

## THE 1<sup>st</sup> BABY CAMP FOR BABIES WITH VISUAL IMPAIRMENT IN BANDUNG – INDONESIA

Weningsih

*Perkins School for the Blind, Perkins International, Educational Specialist –  
Asia/Pacific Region*

**Weningsih@Perkins.org**

**Abstract:** *Young children with visual impairment are spread out across different cities in Indonesia; unfortunately, there is a limited numbers of early intervention programs (EIP) to provide services to the children and their families. Parents feel isolated. Initiatives have been taken to solve this crisis. Perkins International has started to provide support for the development of an EIP, online support to parents, materials for learning and others. In partnership with local organizations, Perkins initiated a “Baby Camp” workshop for families aimed to build relationships among the families. The Baby Camp included opportunities for parents to share feelings, ideas and challenges and most importantly, ways of helping parents create their dreams for their child with disability and their family. 17 families & 5 Perkins International partners attended the 3 day Baby Camp. Various topics and activities on babies and families were covered, such as: feeding preparation, developing gross and fine motor skills, self-help and other strategies. Parents learned to make toys out of available materials; set-up different play corners and activities. Parent happiness is also our concern, as this affects their connection with their child. With this in mind, we created some fun and silly games for families to help them re-discover their joy. The impact of this event is very significant; the Indonesia parent group was established. The event resulted in parents having stronger connections to actively support each other. They gained confidence in raising their children and advocating for them. In this presentation, we also will share many beautiful pictures of the event and testimony from the families.*

**Keywords:** Early Intervention, Babies with Visual Impairment, Parent Training

### INTRODUCTION

In the last three years, the number of babies diagnosed as visually impaired has increased significantly in Indonesia. Until mid 2000's, there wasn't any data of babies with visual impairment in Indonesia, and identification was a significant challenge. However, the situation has now begun to change. The biggest eye hospital in Bandung has initiated a new process to refer babies and young children identified as having visual impairment to the low vision center. In addition, the development of Information and Communication Technology (ICT) has had a positive impact on parents' efforts to find and connect with other parents in similar situations.

In 2014, there were more than 200 babies and young children diagnosed as visually impaired by one national eye hospital. These children and their families were spread out across different cities and towns in Indonesia. Parents were desperate in their searches for support. Unfortunately, there are limited numbers of Early Intervention Programs (EIP) in the country to provide service for young children with visual impairment and their families. Initiatives are now being taken to solve this crisis. Perkins International has started to provide support for the development of Early Intervention Programs, as well as sharing materials for learning. This has provided significant benefits and support to

families who are able to reach the early intervention center and families who are comfortable with printed materials. However, for many families it is not possible to reach the early intervention center or other resources for a variety of reasons, including geographic barriers, distance, economic challenges, etc.

### **What is Baby Camp?**

It is a parent training approach for them with young babies with visual impairment and additional disability. The goals are to provide them with specific knowledge and skills, as well increase their confidence on helping their children; in the same time also build relationship among parents and between teachers and service providers.

### **Process and result:**

On 1 – 3 April 2016 Perkins International, in collaboration with our partners in Indonesia, organized a family workshop, known as the 1<sup>st</sup> Babies Camp for Babies with Visual Impairment. This “Baby Camp” aimed to build relationship among the families, and allowed families to share feelings, ideas, challenges and dreams. Seventeen (17) families and 5 Perkins partners were involved in the 3 day workshop. Parents learned different strategies to teach their children at home. Activities addressed areas including: making toys out of free and easily available materials; creating games with their children; and involving children in daily basis activities. Parents also participated in various classes on topics including: feeding issues; developing gross and fine motor skills; introduction of early literacy and Braille; and other activities to allow children to develop sound and visual awareness.

As parents of a child with special needs, many of the parents often felt un-connected to real life, and forgot about themselves as an individual. Most of them no longer participated in the fun activities they used to enjoy, and some parents even no longer laughed, as a way to relieve their significant stress. We were aware of this situation and created some silly activities in the evening to allow parents to be themselves and have some joy. Parent shared that these fun activities were meaningful for them. Many of them said, “Never laughing anymore since we have this baby, it was so meaningful to be able to rediscover our joy.”

During the first session of the Baby Camp, parents wrote out their hopes and they put these hopes on a “tree of hopes”. Many parents shared their expectations and what they hoped to gain from this workshop. At the end of the workshop, the parents reviewed the hopes they had hung on their “tree of hope”. As the closing, parents worked in groups to discuss their needs and how we could support them. Parents shared several ideas, including starting a parents’ network and finding ways that they could meet each other regularly and stay connected.

### **Outcomes:**

Just two months after the baby camp, we developed a parent online support network, in which currently more than 150 parents of babies and young children are involved. This allows us to share techniques, emotional support and linkages among families. Parents are actively asking questions, sharing ideas and successes, as well supporting each other in many ways. While there are teachers and pediatric ophthalmologist, as well other medical professional in the group who are available as resources to support parents in the online support network, increasingly parents are taking leadership roles in supporting each other.

During this the same time, regular play groups and parents meeting have begun in two cities of Jakarta and Yogyakarta. Parents who live in the same cities and neighborhood towns meet monthly to learn each other and discuss some issues they are facing. Perkins also introduced *Early Intervention Manual* translated from English to local language and now being used as a guide for parents to track their child’s developmental milestones and share ideas for activities to facilitate development when there is a delay in a particular developmental stage (s). More than 35 babies and young children and their families are involved in these programs.

Meanwhile, news of the successes of the Baby camp spread out to the different cities. In the last several months, the Surabaya Eye Center, which is located in East Java, also contacted Perkins requesting support to develop early intervention services. The Surabaya Eye Clinic was identifying significant numbers of babies and young children with visual impairment, mostly due to prematurity.

Medical staff were feeling overwhelmed with the increasing numbers of young children with visual impairment, and were seeking way in which they could support the children and their parents. One of the families has now started an early intervention program in this city, with 78 babies and young children with visual impairment/ blindness now on their list, and about 30 young children and their families actively participating in the early intervention program. An additional national level impact of the baby camp is the initiative of parents to develop a parent support group for families of children with visual impairment in Indonesia.

#### REFERENCES:

- Jacob, N. (2014). *Early Intervention Resources for India*. India: The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities. Retrieved from: <http://www.transitionplanningasia.org/resources/early-intervention-manual>
- Jacob, N. (2014). *Buku Sumber Intervensi Dini Untuk India (Early Intervention Manual Bahasa Version)*. India: The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities. Retrieved from: <http://www.transitionplanningasia.org/resources/buku-sumber-intervensi-dini-untuk-india><http://www.transitionplanningasia.org/resources/buku-sumber-intervensi-dini-untuk-india-ei-manual-bahasa-version>
- Messenger, B. (2016). *Indonesia: Helping Babies Start Strong*. Watertown: Perkins School for the Blind. Retrieved from: <http://www.perkins.org/stories/blog/helping-babies-start-strong>