

# Comparative Policy Brief : Status of Intellectual Disabilities in the Republic of Cuba

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*Abstract* It is estimated that 3.2% of Cuba's population of 11.4 million persons has a severe disability of some kind. Recent economic difficulties have, it may be assumed, had a negative impact on health service provision – which is free to all – and thus, on population health outcomes and nutritional levels. There is a traditional culture of family care for children and adults with intellectual disabilities (IDs), although it is apparent that unfounded beliefs about the etiology of disabling conditions as well as social stigma persist. The Constitution indicates that it is necessary to provide education for children with intellectual and other disabilities in primary schools, while other ministerial resolutions create special schools. ID is construed chiefly as a social problem. Children with IDs are the responsibility of the Minister of Education; it is possible that children with severe levels of disability may not attend school and rely on family support. For adults, rehabilitation includes physiotherapy and other services such as “defectology”; strategies for adults who are evaluated include both segregated and institutional elements. The author suggests that two key issues are related to policy and practice in Cuba. One is the minimal content on special education in teacher preparation programs, and the other, that despite a cultural tradition of family care, family involvement in special education, or in rehabilitative services, remains limited.

## BACKGROUND

### *Geography*

Cuba is the largest island in the Antilles archipelago in the Caribbean. It is approximately 150 km or 90 mi south of Key West, Florida. The total land area is approximately 110,860 km<sup>2</sup> or 42,803 mi<sup>2</sup>. Its climate is tropical moderated by trade winds. The dry season is from November to April. The rainy season is from May to October. The Republic of Cuba is divided into 14 provinces, 169 municipalities and the Isla de la Juventud special municipality. From west to east, those provinces are, Pinar del Rio, La Habana (Havana), Ciudad de La Habana (Havana City), Matanzas, Cienfuegos, Villa Clara, Sancti Spiritus, Ciego de Avila, Camaguey, Las Tunas, Holguin, Granma, Santiago de Cuba, and Guantanamo. Economic and demographic indicators are found in the Table 1.

### *Constitution and Government*

The Republic of Cuba's head of state is the President of the Council of State and President of the Council of Ministers. The President is chosen by the Council of State, which is selected by the unicameral National Assembly of People's Power or *Asemblea Nacional del Poder Popular*. The current government is one of the last communist state governments in existence in the world and is the only communist government in the western hemisphere (del Aquila, 1992; World Factbook, 2006).

### *Culture and Religion*

Cuba's ethnic identity consists of 51% mulatto (i.e., of black and white origin), 37% European heritage, 11% African-heritage, and approximately 1% Asian of Chinese descent (World Factbook, 2006). Cuba was 85% nominally Roman Catholic before the 1950s. There are an unknown number of Protestants, Jehovah's Witnesses, Jews, and practitioners of Santería (Santería is a recent combination of Roman Catholicism and African religions).

## INTELLECTUAL DISABILITY (ID)

### *Epidemiology*

In 2003, according to the Cuban Ministry of Foreign Affairs, information from the two studies within Cuba looked at a total of 366,864 persons with disabilities of all types. One was psycho-social and involved persons with physical

disabilities, and the other was psycho-pedagogic and involved persons with IDs (Lantigua Cruz, Sao, Collazo Mesa, & Lardoeyt Ferrer, 2008). These two studies made it possible to “typify the population with disabilities and provided important information for prevention programs; they also contributed to identify individual needs, provide strategies aiming at solving them, and raise their quality of life” (Perez Navarro, n.d.). The 2003 national screening study indicated a prevalence of ID in Cuba at 1.25%. The national prevalence of Down syndrome was found to be 4.3 per 10,000 population, representing 22.1% of persons with ID attributed to an ascertained genetic cause (Lantigua Cruz et al., 2008). Yet, as Bertera (2003, p. 230) has noted, limited access to Cuban publications and impediments to presentations by Cuban healthcare professionals at professional meetings work to inhibit a better appraisal of Cuba’s accomplishments. The World Health Organization (2006) estimates that 3.2% of the general population in Cuba presents with a severe disability of some nature, and except as noted above, lifespan epidemiological information regarding IDs or developmental disabilities is generally lacking.

Since 1992, Cuba’s indigenous provision of health services has dramatically decreased (Barry, 2000; Garfield & Santana, 1997; Waitzkin, Wald, Kee, Danielson, & Robinson, 1997). This decrease in healthcare can be attributed to two major factors: the dissolution of the Soviet Union and its lessening of economic assistance to Cuba, and the increased effects of the U.S.’s embargo bans on subsidiary trade with Cuba (Garfield & Santana, 1997; Krinsky & Golove, 1993). Half of all protein and calories in food for consumption was imported during the 1980s. Importation of food declined by half from 1989 to 1993 (Garfield & Santana, 1997). This shortage in calories has been exacerbated by increased caloric intake from refined sugar, which increased from 18% to 26% between 1989 and 1992 (Perez-Cristia & Fleites-Mestre as cited in Garfield & Santana, 1997). As a result of this undernutrition, Cuba suffered from an epidemic of optic neuropathy affecting more than 51,000 people beginning in 1992 (Cuba Neuropathy Field Investigation Team, 1995; Tucker & Hedges, 1993).

In addition, Warman (2001) noted that many individuals suffered from Cuba’s economic problems and experienced “nervous conditions.” It is known that poor health indirectly affects cognitive and language abilities of developing and maturing children. As indicated by a number of studies in Central America, South America, Africa, and the U.S., children who are malnourished perform lower on intelligence tests than nourished children matched for socioeconomic status (Brown & Pollitt, 1996; Pollitt, 1995). It is presumed that declines in nutrition, if accurate, have also affected physical, mental, and cognitive aspects of children and adults in Cuba. Another factor is alcohol use; Lantigua Cruz et al. (2008) found that maternal alcohol use during pregnancy was evident in 4.22% of persons with ID and consanguinity was present in 6.89% of the population with ID (10.9% of persons with mild prenatal ID and 14.2% with severe ID).

### *The Nature and Meaning of ID*

Beliefs about illness or disabilities can be often attributed to external causes among Cubans (Brice, 2002). For example, a visible disability such as Down syndrome can often be attributed to an external and nonmedical cause such as *brujeria* (witchcraft or sorcery). Some Cuban parents or family members may believe that if the patient has a disability, the family members are being punished for their sins (i.e., an external locus of control is present) (Zuniga, 1998). Other Cuban family members may accept disabilities as part of a larger divine plan designed by God for them to become a better person. Family members who hold these beliefs may be less open to utilizing the services of an educator or healthcare professional. Roseberry-McKibbin (2002) noted that “some families believe that ‘invisible’ disabling conditions do not exist” (p. 202). Hence, it is extremely challenging for education and healthcare professionals to help families see that invisible disabilities merit treatment as much as a visible disability would present.

Cuban and other Latino cultures typically have very strong beliefs regarding children and adults with handicapping conditions and disabilities (Madding, 2002). Beliefs about what constitutes a disability, its cause, and the concurrent conditions related to the disability, often have an effect upon the entire family. Cuban families and their beliefs may run counter to the medical or etiological approach. Madding (2002, p. 79) stated that “although most Cubans are reported to have higher levels of education than other Latino groups, and thus, to understand modern medical theories, there are still some who hold on to folk beliefs about illness and disability.” Juarbe (1996) reported that Puerto Ricans (this may also be applied to Cubans) often believe that the mother is culpable when a child is born with a genetic defect, such as Down syndrome. She is blamed for not using proper prenatal care during pregnancy. It is also believed that illnesses or disabilities can be attributed to past sins. Thus, the punishment is carried out on the child. If a child is severely

TABLE 1

Selected economic and demographics indicators for the Republic of Cuba

**Selected indicators from the World Development Report 2007**

	Cuba	World's high-income economies (average)
Population (millions)	11	n/a
% population aged 10–14	19%	18%
Purchasing power parity per capita gross national income	n/a	\$32,524
% population living on		
Less than \$1 a day	n/a	n/a
Less than \$2 a day	n/a	n/a
Life expectancy at birth		
Men	75	76
Women	79	82
Under 5 mortality rate per 1,000	n/a	7
Adult literacy rate	100%	n/a

Source: World Bank, 2006.

n/a = not applicable.

disabled, then she or he typically will be taken care of in the home with the women of the household (e.g., mother, grandmother, aunt, older sister, etc.) taking responsibility (Madding, 2002). Cuban parents may resign themselves to the child's disability and possible handicap. This is seen as "God's hand" in that the parents must endure this "cross to bear" and in some instances, it is seen as a "blessing" to be the parents of a special child. Yet, there is a social stigma to having a child with a disability; consequently, parents may hide the child at home, away from the knowledge of outsiders. Parents may seek the help of *curanderos* (folk healers) or *Santero* (priests) to heal the sick or cleanse souls (de Paula, Laganá, & Gonzalez-Ramirez, 1996).

## POLICY

The Cuban Constitution (Ministerial Resolution Number 13/85) indicates that it is necessary to identify and provide education for children with disabilities, that is, including intellectual or developmental disabilities, in primary schools (United Nations Educational, Scientific and Cultural Organization (UNESCO), 1996). Other ministerial resolutions create special schools for children with visual impairments, hearing impairments, language difficulties, or behavioral issues. Cuba defines intellectual and developmental disabilities as social issues. Soal (2004, p. 13), in commenting about ID in Cuba, stated that "there is no doubt that an ID is neither an exclusive nor a fundamental medical or scientific problem, *but above all, a social problem* [emphasis added]. . . because each society determines who the subnormal and defective persons are, why their disability is claimed, and how they should be treated." It should be noted that no special resolutions have been created for children with intellectual or developmental disabilities.

## PROVISION IN CUBA

### *Children*

Children suspected of developmental delay or disability, are initially identified by the Center for Orientation and Diagnosis. Afterwards, children with intellectual or developmental disabilities are the primary responsibility of the Ministry of Education (UNESCO, 1996). Cuba's preparation of special education teachers is limited. General education teachers (who subsequently become special education teachers) are provided a single summer seminar in order to prepare them as special education teachers. Children with intellectual or developmental disabilities are then provided instruction in a segregated special school or when special schools are not available then in special education classrooms (Soal, 2004; UNESCO, 1996). However, it should be noted that a strong sense of family cohesion is seen in Cuban households when children with severe disabilities may not attend school and, instead, be cared for by the family. Therefore, it may be possible that Cuban family members may try to educate severely intellectually impaired children in the home (Brice, 2002).

### *Adults*

The Cuban healthcare system is free of charge and provided locally to its population. Cuba has employed a system of family and neighborhood medical doctors and clinics (Cardelle, 1994). Healthcare workers are expected to live and work in the same community. Doctors and nurses in the local neighborhood clinics provide services for obstetric, pediatric, gynecological, and general medicine to the population. Cuba has sought to capitalize on the provision of health services to tourists (Perez, 2001; Robinson, 1997). This “health tourism” earns Cuba US\$25 million a year (Robinson, 1997). According to Perez (2001), a journalist for the Cuban newspaper *Granma*, Cuba offers rehabilitation services in physiotherapy (i.e., physical therapy), speech therapy, and “defectology.” Defectology is the Russian form of rehabilitation for individuals with IDs. Provision of rehabilitation services in Cuba is not community-based or provided in neighborhoods as is with primary medical care treatment. Anecdotally, according to a speech-language pathologist who emigrated from Cuba to the United States in 2004, rehabilitative services are provided after a child or adult is referred to a provincial or city clinic. The child or adult is then evaluated by an interdisciplinary team, which may consist of a pediatrician, neurologist, psychologist, and rehabilitation professional. The client is then referred to a school or hospital clinic depending on the client’s age, needs, and type of therapy to be provided. Specific rehabilitation strategies for individuals with IDs provided in Cuba are unclear. However, because Cuba followed a Russian model of healthcare, then this type of model may be what is present in Cuba today, one with both segregated and institutional elements (Cardelle, 1994).

## KEY ISSUES

Three key issues relate to policy and practice in serving individuals with intellectual and developmental disabilities. They consist of: (1) provision of education services; (2) rehabilitative provision of services; and (3) family involvement. Cuba’s education system requires that all children with disabilities be assessed by the Center for Orientation and Diagnosis. A child with a mental or intellectual disability will initially be referred to a segregated special school. If special schools are unavailable then the child is educated in a special education classroom. However, special education teacher training is limited to only one seminar (as opposed to specialized degree programs in the U.S. or the UK) (Soal, 2004; UNESCO, 1996). Family involvement in special schools or special classrooms is likely to be limited. Because Cuba follows the Russian model of rehabilitative services, it may also follow a segregated and institutional approach to how rehabilitative services are provided (Rosenthal, Bauer, & Hayden, 1999). Hence, family participation may be limited in service provision to the individual with IDs.

By contrast, Cuban families demand participation in the care of their family members (Madding, 2002). A family-centered approach is characterized by shared problem solving; that is, all participants, the family, and professionals, are involved in determining if a problem exists, its nature, intervention goals, and roles for implementing the solutions are provided in a collaborative effort (Creaghead, 1994). Cuba’s education and treatment of individuals with ID has been heavily influenced by its history as a socialist or communist government (Soal, 2004). Therapy is affected by the limited training of special education teachers and the segregationist model employed in both education and healthcare settings. However, these shortcomings may be overcome by a strong family tradition of caring for children and adults with intellectual and developmental disabilities.

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