? Do parents' views affect the way that they help to implement such plans?

A related issue is how parental views of disability might vary among different cultures. A better understanding of this would enable professionals in countries such as the U.S. to interact more effectively with clients who differ from them culturally. Moreover, an appreciation of cultural variation could have a positive impact in developing countries that want to improve their services for children with disabilities. As more resources become available, these countries will naturally look to the U.S. and Europe for models that they can adapt. A firm sense of the ways that they differ culturally from the countries that produced the models can help them in producing adaptations that are appropriate for their local situations.

### **Context within Latin America for Research on Special Education**

#### *The Land*

With 440,000 square miles, twice the size of France, Colombia is the fifth largest country in Latin America. Its topography ranges from high mountain ranges to tropical forests to savannas. The bulk of the population and economic activity is found in the western third of the country, where three ranges of the Andes run from south to north separated by the Cauca and Magdalena river valleys. Because of this rugged terrain, a greater proportion of travel within Colombia is by air than in any other country (Colombia, 2002). Because the equator runs through the southern tip of the country, the climate does not vary much throughout the year. There are, however, great contrasts due to differences in elevation, from perpetual snow on the high peaks to temperate in the highlands to tropical along the coasts.

#### *The People*

In 2000, Colombia was estimated to have a population of 42.3 million, the third highest in Latin America after Brazil and México. The ethnic makeup is 60% mixed European and Indian descent, 20% European descent, 18% African descent, and 2% indigenous Indian tribes. The population is quite young (80% under 40; 52% under 24) and exceptionally urban (74% in 2000). The movement from rural areas to the cities remains substantial (1.3 million in the last half of the 1990s according to official estimates). This migration is only partly due to changes in agriculture that have led to urbanization in many parts of the world. There are also large numbers of refugees fleeing guerilla and paramilitary operations in the countryside as well as the violence and crime associated with the drug trade. The crisis in the country has also led to substantial emigration (estimated to be as high as 200,000 in 2000) (Economist Intelligence Unit, 2002).

#### *The Economy*

With a per capita GDP of US\$1,920, Colombia is substantially behind other large Latin American countries (México, \$5,789; Venezuela, \$4,985; Chile, \$4,613; Brazil, \$3,682). Inflation has averaged 15.6% from 1996 to 2000; unemployment has increased from 7.8% in 1993 to 19.7% in 2000. In 1999, 54% of the population was below the poverty line and 20% were experiencing extreme poverty (Economist Intelligence Unit, 2002). *Colombia* (2002) provides the following broad summary of socioeconomic conditions:

The vast majority of the population belongs to the “marginal” classes, who lack steady employment and must eke out a living by any possible means, and the lower classes, who are mainly physical labourers. Members of these two groups are largely of African, American Indian, or mixed descent. At the middle and

upper echelons of the social structure are those who have more highly skilled work, including the professions....At the apex of the upper class is a tiny group of wealthy, traditional families, of which almost all are of pure Spanish background.

### **Special Education**

Historically, special education policies and programs in Colombia can be divided into three periods: (a) the period of neglect before 1978, (b) the period of diagnosis and planning from 1978 to 1990, and (c) the emergence of special education after 1990.

#### *Period of Neglect: Before 1978*

During the period of neglect, there was little information on policy or practice in dealing with children who have disabilities. Neither were there any research reports, much less any interest in parents' perceptions of their children's disability. This was a period in which many countries such as Colombia faced the challenge of both improving the quality of education and extending primary school coverage into rural areas (Psacharopoulos, Rojas, & Vélez, 1993). This period also saw the beginning of national educational experiments that are still being evaluated, such as the New School and the Unitary School (Schiefelbein, 1991).

Although there is little reference to disability in the literature, there are many stories that children with disabilities being hidden in their houses and how people frequently made jokes about residents of Buga for being "bobos" or for having *bobos* in their families. This period could well be characterized not only as neglecting those with disability but also as lacking recognition of different kinds of disability. Indeed, the government did not

even recognize that learning disability was distinct from mental retardation (King-de-Larrarte, 1993).

#### *Period of Diagnosis and Planning: From 1978 to 1990*

During the period of diagnosis and planning from 1978 to 1990 (Martínez, 1982; Ochoa-Núñez & Chacón, 1988), the Colombian National Ministry of Education gathered a substantial amount of statistical data through mandated questionnaires for all institutions of special education (Decret 863 from 1980) (Ministerio de Educación Nacional, 1987). In 1985, the Ministry launched a national plan for special education development, the Plan Nacional para el Desarrollo de la Educación Especial (the PNDEE; Ministerio de Educación Nacional, 1987). The plan had two purposes: to obtain a diagnosis of special education across the country and to implement programs for the transition of individuals with disabilities. These disabilities were grouped into six categories: (a) learning, (b) language and audition, (c) neurologic and orthopedic, (d) vision, (e) behavior, and (f) mental retardation (Ministerio de Educación Nacional, 1990). Also, policy actions and projects were proposed for implementation (Balinas, Páez, Bayona, & Medina, 1990). This period provided the basis for the emergence of special education as a field.

#### *Emergence of Special Education: After 1990*

According to the World Health Organization, 7–12% of the world population has some type of disability. The index for Latin America and the Caribbean tends to be higher than 7%. It is 12% for Colombia, perhaps because of the violence in the region (Restrepo de la Calle, 1995).

Although the Colombian Division of Special Education was created within the Ministry of Education in 1976 (Restrepo de la Calle, 1995, p. 16), only in 1994 did Law 115—the general law of education—specify special classes in the public school that integrally included people with disabilities (Gaviria-Trujillo, 1994). However, Law 115 indicated more a symbolic attitude than a policy: regulations and practices did not show up automatically. As a matter of fact, in the implementation of Law 115 in August 1994, special education was not mentioned.

During the emergence of special education, a wider interest in individuals with disabilities has arisen. There is now a focus on the human being within the contexts of culture, history, and societal values (Ministerio de Educación Nacional, 1991). Education is now understood as giving the individual autonomy, an understanding that provides a basis for educating children more effectively. There has also been a focus on the etiology of disabilities and on the implementation of courses of action.

### **Factors affecting the development of special education**

Currently, there are four factors that affect the development of special education in Colombia: the cultural, the socioeconomic, the pedagogical, and the critical. It is important to understand these when considering the future of special education in that country.

Culturally, Colombia is linguistically multiethnic and *casteljanised*, that is, heavily influenced by the Spanish of Castilla (Mar-Molinero, 1995). Colombian education is a centralized Hispanic-colonialist legacy inscribed into a Latin American context. More recently, influences on Colombian education

have come from the United States, England, and France.

From a socioeconomic perspective, Colombia has slightly better conditions than the average of other developing countries and centers, based on specific indicators: life expectancy, access to safe water, GNP per capita, and gross primary school enrollment (World Bank, 1996, p. 74).

With respect to the pedagogical factor, Colombia is giving increased attention to curriculum, teaching, methodology, and the school as an institution. This contrasts with the focus in preceding years, which was on the pupil as the one to be changed or "cured" rather than on the instructional medium (Agudelo-Valderrama, 1996).

Finally, the critical factor involves the choice between an approach that is segregationist and one that is integrationist. Unfortunately, Colombian educational reform is currently more a reactive system addressing immediate political, social, and economic problems than a long-term program for the strategic development of a culture. The importance of the family and the social environment as the primary influences on children's lives has been neglected. Indeed, the opinions and perceptions of parents have not been a matter of discussion in connection with either regular or special education.

Parental beliefs about their child's disability constitute a variable that potentially affects many aspects of the development and education of children with disabilities. Given the reasons for, and conditions of special education in Colombia, an important step would be to consider placement for children with disabilities by clearly attending to the essentially

local needs and culturally sensitive conditions of the families of these children.

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