



Reading Disabilities in Zambian Children

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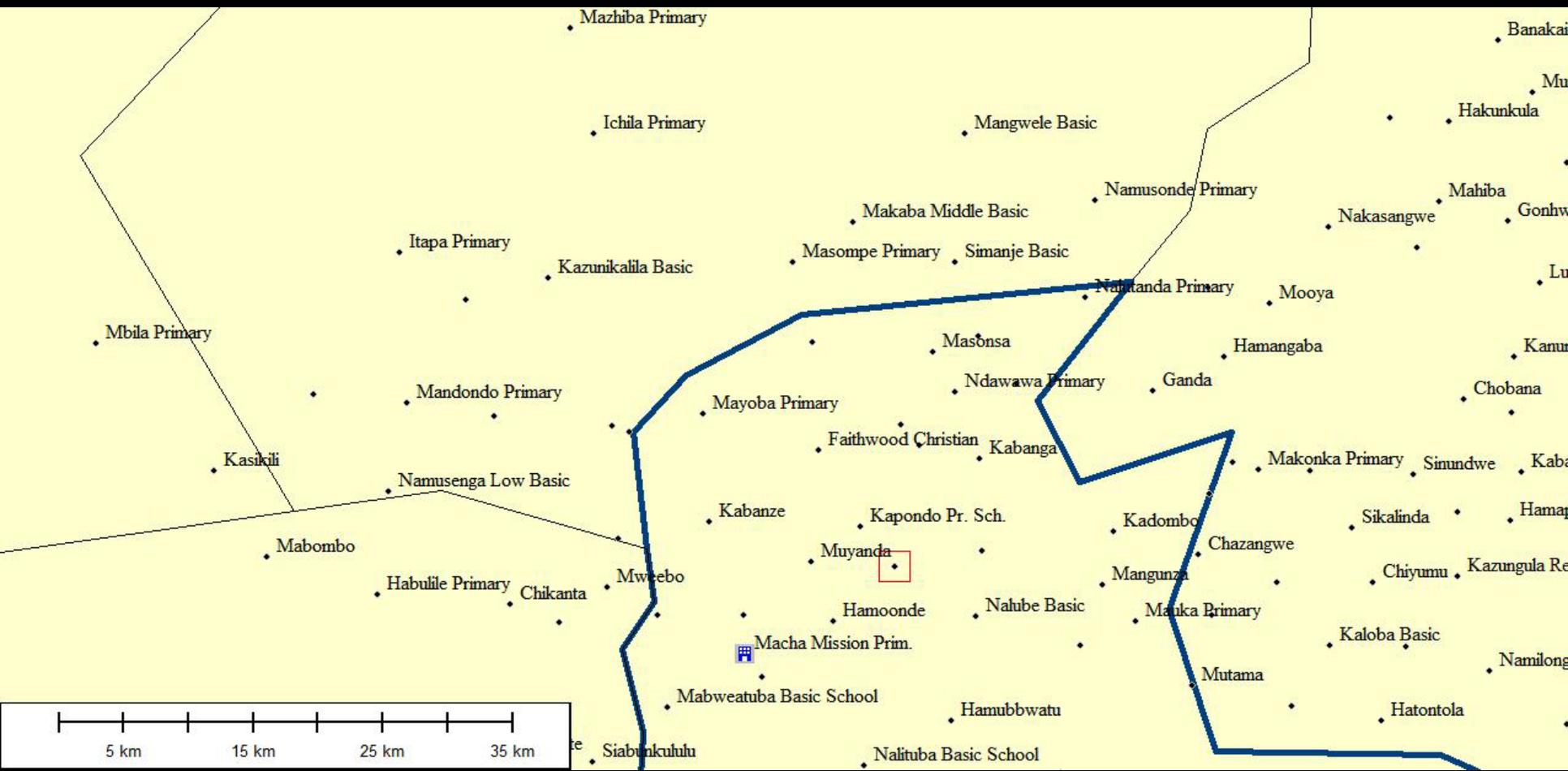


Bala Bbala Study

- **Abstract**: The challenges and rewards of carrying out a screening program for reading disabilities in a rural part of Zambia are ones not easily anticipated until the project is well underway. The presentation will describe the methodology employed in setting up the project in schools that have never participated in this type of research, with some of the lessons learned from collecting data of different types (behavioral, biological, and anthropological), and the progress and rewards to date.

Background

- Prior R21 to Elena Grigorenko at Yale Child Study Center helped develop culturally appropriate instruments (Zambian Achievement Test) in collaboration with UNZA
- Initially R01 conceived as a study to be conducted at two sites, but later restricted to only one study site due to budget constraints
- R01 Project award budget period began in November 2008



Study Outline

- **Objective:** Identify genetic and environmental risk factors for Specific Reading Disability (SRD)
- **Plan:** Screen 3,000 children within 35km of Macha and identify 800 children in two groups:
400 +SRD 400 -SRD
- Administer additional assessments to these 800 children (probands) and their siblings to gain information about SRD
- Collect saliva from probands, one sibling and one parent for genetic studies on SRD

Screen children

Exclude children
with potentially
contributing
factors

Select probands
(+SRD and –
SRD)

Assess children
on additional
reading-related
assessments;
caregiver
interview; enroll
family members

Challenges

- 1) Site development
- 2) Approvals
 - ethical Approval
 - community approval
 - school approval
 - government approval
- 3) Adapting assessment instruments
- 4) Staff training and turnover
- 5) Working logistics
 - rainy season activity
 - school holidays
 - scattered rural population
 - extended family living situation

1) Site Development

- Macha Research Trust was an established research site since 1989, but had mainly worked on clinical malaria studies
- Existing adequate financial accounting system
- Rural area with few qualified potential study employees with appropriate knowledge in educational/neuropsychological assessment methods
- No study budget for vehicles, but study design heavily dependent on transporting teams to and from local schools

2) Approvals

- **Ethical Approval:**

- Yale - April 29, 2009
- Zambia
 - submitted 21 July 2009; considered at 26 August 2009 IRB meeting
 - verbal approval January 2010
 - written approval 07 July 2010

- **Community approval:**

- Meetings with local chiefs, village headmen and community leaders

- **School approval:**

- Meetings with head teachers, PTA chairs and committees

- **Government approval:**

- Meetings with District Educational Board Secretary (DEBS)
- Material Transfer Agreement for export of study samples

3) Adapting Assessment Tools

- Adapting ZAT to more rural environment
- Translating into local dialect (Chitonga)
- Adapting and translating Vineland
- Pilot testing all adaptations and then revising
- Developing parent interview/developmental screener questionnaire

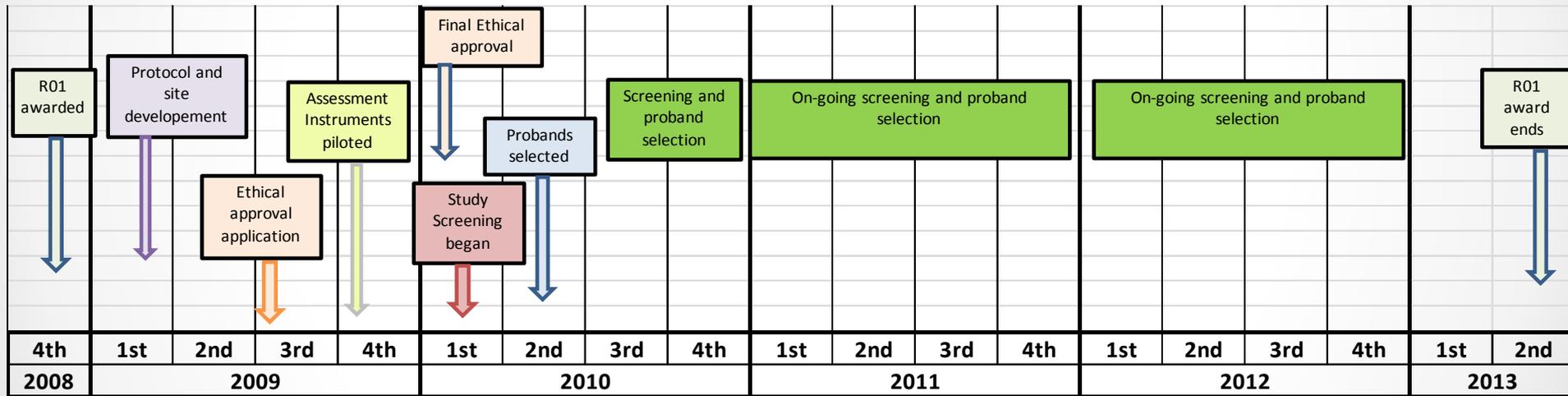
4) Staff training and turnover

- School teacher recruited to manage study locally, but only recently trained as a teacher
- High school graduates trained as study assistants to administer assessment instruments
- Training in hearing and vision screening
- Most study assistants were part time workers, so many left when a full time job came available
- Four of our full time study workers left for further education (1 to university, 2 to nursing school, 1 to lab tech school)

5) Working logistics

- Rainy season disruption of school field work
- Working around school holidays and exam/test periods in schools
- Scattered population in rural area
- “Extended family” - so children often not living with their parents; implications on obtaining consent
- Transportation – 4 wheel drive vehicles, motorcycles, bicycles

Time – Line for Study



Rewards

- Most schools have eagerly participated
- Many study workers have been introduced to, and trained in, use of assessment instruments, and have subsequently been motivated to go for further education themselves
- Despite the challenges and hurdles, the study is close to reaching the planned screening of 3,000 children, though completing the comprehensive assessment of 800 “probands” is proving difficult

Progress to date

	<u>Goal</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>
Number screened	3,000	~800	1,399	2,370
Probands tested	800	~200	308	541
Proband and family completed all items	800	~50	184	131

Presentations / Publications

- Assessing Paired-Association Learning in Rural Sub-Saharan Africa
- Reading Assessment in Chitonga: A Comprehensive (Pilot) Study of Zambian Children
- The effects of socioeconomic status (SES) on the intellectual development of school-aged children in rural southern Zambia
- Adopting Loanwords into Chitonga
- Phonological Awareness in Chitonga
- An Epidemiological Study of Specific Reading Disabilities in Southern Province, Zambia: The Bala Bbala Project
- Exploring Phonological Awareness in Bantu: Evidence from Chitonga
- Examining the Specific Effects of Context on Adaptive Behavior and Achievement in a Rural African Community: Six Case Studies from Rural Areas of Southern Province, Zambia. *J Autism Dev Disorders*, (published on line 03 March 2012)

Conclusions

- The logistics for carrying out a study which is spread out over a wide rural geographic area and includes children from many different villages, is never as easy as first anticipated.
- Using a committed, well trained and a dedicated study team has benefits, but can also lead to staff turnover as individuals see their own potential for further education and training.
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