

NO CHILD LEFT BLIND

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What is worse than failing to prevent blindness in children? Ignoring it when it does happen!

That's precisely what is happening in many parts of the world...

While persons with disabilities (in developed countries) are no longer referred to as "disabled" because of all the medical, social, educational and rehab developments of the past 30 years, the situation is very different in underdeveloped and most developing countries. Persons with disabilities in those countries ARE DISABLED, but not by their disability. They remain disabled because of neglect, lack of care, poor resources and in many cases, the culture of shame wrongly and tragically associated with disabilities.

This tragic situation was brought to our attention five years ago when our lives were changed forever after meeting a blind child named Febi. Since then, she, her parents, and her country (Egypt) have become an indivisible part of our lives (please visit febiproject.com for details).

Except for a very limited number of well-trained doctors, the majority of ophthalmologists in Egypt lack the most basic training and management skills (both diagnostic and therapeutic). Many ophthalmology residents don't see (let alone use) a slit lamp or an indirect ophthalmoscope until they sit for their oral board at the end of their training! Therefore, it is easy to see why children with potential eye problems are harmed three times under this broken system.

First, many of them would not be suffering any visual impairment had they had the proper and timely prevention and/or treatment.

Second, those with end-stage eye problems are not getting any rehabilitation and/or visual aids to cope with their impairment.

Third, the few children with visual impairment who are not hidden from society are committed to the "school for the blind" with no integration.



In the face of these unfortunate discoveries, God blessed us with many dedicated partners who were willing to help change that situation. Most notably, a three way partnership between the ForSight Foundation, Misr El-Kheir and Harpour Memorial Hospitals. His Eminence, Dr. Ali Goma and the most reverend Dr. Mouner Anis have played a pivotal role in developing this project. We have also had a great deal of cooperative effort and support from Dr. Akef Maghrabi and his Al-Noor Foundation, especially Dr. Gamal Ezz Elarab. In addition to several other private, academic and government hospitals and teaching institutions. Febi's mom, Dr. Sally Farouk (a cardiologist) and Dr. Nina Jabbour (a clinical pathologist) went back to school for 2 ½ years and received master's degrees in special education for children with visual impairment. The motivation was not another degree to add to their M.D.s or even to just take care of our Febi, but rather to be able to take care of all the "Febis" in Egypt. We estimate that there are over half a million children with visual impairment in Egypt, many of them neglected and in hiding. Sally and Nina want to make sure that they don't remain neglected and outcast. How can the two of them do it alone? They can't! But the newly formed Egyptian non-profit organization Integration: *Enabling the "Disabled"* is hoping to change that. In partnership with our ForSight Foundation, this organization is launching the "No Child Left Blind" initiative which started in Assiut and aims to bring Egyptian children with visual impairment and other disabilities "out of hiding" for screening, evaluation, treatment, rehabilitation and special education with the explicit purpose of integrating them into regular schools and society. The organization works to increase awareness and encourage cooperation between NGOs as well as governmental organizations and the general population. It was chartered under Egyptian law in 2012 and represents a coalition of representatives from several other organizations working with children with visual impairment and other disabilities, including "True Light," "Gamyat Al said" and "Rouyat hayat." The organization has also cooperated with the Al-Noor foundation and "Misr-El-Khair."

The organization, under the leadership of Dr. Sally, hopes to accomplish these ambitious goals by successfully completing a pilot project for children with visual impairment in Assiut (upper Egypt), then share the experience with the Egyptian government (Ministry of Education and Ministry of Health) to generalize the approach to other governorates, involving the whole

country. The hope is also to inspire, encourage and facilitate copycat experiences with other disabilities. So far, over 1,000,000 citizens and 500 families with children suspected of having visual impairment have been reached. Over 300 children with visual impairment have been screened. Over 60 children were treated for reversible disorders. 40 children were referred to partners in Cairo where over 30 of them had surgery (glaucoma and/or squint). 20 children out of the target 40 are currently enrolled in our special education program (see details below).

By focusing on one country (Egypt) and targeting one impairment (visual), the NO CHILD LEFT BLIND initiative hopes to create a model for preventing and managing blindness and visual impairment in Egypt - a model that can be later emulated elsewhere in the world.

Our model involves the following components:

- Ophthalmology Screening, Referral, Management & Training
- Special Education, Rehabilitation & Training
- Coordination with all caregivers
- Integration with sighted peers, especially in schools



This ambitious program started as a 5-year pilot project in seven phases, in Assiut:

Phase 1: Forming the coalition and registering it in Egypt as a non-profit NGO. (This was accomplished ahead of schedule in May 2012): “Gamyat al Damg.”

Phase 2: Initial screening of children with visual impairment in the greater Assiut area to recruit up to 40 children, ages 4-12, to be included in the program. All children (ages 4-12) with visual impairment (perceived, suspected or actual) were screened. Using media, churches, mosques, civic organizations, etc... All were encouraged to come for screening which was planned in 3 stages.

- Preliminary screening, using two local ophthalmologists, one special education teacher and one social worker: This sorted through the “perceived” and “suspected” and produced a database (90% complete) of all children with visual impairment in Assiut.
- The above list was used to bring these children for detailed evaluation by visiting professors and experts in ophthalmology, rehabilitation and special education. This resulted in three categories of children:
 1. Those with reversible, easily treatable disorders who were provided proper care (and planned follow ups) but required no special education or rehab.
 2. A group of children with active eye disease who were referred to our partner

organizations for surgical and medical care after which they will be evaluated to see if they fit in category 1 (above) or category 3 (below).

3. 28 children were found with (end stage) visual impairment and nothing medical to be offered. These were referred to our 4 year special education project for integration and rehab.

- This screening and referral process will continue until all the affected children are reached or 40 students are integrated (whichever happens first).

Prior to the NCLB initiative there were no eye professionals in Assiut trained to screen and evaluate children with visual impairment. As a result of the first 2 campaigns, 3 doctors are currently trained to provide this service in cooperation with and with additional training from visiting expert partners. This phase is an ongoing service and training program.

(This was accomplished ahead of schedule in April 2012.)

Phase 3: Renting property for training and administrative headquarters as well as special education. Retaining a dedicated facility is

- a. Mandated by the Egyptian government
- b. Needed for training and hosting special educators
- c. Needed for training general educators
- d. Needed for administrative purposes

Special furniture, devices, audio visual equipment and assistive technology are an integral part of equipping this space.

(This was accomplished ahead of schedule in September 2012.)

Phase 4: Training of teachers.

- a. Training of general education teachers is imperative for integrating children with visual impairment into the regular classrooms.
Unless the general teachers learn how to integrate the children with visual impairment, the integration effort will be a failure because the special education teachers can only be partly involved in that regular classroom.
- b. Training of special education teachers is necessary because they are not available in Assiut (and are barely available anywhere in Egypt). The project has to offer the whole training curriculum, courses and equipment.

(Started ahead of schedule in November 2012.)

Phase 5: Modifying existing kindergarten and elementary schools to become appropriately fitted for children with visual impairment. Modification of classrooms is an integral part of integration, allowing for a user friendly and safe environment. This also includes providing the students with, and training them in the use of, assistive technology. Five kindergartens have been redesigned and the teachers trained to accommodate “integration.” Over 20 children have been “integrated” so far. Ten elementary schools have been set up for “integration” and over 40

teachers have been trained. 18 children have been integrated in 1st grade. The “Damg” organization now employs 6 special education teachers, trained by Dr. Sally and other experts from inside and outside Egypt.

(Started ahead of schedule in April 2013.)

Phase 6: Evaluations, adjustments and reporting to the public as well as to the government. Evaluation of progress, especially in a pilot project like this allows for adjustments and then provides objective results and outcomes (measurable) that can be shared with donors, the public and the government.

Phase 7: Generalizing the model to include other cities in other parts of Egypt (government takeover). Sharing a successful and gratifying experience with the government and NGOs improves the chances to generalize this project to other parts of Egypt, other disabilities and other parts of the world.

Less maverick work will also be necessary as a lot of systems and assumptions would have been tested, tried and modified.

No matter what your gifts, abilities and profession are, you can help.

Please join us in any capacity you can...

Out of their darkness, the visually impaired children all around the world are stretching out their hands to you...



NO CHILD LEFT BLIND

International Council

Screening, treatment, rehabilitation, special education and integration of children with visual impairment

USA	Rebecca Coakley, M.A., CLVT – Director CVRP Nina Jabbour, M.D., M.A. – Vice-President, ForSight Foundation Nabil Jabbour, M.D., President, ForSight Foundation
Egypt	Dr. Sally Farouk Nashed, M.D., M.A. – Chairman, <i>Integration</i>
Lebanon	Charbel Fahd, M.D., M.S. – Chief of Service, Ophthalmology Dept. LAU Ibrahim Dunya, M.D. – Professor of Ophthalmology and Director of the Pediatric Ophthalmology Section at LAU and OCB

UPDATE

October 2013

In less than 2 years, the following has been accomplished:

1. Over one million residents in the greater Assiut area have been reached by grass root teams that Sally trained to go to mosques, churches and civic organizations to spread the word about the program and to bring the children out of “hiding.”
2. Over 300 children have been screened by local doctors who were trained by American partners.
3. Over 60 children have received advanced eye care and rehabilitation (over 30 of them needed specialized eye surgery first).
All the provided healthcare was done by American and international professors training Egyptian doctors, while caring for the children.
4. Five kindergartens have been redesigned and the teachers trained to accommodate “integration.” Over 20 children have been “integrated” so far.
5. Ten elementary schools have been set up for “integration” and over 40 teachers have been trained. 18 children have been integrated in 1st grade.
6. The “Damg” organization now employs 6 special education teachers, trained by Dr. Sally and other experts from inside and outside Egypt.
7. Recently, and in an unprecedented move, the undersecretaries of the Egyptian ministries of health and of education joined many other officials and NGO representatives in Assiut for a 3 day conference that Dr. Sally organized for training and planning for “integration.” This is a milestone in the 5-year pilot project that Sally is leading to get the government of Egypt to adopt the American-style plan for the entire country.
8. In March 2014, another American and international team will be in Egypt for further training and healthcare education, operating on 30 children with eye disorders that need surgery; all while training Egyptian doctors to be able to do more of the same quality care on their own.
9. Our dear friends, the Bruderhof community in Morgantown, have volunteered to donate to this project all their compensation for providing custodial services to First Baptist Church!