

## **FIC BRAIN Webinar Full-text Transcript**

### **“The Tumaini Child Health Project Screening for Neuro-developmental Disabilities in a Developing Country: Challenges & Suggestions for the Way Forward”**

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**Angelina Kakooza:** The topic of interest and that is the Tumaini Child Health Project. I would like to give you a brief of how we began this project. It was conceived following a visit by one of the NIH pediatric neurologist and that was Dr. Deborah Hirtz who came to Makerere University College of Health Sciences in November 2006. During her visit, she gave us a talk in Davis Lecture Theater about the opportunities for research at Fogarty International Center and at the NIH. And she talked about the Brain Disorders in the Developing World: Research Across the Lifespan. I expressed interest in pursuing this research and following her visit, she put me in contact with a perinatal, an experienced perinatal epidemiologist, Dr. Judith Grether. Our communication initially was by e-mail, but later on we started--as our discussion drew much more data, she decided to come over to Uganda which was really a very good thing because when she came on the ground, she was able to really see why I was pursuing this particular interest in neurodevelopmental disabilities. So we entrusted other colleagues in my department, namely Professor Sarah Kiguli and Professor Charles Karamagi, who joined our team and we're able to write up this research project and later applied for funding and fortunately was funded on the first round. So as I mentioned, the funding for this project is from Fogarty International Center and National Institutes for Neurological Disorders and Stroke (NINDS) and the funding was for a two-year planning grant. That is from July 2008 to June 2010. In this presentation, I would like to go through the definitions of neurodevelopmental disabilities, talk a bit about the literature review, the situation of neurodevelopmental disorders in Uganda, the aim of the project, the outcome measures, the long-term vision, what are the challenges and the way forward. Now, neurodevelopmental disabilities are identified as one of the greatest threats to global public health. As quoted from the WHO publication in 2006. When you ask yourselves, what are neurodevelopmental disorders? These are a diverse group of chronic conditions, often severe, that originated during neurological development and typically persists throughout the life of an affected individual. They are due to mental or physical impairments from the affected brain

and special senses in neuromuscular systems. They usually begin at any point in development up to 22 years of age and the impairments most often last throughout a child's lifetime. Now, the etiology is diverse, they may be congenital or they may be acquired through accidents, trauma or infections during the early life. This cunning three, they have limited data regarding the etiology and it's been postulated that it could lead to multifactorial causes including genetics, environmental, prenatal, post natal, and miscellaneous contributors. Now, it has been mentioned that it's important to identify these developmental disabilities earlier. In recent years, conservative evidence is accumulated supporting the benefits of early intervention for improving long-term outcomes for children with neurodevelopmental disabilities, particularly autism spectrum disorders and other complex behavior or learning disorders. This can be a primary, secondary, or tertiary level. For example, clinical investigations have demonstrated that even in the absence of special life intervention programs, improvements in cognitive and language field in children with autism are more dramatic between the preschool years and middle childhood and have been observed from mid-childhood to adolescence. This fact has actually leading many countries to increase public awareness of the value of early screening for developmental--early screening--the development of early screening tools to develop, to identify young children at risk for developmental disabilities and the initiation of intervention services. Now, neurodevelopmental disabilities are of various types, and among the common neurodevelopmental disability that often leads to severe impairments and which result in considerable personal and public health cost are autism spectrum disorders, cerebral palsy, epilepsy, mental retardation, speech and language disorders, hearing impairments, and visual impairments.

There are very few studies on the rate of neurodevelopmental disabilities among children, most so in the developing world. And it is thought that there may be much more common in the developed world due to multiple known risk factors such as malaria, HIV/AIDS, malnutrition, poor obstetric and neonatal care. Professionals and planners have been urged to assess the burden of these neurodevelopmental disabilities, so as to take appropriate action in their management, with Sub-Saharan Africa being one of the areas in greatest need. The data on disability in Uganda is now discussed on what we have currently is from the Population and Housing Census of 2002 which reported that 3.5 percent of people surveyed had one or more disabilities. For the survey, disability was defined as any difficulty in moving, seeing, hearing, speaking, and any

mental or learning difficulty, which would last--which had lasted--we expected to last six months or more. For the general population, 3.5 percent of the people surveyed had one or more disability with higher prevalence in the northern and eastern regions compared to other regions. The prevalence increased from--with age from 3 percent for the age group 5 to 9 to 5 percent for the age group 35 to 39. And the most common disability was difficulty with legs at 29 percent, followed by sight problems and hearing problems. Majority of these disabilities are acquired with diseases and illnesses being the lead cause in more than 50 percent of cases. And nearly 45 percent of these cases that was surveyed at this time had not received any form of rehabilitation during the 12 months preceding the census. This implied that they have either lack of available resources for people with disability in Uganda, or facilities to manage these people are hardly existence. Sorry. Due to the stigma attached to some of these neurodevelopmental disabilities, many of the children were noticed not to access health facilities giving inaccurate records. And this has been found in studies done in Kenya as well as studies done elsewhere in Africa. This was a lack of consistent administrative databases and medical records in the developing world to enable case identification of neurodevelopmental disabilities. This is why Maureen Durkin and colleagues developed a two-stage approach for population surveys for childhood disability to answer this question. Now, this two-stage methodology that was developed for population-based studies for childhood disability includes one stage which is the first stage of screening door-to-door, followed by a second stage of comprehensive assessment, examining what type of disabilities are present. And information on any other thing of severity of the condition, the causes, any rehabilitation needs and referral for appropriate services. Now, the stage one screening that was developed by Maureen Durkin and colleagues used some instrument called the "Ten Questions" screen. This "Ten Questions" screen was for surveying children between the age range of 2 to 9 years, is administered by non-professional community members. You ask the mother to compare her child to others of the same age and cultural setting. And the answers are given in a yes or no some formats. What is notable about this Ten Questions screen was that there are no questions that were developed for autism spectrum disorders at that time. Stage two involves the comprehensive clinical assessment where the children who registered a yes response to any of the questions were referral for further assessment. This was necessary due to the inability of the Ten Questions screen to actually establish an actual diagnosis. So this was carried out by a trained professional staff in their respective disciplines. Now, what is the

neurodevelopmental disorder situation in Uganda? Neurodevelopmental disorders are a global health problem whose burden is not clearly defined in the developing world, Uganda inclusive. Apparently, there are no accurate figures for Uganda on the burden of neurodevelopmental disabilities to permit effective policy responses. And a large number of the cases with disabilities in Uganda do not accept any form of rehabilitative services. Furthermore, case identification methods with neurodevelopmental disabilities in the developing world are hampered by lack of reliable medical records and the Ten Questions screen that I illustrated about earlier used to identify these cases does not address other conditions like autism spectrum disorder. In Uganda, we have currently no screening or assessment tool for neurodevelopmental disability. Now, the aim of our TUCH project, the Tumaini Child Health Project was to establish and evaluate a three stage system for surveillance of moderate to severe neurodevelopmental disabilities in two pilot communities in Uganda. In addition, we wanted to establish an effective interdisciplinary collaborative network of Ugandan and international clinicians and epidemiologists. The fourth stage of our project involved a door-to-door screening where a research assistant together with the mobilizer went to the house of a child within the age range 2 to 9, ask whether the child had any of those symptoms using our adapted tool. Now, our tool was adapted following a technical advisory group meeting in which we adapted questions to involve other conditions like autism spectrum disorders and added on other questions for vision to make it more robust and come up with 23 questions. Now, these 23 questions were the once we used for the door-to-door screening. Now, at the door-to-door screening, there was a child who answered a yes. That child was a positive screen. If a child answered a no to any of the questions and that was regarded as a negative screen. So, we collected all the positive screen together with a sample of the negative screens. Now, the negative screens included every third negative child who are then referred to the second stage which was the core exam with a medical officer at a health unit within that community where we had done the screening from. Now, the medical officer at the health unit would examine this child and decide, determine based on Ugandan pediatric protocols that had been developed for this project becoming whether this child required referral to specialist attention in Mulago Referral Hospital if indicated. That was the third stage. And at Mulago National Referral Hospital, the specialist attentions included vision, hearing, speech and language, epilepsy, or cerebral palsy, autism or--mental retardation or cognitive impairment. So, the stages were three, door-to-door screening as the first stage. The second stage was core exam

with a medical officer at the health unit. And the third stage was referral to Mulago National Referral Hospital for specialist attention. Now, the main outcome measures of this research project will be the development and evaluation of the expanded screen up, 23 questions, screen up questionnaire and the secondary outcomes will be preliminary data on the prevalence of neurodevelopmental disabilities in Uganda, development of a comprehensive training plan for screening and assessment of children with neurodevelopmental disabilities, and establishment of neurodevelopmental disabilities technical advisory group in Uganda, and collaborative network of Ugandan and International Clinicians and Epidemiologists. Our long-term vision for this project is to establish a center for neurodevelopmental disabilities and research at Makerere University College of Health Sciences in collaboration with the colleagues in the United States. What are some of the challenges that we faced during this project?

Now, we start with the first challenge which was administrative issues. Before we set out to begin this project, we have to establish institutional review board permission from two centers. That was Makerere University College of Health Sciences where I'm based together with California where my colleague, my--the PI for this project, Dr. Judith Grether, is based. Now, before you start such a project, there are times that you cannot anticipate the delays that are involved in setting up such a project. There were issues that coped up because the institutional review board at Makerere wanted us to review the consent forms several times. This means that we have to keep revising these consent forms and also have them revised at the other side in California on several times and by that time they have --a lot of time between what we had anticipated between the research assistant training and after starting of the field work. That caused a little delay and by the time we had to actually start a study, a lot of time had been--a lot of time had taken place between when we had to train the research assistant on the actual starting of the research project but we have to do some refresher training. Secondly, amongst the other administrative issues that we faced was that the research assistance that we employed often experienced delayed in getting the allowances. Now this is an issue regarding the fiscal agent that you employ to run your project. We did not use the Makerere University Institution, but we use another institution that was affiliated to Makerere University. Now there are issues of bureaucratic procedures, signatures over checks that have to be issued require a number of signatures before the actual amount of money can be realized. Now, all this bureaucratic

procedure leads to delay in terms of payment on time and is led to disgruntlement with the research assistance which could--which required us to reassure them, to ensure that the work was done despite this hiccup. Then, as we were recruiting this research assistance, we went through a process of advertisements. After the advertisements, we conducted a series of interviews. Now, in the interviews, we tried to the best of our ability to choose the best research assistance that we thought could actually be of benefit to our project, that also realized when have started training these research assistants, some of them were actually committed to other project, but had much told us before that. So when these projects were reactivated, they came to us and asked to be excused. That has meant we needed to train a new batch of research assistants which was quite cumbersome. Then in the development of the neurodevelopment disabilities screening tool, remember that this Ten Questions screen that was earlier developed by Maureen Durkin and colleagues did not cover the additional domain of autistic--autistic spectrum disorders and we wanted to screen for this condition amongst our children. It has required us to develop these questions that were relevant and that could be able according to what we thought pick up this condition. Now, there have been various tools that had been applied in the developed country, but their value in being applied to developing countries is still questionable because there are issues like casual factors and the way that people interpret the questions that have got to be put into mind. For example, in some cultures here in Uganda, it's considered rude to look somebody in the eye and yet the autism spectrum disorders we want to find because the child have positive eye contact. So, such examples, a need to partition of behaviors vary amongst the cultures. In addition, as we were developing this Ten Questions screen, we had to translate it into a language that is understood by the community in which we we're going to apply it. Now, we worked in two communities. That is an open community which is Kampala, housing the capital city and the rural community which was district where the language spoken there is mainly luganda. Now in Kampala, it's more cosmopolitan in English and luganda are spoken. So that require that I had to sit with the local experts at the Department of Languages in Makerere University and translate this--ensure that the translation into luganda was pertinent and above translation was also pertinent then pilot test this tool in Mulago National Referral Hospital on a sample of 30 mothers with children with known disabilities and another sample without known disabilities. Ask the mothers whether there were any ambiguities or whether they understood the questions, later engage them in a focus group discussion to obtain feedback on the wording and its application. I

know this requires time and a lot of care and attention. Now, regarding those communities for selection, as I mentioned earlier, we're watching two communities or two areas, the urban which is Kampala districts and the rural which is Wakiso district. Now, before we went----before we could start working in these districts, we have to meet with several district administration personnel before we could get their permission to actually start. Now, meeting the district administration personnel is not an easy task. You'd go one day and find there's no one in office that day. They have all gone to the field. You come back another day, they are maybe involved in some other activities. They cannot meet you, "Can you come next week?" You go the next week, you find they're involved in several other activities. So this means that we have to incur extra cost for travel. Make several visits to the district administration before actually finally meeting with the concerned authorities. Now, when we meet with the concerned authorities, you find that the authorities try at times to manipulate you in terms of which community you are actually going to screen. We'd tried as much as possible to explain to them that this is a random selection and there was no way that we were going to be influenced in terms of selecting these communities. The way we call it--We selected our communities was by a class of sampling strategy with probability proportionate to the most recent census of the community population size. We selected 10 parishes in each district from a list of cumulative population ages and in Kampala district, we actually divided the clusters of selection into the up skill that is the more well to do community and the slum areas to get a bit of representation of the urban dwelling. And in each selected cluster, the interview team with the assistance of the parish mobilizer known in the community becoming the midpoints of the parish and then blindly selected the direction in which all eligible households in that root will be screened until the desired sample size was achieved. Explaining this to the community members was a bit vague to them. The studies have--dealing with neurodevelopmental disabilities, we can even take you to these homes of these children who have these disabilities, but we have to explain to them the truth. This is not the way that we want to carry up these researches. It has to very unbiased and this is the strategy that we have to employ. In addition, we noted that there was lack of up-to-date local village records to determine the latest population size of the village. So we have to use old records and remember that a facility rate is 6.7, so most likely this village records were not accurate at that time. Now, in the preparation of the communities, we had to involve ourselves in a series of sensitization and community engagement meetings, having representation of the district

personnel that would be pertinent to help us carry out this project. Unfortunately, you'd find that we had to accommodate very--quite a number of irrelevant personnel. These personnel were mandatory if we needed to get the permission to have this study carried out. And in addition, these personnel that were irrelevant, we have to cater for their facilitation, we have to cater for their refreshments, transports, and all these persons, we are not budgeted for initially, but we have to bend because we needed the permission to conduct the study from that community and there was no way that we could jump this important people according to them to be able to carry out our study. Now, regarding the data collection procedures, we conducted these--we conducted these studies, in the morning would--a team would collect, get all the items that are unnecessary for the project, for the exercise in the field and then go out to the respective homes, door-to-door with the village mobilizer to try to find out--to try and ask which children would be eligible for us to recruit. Now, we noticed that our age range was--our age range was 2 to 9 years, but most of the children in the higher age range who needed to ascend because the institutional review board at Makerere College of Health Sciences required that all children above the age of 7 needs to ascend for participation in a study. So most of the children that needed to ascend were not available at the time of the screening, necessitating us to have the second or the third visit before we could actually pick up these children's information. And by starting too early in the morning, we found that some of these caregivers were still in the gardens and not available to answer the questions. It required us to even move to the garden or come back and revisit them to ask the questions. Some of the caregivers were also busy with household obligations like cooking the food, taking care of the home, or taking the animals to pasture and see that the interview was inconveniencing them. So that meant that maybe if there was an eligible child in the particular household, we had to skip that house because the caregiver found that the interview was going to inconvenient her. Now, in the urban city, that is Kampala District, many caregivers and parents were not at home during the weekdays as they were away at work. And the only time to contact them was Saturday or Sunday. So, the research team would come to our house and find probably only a maid and the maid was given strict instructions not to allow any strangers into the house. So that meant that on Saturdays and Sundays, the research team had to make repeat visits to these homes to be able to interview the parents. And a number of these caregivers in the urban setting were not as were coming as in the rural setting. They wanted to know how are they going to benefit financially and some were actually asking for a fee before we could interview them.



Now, these bill of state of child kidnapping in Kampala city and other cities in Uganda and they were--and these created fears among the caregivers that these fears with recent child kidnapping made them suspicious about the intentions of the research study and reluctant about disclosing child information. Some parents in addition declined to be interviewed because of stigma, this we noted specially with epilepsy with some caregivers who actually had children having epilepsy, we were told to be fool by the village mobilizer that, "You know, this house they are going to--there is a child who actually have epilepsy," and some caregivers because of the stigma around it, would fear or would be very reluctant to disclose that actually their child could be having epilepsy. Being--The fact that we were actually asking about conditions of these children could be having, some of this children actually had acute illnesses at the time of the interview, conditions like malaria, probably diarrhea, and parents actually wanted the medications for the common diseases for their children, but this was and as you know, original budget and the TUCH project tried to meet this cost where it's called but we were not able to meet this expectation or the situations. Now, the time that we conduct the study was a very tricky situation. It was a time of a political campaign and voting, going on for the presidential election as well as for the representatives of the districts. And this prevented some of the caregivers from bringing their children for the scheduled appointments, they use the aid they needed to go to vote or they were campaign managers or the--actually they wanted to involve themselves in the political activity that was taking place at that time. And we noted that some of the village mobilizers were pretty backing on this situation of conducting the study. Informing the community members where we we're participating that they were the ones responsible for bringing us into the district so as to get most approach from the community members. And sometimes they actually promise--mostly promise them mosquito nets, money, and other incentives to the family members as a political gimmick to be able to obtain votes. Now we have challenges also with the female village mobilizers. We noticed that they were not as good, like managing the long walking distances especially in the rural community and the increment with the--of the male village mobilizers were. What kinds of village--female village mobilizers complained that it was rather hard. The distances were too long for them and this hampered the work progress [inaudible]. In conducting the assessment, some caregivers did not show up for the medical officer exam. This is the stage two after the door-to-door screening. We found that the caregivers at a sudden time were not showing up and this required us to make frequent phone calls. Fortunately, we also

have the Global Positioning Systems coordinates of these homes so we would use them also to help us identify the particular home and go back and ask the mother, or the caregiver to come back for the medical officer exam. Some caregivers actually book children who had not been screened initially because they look at this as an opportunity. We went into our home, we screened children whether they had a neurodevelopmental disability and those who went positive and every found negative were the ones who are called for the stage two for the medical officer exam. But some tribal parents took it as an opportunity, "Why didn't I bring this other child? Possibly examined by the medical officer." So we ended up loading the medical officer with quite a lot of work that was quite strenuous for them. In addition, the husbands, some husbands refuse to let their wives come to the exams, for the medical exams or the specialty exam because they were suspicious that probably their wives we're going to other activities. We try to explain to some husbands and they relented, but there were some who actually refuse to let their wives come over. Some caregivers of the children who was screened, those who screened negative because we have to get a sample of every third child who was screened negative to come over for the medical officer exam. They realized that their children did not have any problem. So they keep asking, "If my child doesn't have a problem, why do I need to come up?" We explained to them that this is necessary for our research project and we explained to them the reason why we needed them to come over. Some did come, but others did not really found--find it necessary to come despite the fact that we were catering for the transport, we're catering for their refreshments, and were insuring that they really would get it for during the time that they were here with us for the medical officer exam and the specialty exam. Some caregivers also changed their mind after the medical official exam. So, they would come for stage one screening, stage two screening for the medical officer. Now the final stage three, where they have to have a specialty examination, some caregivers change their mind and said, "Well, I think I had enough, I don't think I'll come back." And the fact that we are accepted that they could decline at anytime of the study, we restricted their feelings and let it be. Now, the initial plan was to get--when were having the technical advisory group meeting, the initial plan was to have each child who would be referred for a disability to be reviewed for all the disabilities that that particular child was referred for. For example, if a child was referred for visual impairments, epilepsy, autistic spectrum disorders, and probably mental retardation. If that child would come and have all those disabilities reviewed in one sitting, however, we realized that this was not feasible. This initial

plan could not work because the specialist in Mulago National Referral Hospital had various other duties, duties of the state that they had to care for, they also had other issues that they have to deal with, and you find that the timing was really conflicting. So, that necessitated us to actually transport these children on several occasions depending on that number of disabilities that they were been screened for. So week one, probably would come for cognitive impairment or mental retardation. Week two would come for vision, but even to come for vision, it will require us to find out from the specialist, are you available at that point in time, sometimes you say, you know I have to travel or probably I'll be out of the country. So it keeps the patients waiting and of course if they keep waiting, they get bored and then they decline. So, all those issues are to be factored in because we could not keep everything working smoothly the way we wanted it and there are also limited numbers of specialist and their demanding nature of their work could not put out initial plan into practice. So based from all of these challenges, what is the way forward to try to combat some of these challenges?

Our advice that we--you allow for adequate time to process institutional review board permission before the start of the project because the log time and the delay needs to be factored in before you actually start the project. Now, if the budget line permits depending on how much funding you get, it would be advisable to train a number of research assistance to have at least some that you can have on standby in case others abscond the midway of the project and this can prevent you from getting disorganized. Because we have to make several visits to the district administration and find sometimes they're not available, sometimes they're in a meeting, other times they're out of the country, it would be important to identify a liaison within the local district authority. This person would help to facilitate your communication with the administrative issues at the local district so that you don't need to incur extra transport costs or make visits where you may be failed to meet the people that you'd want to meet and incur unexpected costs which would be detrimental to your project budget timeline. It will also be advisable to have a very substantial contingency fund to fit up for unexpected expenses in the field and research regarding school age children. Ideally should be done during the school holidays when the children are around for the *[inaudible]* issues. Regarding the village mobilizer, many times you find the local district tries to influence you to have village mobilizers who are either influential within the community or they really have some association with the

people at the top. But try to recruit well-known, energetic, versatile village mobilizers who'd be able to travel the great distances within the community with ease. And before you stop the project, try to familiarize yourself with the prevailing circumstances in the community you are to walk in so as to avoid unnecessary delays. These delays could be hampered by things like harvest season, circumcision season, political campaign season like in our place, and these can cause unnecessary delays. And when dealing with caregivers, do not forget the male figure, the husbands and fathers who equally need support on ongoing counseling. You should exercise transparency at all stages of the research study and invest in effective communication like mobile phones. We had--We catered for mobile phone, mobile money--we loaded the mobile phones of our research assistance to ensure that at any one time, the communication between the supervisors, the research assistant and the field coordinators works through it. And in the rural areas where homes are fairly distant from one another, it's advisable that a convenient location be identified within the community to accommodate the research team. When we were in the rural community, we identified a home or a house where the research team was housed. This was very, very convenient for us because the research team was in one location, we were moving very short distances within the community, we would meet at the end of the day, discuss our shortcomings or what challenges we've met so that the next day, all of us are on the same page. So, identifying a convenient location to house the research team involves particular communities that you're going to working is very economical as well as efficient. I would like to thank the TUCH--the Tumaini Child Health research team, Professor Sarah Kiguli, our core investigator, Professor Charles Karamagi, to Mr. Keron Ssebeyla, our Project Manager and also our United States colleagues, Dr. Judith Grether, who was very, very instrumental and very helpful on this project, Dr. Edwin Trevathan, Dr. Robin Hansen, Dr. Lisa Croen, and Ms. Karen Smith. I also like to acknowledge the caregivers on the children that participated in the study, the local district authorities in Wakiso and Kampala districts. The NIH Fogarty International Center and NNIDS and the Department of Pediatrics and Child Health, Makerere University, Mulago Hospital staff, and the very versatile TUCH researcher assistance and study team. Thank you very much for your attention.

I group a series of questions that I would like to address at the moment. And one of the questions, two of the questions have already answered in my presentation--what's--one question

was from Dr. Kathleen Michels, how did you get started on this research and what role the FIC NIH brain disorders program play in starting and continuing the work? Probably at that time, the mic was not on at that time. Probably, I can just repeat what I've said at the beginning. The word--These projects which is to Tumaini Childhood project was conceived following a six successful application for an R21 planning grant from the Brain Disorder in the Developing World: Research Across the Lifespan. You may be asking yourselves what the words Tumaini means. For those not familiar with swahili, it means hope. And the slogan for our project is bringing hope to the child. So I obtained information about this program. The brain disorders in developing world from a visiting pediatric neurologist from the NIH, Dr. Deborah Hirtz, who presented a talk on the Fogarty Center and the other NIH grant opportunities for pediatric research at Makerere College of Health Sciences, Davis Lecture Theater in November 2006. After expressing interest in pursuing this line of research should put me in contact with an experienced Perinatal Epidemiologist Dr. Judith Grether. We initially communicated via e-mail then later Dr. Judith Grether came over to Uganda. We discussed further on my selected area of research interest which was pertinent to the needs of the Ugandan children. We've interested other colleagues in my department and then together we wrote up this project proposal, applied for funding, and we're very fortunate to be funded the first time round. The second question was by Dr. Richard Ethrow, what is the current state of screening for neurodevelopmental disorders? How can we overcome these challenges? I think I explained that on this talk and given also possible solutions how we can overcome these challenges. The other question--I'm not certain about who exactly us, but the question was, how do we apply ethical values to populations with low education levels and application of informed consent process? We--Because it was a requirement for both institutional review board, that is the California, the Californian one for my colleague in the United States and the Makerere University Institutional Review Board requirement, we have to apply the informed consent process for those people who had low educational levels and were not able to sign, we use the thumb print as a proof that they had actually agreed. We read them the consent form in a language that they understood and when they understood what it was that we are going to do, they show their acceptance by using the ink pad, pressing the thumb on the ink pad and then pressing the thumb print on the piece of the consent paper. They keep the copy and we keep a copy. What are the practical--The other question was what are the practical ways of planning an applicant network on the diagnosis and

prevention of neurodevelopmental disorders? Now, the TUCH project was a planning grant and we have tried to demonstrate how we tried to develop a network of colleagues within Uganda to try to set up a neurodevelopmental disorder network. We convened a team of experts which we call the technical advisory group including experts from various fields, ear, nose and throat, vision, physiotherapy or professional therapy, neurology, pediatrics, and all of these to mention but a few all of these came together and form the technical advisory group together with other colleagues, epidemiologist, commissioners from the United States and we worked together to form a technical advisory group which then was the one propelling or advising these projects within. Now, we can go borrow from this to set up an African network for the diagnostics and prevention of neurodevelopmental disorder. Set up, I mean, inform those or find out those who are interested in your developmental disabilities. Now we have a webinar presentation series or we can use the LinkedIn, make a group, interest group and then walk along that to try and develop a network for diagnostics and prevention of neurodevelopmental disabilities. The other question was, how do we deal with the disparity in research trend of collaborating low-middle income scientist when applying for collaborative research grants? Now, you notice that the experience of neuro--of scientists in the developing world is not as much as that--or is not as great as that in the developed world but it could be a good thing if those who are reviewing these grant processes could have that in mind that actually our experience is not as robust. I was pertinent that I was working with a very experienced epidemiologist, Dr. Judith Grether, so she mentored me and she helped me and we tried to work out these projects together. But in terms where it's just somebody beginning, really need a lot of help and it's advisable that these particular aspects that we may not be as well experienced as other research commission in the developed world should be put into consideration for those that are reviewing and scoring our project proposals. The other question was from our principal from Makerere University, College of Health Sciences, Professor Nelson Sewankambo who is asking about the major ethical challenges that we faced in this project. Well, amongst those that I can recall are issues regarding these children not being available because they were at school and sometimes finding a husband or probably a husband who is reluctant to have his wife consent or the wife reveal--give us information regarding the child or permit the mother of child to come over for father assessment and diagnostics. In addition, we failed--sometimes the ascent process was not really very well-done because some children--we try and explain to them what it is that we were trying to do and

the mother would say "Whoa! I think they've understood." I think they've understood. So, sometimes these--some of these ethical problems were faced during the presentation or during the research project. Those are the questions that I received prior to the presentation. And now I would invite any other questions from those listening, I appreciate your staying on and listening to my presentation and I look forward to any questions. I had another question from Kathleen Michels who says, "You had a lot of challenges." Yes we did. From the screening and followup you are able to do what neurodevelopmental disability problems that you identified for the children that were a highest priority. From the screening and follow up you were able to do what neurodevelopmental disability problems, did you identify? Well, I think the question is, what children, what were the...The neurodevelopmental problems that we identified that were highest priority to followup were the ones that we set up to investigate, and these were seven, autism spectrum disorders, hearing impairments, visual impairments, cognitive impairments goal, mental retardation, cerebral palsy and epilepsy. That was our main focus. As you know that there are other development disabilities like attention deficit disorder but we did not focus on that in a research project. And if you have not answered question well, please copy and you can type again. What--the other question we have is from Kristine Isaac who asked about what neuro development of problems did you identify for the children that's where our highest priority for follow up. Okay, sorry, it was repeating capturing question, okay. Yes another question from Kathleen Michels was, was there any surprises? Yes there was surprises in that we had expected to find a number of cases--a number of children having visual problems as we ended up having quite a few, I mean less than we expected in terms of those who had visual problems. And regarding the children who had hearing problem, we found quite a number that's had hearing problem associated with other disabilities and these children who had hearing problems had not been identified by or not been identified by the caregivers or the caregivers had identified them but were not really certain. And we found that on close diagnosis, some of these children were actually had been going around or have been being treated for in their homes with some attention but not that--the attention that has been given to these children for with hearing impairment had been quite intense for the families so we were surprised to note that these families not actually been able to cope despite the disability that they were facing with their children. Some other surprises that we found where finding people in the urban setting who already knew that their children has a disability but where sort of like, "We shall come. We know about this but we're

coming so you don't need to remind us, we already know that our child have epilepsy, or our child have this and this problem so we don't need you to remind us." So it shows that some patients or some caregivers do know that their children have problems. It's either they're not seeking attention where they supposed to seek it or are probably going else where, where they believe the attention should be sort. Another question is, did you find that parents value these diagnoses and wanted to pursue treatment? I've got the question from Judy Rich which said, did you find that parents value these diagnoses and wanted to pursue treatment? Yes, many--I should say the majority of parents value these diagnoses and they actually wanted to pursue treatment. This was more so, of those parents that who were actually at a loss they had known that probably their child was not like other children and somehow were not aware or they did not know when to take these children. So some are really, although over very enthusiastic to actually come and have their child assessed by the medical officer and then go on for specialist attention.

I've got another question from Kathleen Michels who says, is there a high stigma for epilepsy and do they actively seek care? Are the drugs readily available to treat epilepsy? Yes, there is a very high stigma for epilepsy in Uganda and I think it is there for several other African countries. Epilepsy is viewed as a cause or something that someone acquires because of something bad, either the parent's did or something in the family that has gone wrong. So if you are branded or let's say given the diagnosis of epilepsy, if it something that is not to be gloried in. You either have to hide or you either have to say if there's something wrong, and some children or some caregivers would rather say, "My child has several convulsions," rather than saying that it is epilepsy. Unfortunately, the drugs that we have available for treating epilepsy are the older generation drugs. Drugs like phenobarbitone, carbamazepine, and--sodium valproate is not as available as the other phenobarbitone and carbamazepine. And as you know, this older generation drugs are faced with several with other side effects and now is the era of HIV. There is cross-reaction between this past generation drugs, this older generation drugs with the HIV drugs. So having a problem or stigma with epilepsy further on added on the issue of not enough drug compounds this problem. I think we heard Dr. Donald Silverberg entering the room. You're welcome Donald if you have any question. Yes, thank you, Dr. Donald, for the question. The question is, will the conduct of our study and its result influence public policy in Uganda? The plans for dissemination of this study are two-fold. We are going to have scientific papers



published from this work but in addition, we need to write up or we plan to write up reports which reports are going to be shared on the local scene. And the local scene includes the Ministry of Health, Uganda, various non-governmental organizations that are involved with disability and based on this information, we are also going to have a dissemination workshop in which we're going to call the important stakeholder concerning issue of disability to come and seek what information we have to share with them and we really hope and it's really our hope that based on our findings, we will be able to influence a public policy in Uganda. Thank you very much everyone for your attention. I appreciate your staying on to listen to results of the project and I'll hand over to--If there's no any other questions, well I hand it off to Jeff for any other things.

**Jeff McAllister:** Great. I'd like to thank you once again Dr. Kakooza for an excellent presentation. And if there are no more questions, I'd like to thank you all for participating. And I'd also like to read a note from Kathleen Michels, "I would like to remind everyone that the Brain Disorders in the Developing World Program is accepting applications and the next deadline is January 10th."

**Angelina Kakooza:** Thank you very much.