Visually-impaired Children in Havana: Challenges of Education, Rehabilitation and Inclusion

By Gail Reed MS

The Abel Santamaría school in Havana had moved since my last visit there in the late 1970s. Once occupying a converted residency in the Miramar section of the city, the school is now in a more modern building with open-air hallways surrounding an inner courtyard. Devoted to visually-impaired children, it is one of Cuba's 396 schools for special-needs children, which enroll some 40,000 students across the country and employ 15,000 professionals.

But not only the physical plant of this school has changed: added to its original goals—rehabilitation and education—is a third mission indicative of an evolving national policy on the role of special education institutions. In a program begun just two years ago, the Abel Santamaría now prepares its students to eventually transfer to regular public schools. Its faculty work with teachers and classes at the new schools to develop a nurturing, inclusive environment.

Dr Susana Rodríguez: early diagnosis and therapy is key.

Successful inclusion or "mainstreaming," in a way that ensures meaningful learning for blind and low-vision youngsters, is a goal now espoused throughout the world by many specialists and disabled persons' organizations. Educational inclusion is also among the guidelines of the UN Convention on the Rights of Persons with Disabilities, which came into force in 2008.

However, in developing countries, where general primary education for millions of school-age children is far from guaranteed, special-needs children are further marginalized, with little chance that their needs or aspirations will be met. The fact that Cuba has universal public education and health systems gives implementation of inclusive policies a head start.

But it is a process that not only requires vision, but plenty of commitment and innovation in a resource-constrained setting, as Abel Santamaría administrators and faculty attest. And it means starting early to strengthen preparation of students and their families.

The first goal is to enroll children at an early age in the school's outreach program, which in turn depends on early diagnosis by primary care facilities and hospital ophthalmology services. The most common causes of visual impairment in Cuban children are retinopathy of prematurity, congenital glaucoma, congenital cataracts, and uncorrected refractive errors, according to national advisor on low vision Dr Susana Rodríguez of the Ramón Pando Ferrer Ophthalmology Institute, who also heads the Support Program for Rehabilitation of Low-Vision Children carried out in Havana and seven other provinces. Once a child is diagnosed, a local multidisciplinary Diagnosis and Orientation Center (CDO, its Spanish acronym) works with the family to suggest a course of action that "aims to develop the child's physical, intellectual, psychological, cultural and social abilities to the fullest," she told *MEDICC Review*.

The CDO also provides the early, vital link between medical services and the special schools, to see that children receive early sensory stimulation and well-guided support from their families. "This means that both physicians and teachers make home visits even before the child is a year old," explained Dr Rodríguez. "We have four pre-schoolers coming with their parents to the Abel Santamaría now," noted rehabilitation specialist Barbara Baute. "They come once or twice a month, when the ophthalmologist also evaluates them to prescribe individualized therapy. We also spend a lot of time working with their parents."

"Inclusion and enabling begin at home," emphasized José Manuel Pérez, director of the Abel Santamaría school. Pérez, who joined the faculty in 1984, admits this is still one of the school's biggest challenges. Dr Rodríguez agreed: "Sometimes even a loving parent will be embarrassed to walk down the street with a disabled child; another parent will isolate this child among his or her siblings. This causes not only emotional, psychological damage but also a lack of necessary sensory stimulation."

Overprotective families present another set of difficulties: "Some parents won't let their child run or play outside," said Pérez, "and this of course tends to make the youngster more dependent, less self-assured."

"When I'm tempted to get frustrated, then I ask myself: who is prepared for their child to be visually impaired? No one," says Baute. Yet, family acceptance and support is crucial to the child's healthy development. Pérez says the school's faculty has regular parent-teacher sessions, and its specialists offer counseling services to family members, as well as various courses such as Braille and techniques for teaching their children movement and orientation. General parent meetings are held monthly.

Rehabilitation and sensory compensation activities, special skills training, and general education are tailored to each student's needs, abilities and pace of learning—although the general curriculum itself is the same used throughout the school system. Participating in the student progress evaluation is a resident core team composed of the child's teacher plus an ophthalmologist, optometrist, visual rehabilitation specialist, psychologist, speech and language therapist, specialist in mobility/orientation, social worker, pediatrician and family physician.

In addition to optical correction, rehabilitation for Abel Santamaría's low-vision students includes a range of methods to stimulate, strengthen and take maximum advantage of residual vision. Students may also have multiple problems needing other kinds of expertise, and thus speech and other therapists are on staff at the school.

Braille reading and writing; handwriting; movement and orientation; daily routines; and other skills are handled both in the classroom and in workshops.

From kindergarten through ninth grade, nearly 100 students are enrolled at the Abel Santamaría school—68 low-vision and 30 blind youngsters. Among their teachers, counselors and specialists, 20 hold master's degrees in special education. Class size varies, but averages six to seven; nationally, special-school classrooms average 12 students (except for schools devoted to autistic children, where the average is one to two pupils).

Incorporation of computers and several innovative therapies have accelerated students' development, says Pérez. Psychoballet, equine therapy and dolphin therapy have proven effective in assisting some students with relaxation, expression, movement, and improving their emotional health.

Speech therapist working with a young student.

A second grade class at the Abel Santamaría school, Havana.

In some ways, the more difficult challenge begins when students are ready to transfer to regular public school. The timing is determined by the same core team in consultation with the student and their family. The student may be well prepared—even traveling with their own textbooks and learning aids—but this is not necessarily so for their new teachers and fellow students.

To meet this challenge with their admittedly limited human and logistical resources, the Abel Santamaría core team decided to begin by selecting only one school per Havana municipality for their students to attend. The schools, according to Pérez, were chosen both by building standards (better maintained, fewer architectural barriers) and by the quality of their teaching staff.

The Abel Santamaría faculty offer these teachers continuing education involving new educational methods, as well as workshops to make them more aware of the needs of their new students, and the importance of learning to accommodate a diverse student body. "This is a very tough job," says Pérez, "and it requires maximum dedication." Some 50 teachers throughout Havana are involved in this program.

For the 2010-2011 school year, about 15% of low-vision and blind special-education students are expected to transfer into the regular school system nationally. Dr Rodriguez says she is encouraged by these results—especially since they were produced by a better integrated approach between health and education professionals--but emphasizes it is much too early to evaluate the two-year-old program. "The students—their feelings as well as their performance—will eventually be the judge of how we are doing. And we'll also have to see how much of what we do manages to raise awareness beyond the schools themselves."

Santiago Borges, head of the Latin American Reference Center for Special Education in Havana, told *MEDICC Review* that in fact "inclusive education is a sign of an inclusive society, one that makes essential services accessible, and also respects diversity and accepts differences."

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