**Mid-term evaluation SIB supported low vision programs – Indonesia**

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**Rationale/Purpose of the low vision consultants’ part of mid-term evaluation**

1. Assess the quality of low vision assessments of, and advice and trainings given to clients with low vision by the Layak Jakarta and UNHAS low vision teams, and give recommendations for further improvements

2. Compare and discuss the client related results of the low vision services of Layak Jakarta and UNHAS, using the current available low vision data collected over 2016 and 2017.

**Expected key results from the visit**

* Strengths and weakness of currently performed low vision assessments and trainings of clients at 2 low vision services and recommendations for improvements
* Comparison of general and vision related client data between an NGO run low vision service (Layak Jakarta) and a low vision service based at a government hospital (UNHAS)

**Methods used**

**- observations and studying of records**

At UNHAS I observed both infant, school age and adult clients (5) being assessed, while at Layak I mainly saw infants or children (2 with multiple disabilities); we also made a school visit.

In addition I studied 10 randomly chosen 2017 records in Makassar and 20 in Jakarta.

The following activities were observed over 1.5. day at each low vision service: communication with client/caregivers; assessment; sequence and- completeness of assessments,; team work and division of tasks among the team; technical low vision skills including use of appropriate tests and training of clients.

***-* recommendations in the August-September 2017 report**

There was little time for the low vision services and Layak to work with my previous recommendations: these are still valid for this mid term evaluation.

**- data analysis**

Screening and client data over 2016 and 2017 were analysed and the results of the 2 different types of low vision services compared.

In my previous report I already commented on the lack of data on use of spectacles and devices and the urgent need to use the telephone questionnaire. We agreed at both services staff would speed up the use of the telephone questionnaire to ensure information on 2016 and 2017 clients (up to July 2017) would be collected and entered in the data sheet by end of November 2017.

**1. Quality of low vision assessments: findings and recommendations**

Overall I saw real progress in the quality of assessing and training clients and their caregivers, as well as in the time needed to provide the low vision care and the recording of the results. Accuracy of recording and data entry has improved substantially compared to work done in 2016.

The fact the refractionist in Jakarta is totally new to low vision meant I could not assess his skills yet. What is clear though is that he needs more supervised practice of vision assessments, refraction and magnification assessments of clients with low vision of all different ages, and especially of those with additional special needs

Assessment of babies and MDLV clients, esp CVI, ROP was identified as an area needing improvement in both services but is is expected that the training in India in October/early November will address these gaps.

**UNHAS**

The core team consists of 2 people, an ophthalmologist and a low vision rehabilitation worker. The smallness of the team contributes to good teamwork and a relevant division of tasks. Recently the rehab worker created her own working room which greatly improves the more functional vision assessment elements, such as measurement of reading speed, and the training of clients in use of devices, as well as counselling.

*What is done well*

* Quality of assessment, including sequencing, of (pre)school age children and adults good
* Relevant teamwork between Adele and Mita seen (e.g. a joint assessment of a 4 year old)
* Division of tasks relevant to skills of team members, e.g. Mita can now check VAs well
* Technical low vision skills good, e.g. reading speed checked in a good way
* Good focus on refraction and distance spectacles
* Appropriate age- and development- VA tests used
* Training of a child and mother in use of device was good, with attention to both people and a strong focus on letting child become independent in the use of the device
* Children with suspected hearing loss are referred for audiology check
* Results are written immediately and records are complete, including general data
* Time is taken to explain results to clients and caregivers
* Training of residents is done practically during assessments

*What can be improved*

* Taking of a good history and asking relevant, structured questions of client and caregivers ***before*** starting the assessment as part of preparing what needs to be assessed and how
* Use of functional, daily questions (on use of vision in relation to visual functions/elements of vision and visual skills) as a structured method of assessing needs of infants and those with MDLV
* Creation of a quiet atmosphere without too many distractions (people, objects) to assess infants
* Use of real objects, toys to assess use of vision in infants
* Use of handheld tests, such as Cardiff: maintaining a constant distance and lighting conditions
* VA measurements of clients with nystagmus needs to be done by blurring, not occluding, one eye
* Measurement, interpretation and interventions relating to contrast sensitivity
* Assessing the need for and prescribing magnification for near activities especially relating to preschool children
* Consistent use of advice form, not only for (pre)school children, but also for adults (short version)
* Provision of paper instructions on use of prescribed magnifying device
* Use of relevant, age appropriate questions on use of spectacles and devices, and reasons for non-use as a structured method of assessment
* Use of telephone questionnaire, to follow-up on use of spectacles and devices
  + Secretary of the children’s eye centre could be trained to use these
* Scheduling of (mainly one time) home visit (mainly to be made by the rehab worker) to families with an infant with MDLV

*Other recommendations*

* Training of an additional ophthalmologist (and of residents, and of the optometrist Fauzi) to give them enough skills to assess clients independently if Dr Adele is not present
* Demonstrate to Dr Noro in practice the complexity of, and staff and skills needed for providing a comprehensive low vision service at UNHAS

*Need for additional materials*

The following tests and equipment are still needed (in addition to those listed in previous reports)

To make:

- standardised toys, objects of different sizes

To buy:

* Cardiff
* Lensbar
* Flexible trial frame, size 58
* Laptop/desktop computer for training clients in using accessibility, magnification options

**Layak low vision Jakarta**

The core team consists of 4 people, a (new) refractionist, 2 low rehabilitation workers (one of them is also the senior coordinator of all the work), and a receptionist/data entry person.

The larger size of the team as compared to UNHAS low vision team necessitates a clear division of tasks to facilitate good teamwork and an efficient use of everyone’s time.

*What is done well*

* Use of functional, daily questions (on use of vision in relation to visual functions/elements of vision and visual skills) as a structured method of assessing needs of infants and those with MDLV
* Taking of a good history and asking relevant, structured questions of client and caregivers *before* starting the assessment as part of preparing what needs to be assessed and how
* Keeping of complete records (except sometimes for diagnosis)
* Measurement, interpretation and interventions relating to contrast sensitivity
* Children with suspected hearing loss referred for audiology check
* Follow-up on clients needing (cataract) surgery
* Scheduling and making of home and school visits
* Referral of clients needing Braille and O&M training to other service providers
* School visits:
  + Efficient use of team’s time by assessing a large group of children at a school
  + Including other children complaining of vision loss (refractive errors, staff)
  + Working with one key person at each school who can help organise and communicate
  + Asking caregivers to be present during school based assessments
  + Use of one assessment room at the school
  + Classroom visits to children in secondary school
  + Teaching correct use of a magnifying device (near, distance) in the classroom

*What can be improved*

* Division of tasks between the low vision team members
  + when assessing babies or infants: decide beforehand who does what and limit the number of staff working with the child and caregiver
  + when making school visits: again only a core team is needed
* Sequence of assessment of an infant/baby: explaining to the caregiver what you plan to do and first using functional questions, before assessing (use of) vision
* Creation of a quiet atmosphere without too many distractions (people, objects) to assess infants
* Consistent use of standardised, real objects or toys to assess use of vision in infants
* Obtaining of a complete diagnosis of causes of low vision; as there is no ophthalmologist present in the LV centre, diagnoses are not always complete or clear in the records
* Assessing the need for and prescribing magnification for near activities especially relating to preschool children
* Correcting presbyopia in older clients before assessing the need for near magnification
* Use of telephone questionnaire, to follow-up on use of spectacles and devices
* Consistent use of advice form, not only for (pre)school children, but also for adults (short version)
* School visits:
  + Communication with classroom teacher and child on abilities and needs of child in the class, including provision of advice form (this requires observations and a visit in the classroom)
  + Promotion of use of progress form as a way for the teacher and the LV team to monitor progress
  + Informing caregivers on which interventions are needed, and when and where: skin protection for children with albinism, use of spectacles and devices at home

*Need for additional materials*

The following tests and equipment are still needed (in addition to those listed in previous reports)

To make:

- standardised toys, objects of different sizes

* Laptop/desktop computer for training clients in using accessibility, magnification options

**2. Comparison of socio-demographic and clinical data between Layak’s and UNHAS’ low vision services: January 2016 – September 2017**

Results from May – December 2015 have not been included as this period is considered as a start-up period and learning time, and only Layak has entered 2015 data.

Overall the entry of data has improved tremendously compared to the end of 2015 and is good, notwithstanding some missing data. The consultant has contacted the services about any data errors found during the current analysis of the 2016= September 2017 data.

**2a. All visits**

\* Percentage columns read like this, using the example Sex: 54% of Layak’s clients were male

* No statistically significant differences between Layak’s and UNHAS’ were observed for sex, disability, if client was paediatric or adult
* The target for the first 3 years was 580 low vision assessments for children, with 690 referrals made: These targets were exceeded:
  + 639 paediatric assessments made (and 2015 is not yet included in these numbers)
  + Contacts with special schools resulted in many children listed for a vision check and possible referral for low vision services:
    - Layak screened 850 children in 2016 and 447 in the first 9 months of 2017.
    - UNHAS screened a total number of 1353 screenings (including 2015, 2016 and 9 months of 2017)
* Layak’s service has a substantially larger proportion of follow-up visits

**Interpretation**

* Follow-up visits: Layak as an NGO service has much more flexibility to organise follow-up either at the low vision centre or by going out to assess clients. They also have a dedicated receptionist who can phone clients, while UNHAS has one person who combines rehab work with organisational work
* Proportion of female clients is good compared to other Asian CBM supported programs where 38-42% of clients are female
* The distribution of clients with low vision only and those with other or additional disabilities is considered excellent in both services: they make an important contribution to the development of inclusive eye health

**Recommendation**

* Investigate if the receptionist at the child eye care centre in UNHAS can perform fixed tasks, such as phoning clients attend for follow-up

**2b. First visits in 2016 or 2017 only: 679 clients**

In total 679 clients received low vision services over 2016 and 20171 year and 9 months. Most of these were new clients, with 63 (9%) follow-up clients first seen in 2015. These are included to describe socio-demographic data of all clients seen in 2016 and 2017 (Table 2).

* UNHAS saw a higher proportion of children of 0 -6 years, 33%, versus 23% for Layak.
* No statistically significant differences between Layak’ and UNHAS’ data was observed for sex, disability, ‘if client was paediatric or adult’, ‘age at first presentation’ or ‘if vision was measurable’.
* The following statistically significant differences between Layak and UNHAS were observed (Table 2).
* number of clients seen
* how clients learned about low vision service and sources of referral: the vast majority (86%, 82%) of clients seen at UNHAS are referred by and learn about low vision services from health programs, while Layak shows a variety, with both health and education as 2 the main sources for clients



* time period between low vision assessment and last eye check: however many entries are missing (22%; N= 149 missing. A first cautious comment can be that UNHAS clients’ seem to be more likely to have a recent eye check (89% < 2 years ago, versus 70% for Layak). The same results is observed when looking at children only or adults only.
* health insurance: more UNHAS clients have health insurance (but 10% of data is missing).
* travel time to LV service: the mean travel time for UNHAS’ clients is 5.2 hours, and for Layak 1. 7 hours. However many entries are missing: We do not know if most missing data is for example for people coming from far.

**Interpretation**

* Numbers:

- The fact UNHAS sees more babies and infants is logical as paediatric ophthalmologists are working in the rooms next to the low vision service and direct referrals and joint consultations are common. Layak’s service can only cooperate with external ophthalmologists: however referrals of babies and young children is expected to increase with their expanding network.

- Layak has more staff and more flexibility to find possible clients. In addition the UNHAS ophthalmologist is not always available.

* Referrals and how clients learned about the low vision service:

Logically many UNHAS clients come from either internal referrals or other health services as that is where their connections are already established.

However looking at the number of school screenings UNHAS implemented it is somewhat surprising most clients still come through referral by health services. It is possible the referral source has not been correctly entered or that among the 1300+ children screened almost all had normal vision levels.

Layak, as an NGO service, had to create networks and connections themselves and was active in both connecting with education and health.

Leaflets were only distributed very recently so their contribution to making low vision services known cannot be seen yet.

* Health insurance:

Although around 10% of data is missing, some comments can be made. Further analysis showed that the time period between low vision assessment and last eye check did not differ by Sex, ‘disability’ ‘Child versus Adult’ for UNHAS or Layak. However clients with a health insurance were much more likely to have had an eye check recently. This finding warrants more investigation once data is more complete.

**Recommendations**

* Ensure all socio-demographic data is systematically recorded on the forms
* UNHAS can create wider, more varied networks to ensure a greater variety of referral sources
* Both programs can strengthen connections with DPOs and rehabilitation/CBR programs (if available in the catchment area) to increase referrals.

**2c. Results on vision improvements for 455 clients whose vision was measurable, made in their first visit in 2016 or 2017.**

Among the 455 clients whose vision could be reliably measured (meaning babies and infants, especially those with CVI and, blind clients are excluded) were 285 paediatric clients. Layak assessed a total of 176, 64% of the 277 clients they assessed and UNHAS 109, 61% of their 178 clients (Table 3).

There are still substantial amounts of missing data especially regarding spectacles and magnifiers. Results on obtaining and use of spectacles and devices can only be presented and discussed once data is (more) complete.

The following observations apply equally to Layak and UNHAS’ low vision services:

* There were no substantial differences in the proportions of males versus female
* There were no substantial differences when comparing paediatric patients with adults, unless a separate result is given for paediatric clients in table 3.
* Differences found in both services when comparing the reduced group of 455 with all 679 clients:
  + 97% were first-time clients, only 3 % (was 9%) visited the low vision services in 2015
  + 63% were paediatric patients (was 70%)
  + 10% were people with multiple disabilities (was 17%)
  + 18% were clients with disabilities but not low vision (was 12%)

**Interpretation**

* A mean improvement of 0.15 logMAR or more is considered a good, measurable improvement and is also found in other CBM supported low vision programs in Asia. The same applies to proportions presenting with spectacles and prescribed spectacles.
* All these results show the quantity and quality of vision improvements is comparable to other programs in Asia. The great importance of quality refraction and ensuring clients obtain spectacles prescribed is clearly shown in the data.
* For all clients the mean improvement in distance VA is similar for both low vision services, however for paediatric clients the mean improvement is larger for Layak’s clients.

One of the reasons may be that a higher proportion of children at Layak as compared to UNHAS has refractive errors as the main cause of low vision (see second part of table 3). This will need further analysis next year.

\* An improvement of 0.1 logMAR (-0.1) is an improvement of one line on the distance VA chart.

\* the standard deviation expresses by how much the measurements of the group differ from the mean value for the group: meaning here that there is a great variety in improvements

\* Near VA: all M sizes and distances recorded have been standardised into an M size at 40 cm. For example 4M at 40 cm can mean 1M at 10 cm or 2M at 20cm

* There are missing data for near VA in both services: one reason may be that those with ‘ normal’ or very poor levels of distance VA the near VA has not been measured or recorded.
* Hardly any preschool children were prescribed a magnifier

**Interpretation**

* The mean improvement in near VA is higher for all categories of clients from UNHAS as compared to those seen as Layak. In total 36% of clients were prescribed magnification at UNHAS versus 28% at Layak.
* Both services record a mean ‘minimal’ improvement in near VA for children. For near VA a mean of 0.14logMAR (1 line and 2 optotypes on the next line on a near VA chart improvement) is considered a good and measurable improvement.
* For adults a larger mean improvement in near VA is observed. This is not unusual as most adults come to low vision services because they cannot do their near activities such as reading any more. This is also evident in the high proportion of adults who have been prescribed magnifiers compared to the much lower proportion of children.
* Causes of vision loss: The top 3 are a common distribution also found at other low vision programs in Asia. Other causes, such as those related to the whole globe (e.g. microphthalmia, glaucoma) or to the optic nerve represent each 6-7% of the causes.

When looking only at children the sequence of the 3 most common causes of vision loss changes: refractive errors stays number 1 (38%), but lens disorders rise to number 2 (20%) and retinal disorders go to 3 (17%).

This is partly caused by the fact children with disabilities (and not low vision) are also assessed by the low vision service. The majority of these children has refractive errors.

**Recommendations**

* Continue a thorough refraction for all clients presenting to the low vision services
* Ensure all children receive a thorough assessment of their need for magnification for doing near tasks for a longer period of time.
* Prescribe magnifiers for near activities also for preschool children if needed