

Sam Pauly: Welcome to the One Voice for Neurology Podcast, a series of podcasts exploring why it's time to make neurology a priority, how that can be achieved with a global and uniform response, and what that could mean for the future of neurology in those living within neurological disorder. I'm Sam Pauly and you are listening to episode 13, Zooming in On Africa, Accessing Services and Care.

Sam Pauly: Hello, and a very warm welcome back to the One Voice for Neurology Podcast. It's great to be back after our previous series of episodes during Brain Awareness Week in the spring. Since our previous episodes, much has happened. Most notably, the Intersectional Global Action Plan on epilepsy and other neurological disorders was adopted at the 75th World Health Assembly in May. The aim of the Global Action Plan, or I-GAP as it's sometimes known, is to have a positive impact on people living with neurological disorders and will address the worldwide challenges and gaps in providing care and services for people with epilepsy and other neurological disorders, and it'll ensure a comprehensive coordinated response.

Sam Pauly: So here at the One Voice for Neurology Podcast, we're taking the opportunity over two episodes to zoom in on two areas of the world and look at the particular challenges they face, how the I-GAP can be implemented and the impact that that could have. We're also releasing an episode on India in which we're looking at the importance of better awareness and prioritization of brain health. We've had some great discussions, so do check it out if you get the chance.

Sam Pauly: But today we're focusing on Africa, a diverse continent comprising 54 different countries and a population of just under 1.4 billion. In today's episode, we'll be primarily focusing on access, the importance of good access to services and diagnosis, and what the current situation and challenges are, and how better access can be achieved. Throughout the episode, we'll be hearing from a variety of voices as we explore the issue and importance of access. We'll be hearing from the WHO, from neurologists on the ground, and we'll learn more about what it's like to live with a neurological disorder in Africa.

Sam Pauly: Now, before we start, just a quick reminder that accessibility is really important. The team here at the One Voice for Neurology Podcast, that's why we transcribe all of our podcasts. So if you prefer, you can read along. Now, if you can't see the transcript on the platform through which you are listening, then you can contact us by email at podcast@oneneurology.net.

Sam Pauly: Right, that's enough from me. Let me start bringing in some of our guests.

Sam Pauly: You're listening to the One Voice for Neurology Podcast with me, Sam Pauly.

Sam Pauly: Our first guest today are both neurologists and we'll be discussing some of the challenges and potential solutions with particular emphasis on the importance of good access. That's quite a broad term of course, and we'll be exploring what

we mean by that and what areas of access need improvement. So to do that, I'm delighted to be joined by Professor Mayowa Owolabi, a professor of neurology and a Director of the Center of Genomic and Precision Medicine at University of Ibadan in Nigeria, and also a One Neurology ambassador. And Dr. Tina Charway-Felli, President of the African Academy of Neurology and a practicing neurologist in Accra in Ghana. Tina is just one of 10 neurologists working in the whole of Ghana.

Sam Pauly: A very warm welcome to you both, thank you so much for joining us. Now Tina, let me start with you because in this conversation we really want to focus on and understand more about the current situation in terms of access to services and care. And Tina, because in my introduction I mentioned that you are just one of just 10 neurologists in the whole of Ghana for a population of just over 30 million, now that seems like an extraordinary statistic. Why are there so few neurologists? And indeed is that few compared to the rest of Africa?

Dr Tina Charway...: So I wish I could say that this is not typical for most of Sub-Saharan Africa. The situation is a little bit better in the North African countries, but this is generally the average amount of neurologists that we have available per 100,000 population. So the average across the entire continent is 0.12 neurologists per 100,000 population.

Dr Tina Charway...: There are many reasons why the situation is as it is. First and foremost, healthcare professionals in general are in short supply. And then when we go further and look at specialists or sub-specialists, it depends on how you categorize us, the difference becomes even more stark. And I'm sure Mayowa would say the same holds true for Nigeria. There are parts of any country that are better, have greater access, there are more neurologists.

Dr Tina Charway...: So again, I'll use my own country as an example. The majority of the neurologists we have are in the capital city and the majority of them are in the teaching hospital, the premier teaching hospital in the capital city. That means for most of the country it's not as simple as there is one neurologist per X amount of population, because it doesn't quite work like that, because not everybody will still have access to the few that are available. And it's practically the same across all the continent.

Sam Pauly: Mayowa, does that ring true for you as well in Nigeria?

Professor Mayow...: Absolutely, and unfortunately so for certainly over a decade. In 2008 I did an article for the Archives of Neurology titled Mapping Africa's Way into Prominence in the Field of Neurology. And I looked at the strengths in terms of numbers of neurologists as well as resources for neurology across the continent. And indeed as at that time, more than 10 countries actually had no neurologists and many countries, the neurologist to population ratio was really abysmally low. And unfortunately remains even low up till now. In Nigeria, which has a population of over 200 million people there only 120 neurologists out of which

only 95 are in Nigeria, many have gone to other places outside of Nigeria. That's one neurologist to 2 million people. So that's really very, very small. And there is massive brain drain of world professionals outside of Nigeria. I think that may be true for many African countries as well. And I agree absolutely with Tina, for those who stay within the country, I think for professional and job satisfaction, many of them are in cities, also because of amenities, education for their children, opportunities for research.

Dr Tina Charway...: Absolutely that is the case. There are more than 10 countries that still have no neurologist at all within the country. I do have to say that in the past, at least two decades there has been improvement but it's not been enough. And in the last five years have had a very significant toll on the brain drain from the continent. And that together with the population is growing, the numbers of neurologists are growing but not fast enough, and then we have the added problem of the brain drain.

Sam Pauly: What do you mean by the brain drain?

Dr Tina Charway...: So this holds true for all professionals and professionals within healthcare, but in particular specialized healthcare, the economic situation in parts of the continent though had improved somewhat in the last two decades, there has been a slide back and it is just simply more fulfilling I guess to practice your trade elsewhere in Europe, in the Americas, and you really can't blame people. But the situation is that the population that needs most those specialists are left without anybody.

Sam Pauly: And so we've talked a lot there already about the number of neurologists working is a major challenge. What other challenges are there, overall in terms of access to services? Tina, maybe you could just start by painting a brief overall picture.

Dr Tina Charway...: So the problems are all intertwined really. So there is neurophobia amongst many health personnel. They're not interested in or afraid of neurology and what it entails. But the practice of neurology itself requires a fairly hefty infrastructure to go with it. So it's not just the doctor. The doctor needs infrastructure to be able to practice their trade, to be able to provide services appropriately for the personnel. So it requires investment. And unfortunately for most of our countries, the healthcare budget is already very small and there is almost no dedicated to neurology or neurological disease budget. So that means that unless an individual hospital has a plan and is building this infrastructure, it makes it very difficult for the professional to work. And that again, by itself, the fulfillment you get from practicing your trade is very complicated because you don't have the tools, sometimes they're parts of your training that are missing, exposure is missing, et cetera, and it makes it difficult to practice. So again, the access to care is not simply access to the doctor, it is also access to the services that the doctor can provide.

Sam Pauly: And Mayowa, what about from the patient perspective in terms of other things that they might want to access, perhaps diagnosis or treatment of course, or maybe rehabilitation, or perhaps palliative care? How is access to the whole range of services that somebody living with a neurological disorder would want?

Professor Mayow...: The situation is even more complex. In terms of the fact that many of the patients are not even aware of any field called neurology or even neuro rehabilitation. So sometimes there is even an issue with demand because they do not just know that such services exist that could either help them recover, or help them prevent neurological problems, or help them to live a good life after surviving a stroke or living with neurological conditions. So there is the issue of awareness at the population level to even begin to demand consortium services.

Professor Mayow...: Then there is also the issue of access and there is the issue of affordability. And then those services in terms of access, in many of the services that are required for neurological conditions are multidisciplinary or interdisciplinary. You need other specialists, you physical therapist, you need speech and language therapist, you need cognitive psychologists, psychotherapist or occupational therapist and so on and so forth, apart from the machine and equipment that you need to make diagnosis, laboratory equipment, neuro imaging, neurophysiology and so on and so forth, that can help you to arrive at that. And sometimes even expensive medications. Or what should actually be essential medications, but some of which are also expensive that are required for specific conditions that you need to treat. So it's a very, very complex situation that requires a holistic solution, including the patients, raising awareness and also providing these services.

Dr Tina Charway...: If I can also add, with respect to awareness amongst the population or the person living with neurological disease, part of the problem is neurological awareness in our own colleagues that are not neurologists and awareness of referral pathways. Because sometimes it is just because the problem has never been recognized, number one, or it has been recognized but the doctor doesn't know where to further refer the patient and what services are available.

Professor Mayow...: Another thing we should quickly mention is that for neurological conditions in many parts of Africa, and that's what we've found, many of them believe that, oh they had a lot of superstitious beliefs attached to some of these neurological conditions, and they would rather seek healthcare in non-orthodox settings. And that's again another complex aspect of the awareness problem and also the demand side of the equation.

Dr Tina Charway...: That's absolutely true. And the other thing is not only considering that this is a medical problem and there are medical ways to treat it, some especially for conditions that affect the elderly, it's understanding the difference between what is normal, and what is not normal, and what should be sought medical attention for.

- Sam Pauly: And so you touched there upon stigma, and I did want to talk about that a little bit further. So not only maybe are they not right accessing, trying to access the services that they should be trying to access. But what other challenges does it leave to access? I mean are people reticent to leave their homes because of stigma and therefore that's difficult to access services? Are there other challenges that are associated with stigma and accessing diagnosis or care?
- Dr Tina Charway...: Because the basic understanding of what constitutes disease and what doesn't is sometimes not sufficient. So let's take something like dementia for example, the person may be considered it has something to do with witchcraft, this is the person is possessed and things like that. So it's not necessarily the stigma of the condition that impedes access to care, it's understanding the need to access care. But of course the stigma definitely does influence people get hidden away, sent to a village, out of sight, out of mind, and therefore do not access care. But again, it's because of the understanding of this is a medical problem rather than this a result of witchcraft or things like that.
- Professor Mayow...: With many neurological conditions, of course many may not have stigma like headache. I mean almost everybody has headache so they won't really see that as something that is stigmatizing. But apart from stigma, there is also issue of discrimination in those who have disability, I mean like Parkinson's or stroke, and they're not able to function well either at home or at work, and there might be some discrimination. Services may not be available, social services, transportation services, and things like that. Which even without stigmatization and that's already a disadvantage.
- Professor Mayow...: But in terms of stigma, I think the one that is most stigmatized of all of them appears to be epilepsy. In fact, so much so that one is very careful to use that terminology, epilepsy, while seeing a patient because they may misconstrue it or misunderstand it. I have to break it down and explain to them that, look, these are just abnormal discharges in the brain and anybody can have it. Everybody has a threshold to develop epilepsy if the right condition is imposed. And then there are other things that are attached to it, which makes it even more stigmatizing. Many people believe people who have epilepsy, they foam from the mouth, and if you touch the saliva coming from their mouth it's infectious, they also start having epilepsy. So it's just a lot of misinformation, misunderstanding, myths that we need to really dispel.
- Dr Tina Charway...: But even worse, sometimes the parents are the ones who take their children out of school because of fear of stigma, not because the disease is not being managed or it's difficult to manage, but just because they don't want anyone to say anything about the child. But Mayowa, you mentioned headache and no stigma to headache. I will beg to differ for those who suffer from chronic headache, they suffer the stigma of being told they're lazy because they can't function because they have a headache. So it's multifactorial, it depends on what kind of stigma we are talking about, but stigma definitely plays a role.

- Professor Mayow...: Yeah, well I mean that may be more of discrimination, but...
- Dr Tina Charway...: Yes, because of stigma.
- Professor Mayow...: Not the same level as epilepsy, where people say, "Don't touch him, you're going to get infected."
- Dr Tina Charway...: Fair enough.
- Sam Pauly: Clearly a complex issue with a range of issues. So clearly education is important. How can awareness be better raised in Africa? And in a minute we'll talk about what solutions you see more generally. But Mayowa, just very quickly, how can people raise awareness better about this sort of thing?
- Professor Mayow...: I think to be able to raise awareness, first of all, one needs to understand what the problem is. You need to really do some ethnographic study, understand from the anthropological perspective what people think about the condition you are dealing with. When you have an understanding of the misunderstanding, then you can address that misunderstanding with solutions. And those solutions will then be targeted to different populations. You need to educate the entire populace. How do you do it? You have to use different channels of education. You could use social media for those who are on social media.
- Professor Mayow...: And you'll be surprised that Africa is one of the leading continents that are using social media. I think Ghana and Nigeria are among the top three countries across the globe that are on social media. So social media is something that can be used at least for the young population. And believe it or not, Africa is the youngest continent with an average age of 19 years. So we have a lot of young people that can be educated. And once they're educated they can also transfer these education in their homes to their fathers, their parents, their grandparents. So pupil curriculum in schools can be used to educate. You have to look at different things that different audiences appreciate.
- Dr Tina Charway...: Totally. And we shouldn't forget about conventional media, the radio, the television, still utilized on mass in the hinterlands of our countries.
- Dr Tina Charway...: But I think an important aspect, especially for the way our culture is set up, is to have spokespeople, prominent people who do not shy away and who do not reinforce that stigma to help in the advocacy across all levels. So from very basic population, to our policy makers, our policy makers have to be part of the process because there will always be a disconnect if our policymakers who are responsible for making the policy so that we can implement all the things that we're planning and all that education we're trying to do, if the policymakers are not part of that program, we will find it very difficult. It won't be impossible, but it will be difficult.

Sam Pauly: Let me pick up on that point, Tina. Would you say that at the moment they are part of that process? That's the first part of the question. And the second part is that of course in May this year the World Health Assembly, the Intersectoral Global Action Plan was adopted, what are you hoping that that's going to achieve and how will that support policymakers? Do you think this is going to be a good solution?

Dr Tina Charway...: So I'll take it from the second part of the question. Yes, the I-GAP, [inaudible 00:19:57] Global Action Plan was adopted by most of our countries. It won't be very flattering here, we are very fond of adopting popular things, it's implementation that's going to be difficult. And I think because they have adopted it, we are now in a position, as important stakeholders in the process, of holding them accountable. So adopting the action plan is not enough, now you have to act on it. And I think by holding them responsible and accountable for having adopted the process, we can again get them involved in the process

Sam Pauly: And how do you hold them accountable? Mayowa, you wanted to add to that?

Professor Mayow...: I think to be able to hold them accountable, you need not only the policy makers but the policy actors, including the populous, including the electorate eventually, the citizens. Because if they put some of these things as [inaudible 00:20:55] in their manifestos or their plans, when it's time to re-elect, people are going to take them to accountance and say, "Look, have you really done this?" So I think that's very important.

Professor Mayow...: Again, it's an ecosystem. All the Ps and I said there about six Ps. The policy makers is one P, okay, which is very important. But it's also the populous, we talked about the populace, how do we engage the populous across the life course. Patients themselves who are already suffering from this and their care providers. Then we also mentioned the professionals who are involved. Professional societies like the like [inaudible 00:21:33] for instance, like neurological societies in different countries, like stroke societies, they have roles to play and they also implementation of partners, which is another P. They really have a lot of role to play in terms of advocacy. Then funders, payers, health insurers, those who pay for health services, they're also important. So all of these Ps working as an ecosystem, each one can hold the other accountable.

Dr Tina Charway...: Mayowa, I'll steal a page from your playbook and talk about brain health. If we approach this from a brain health perspective and we educate each other about brain health and how it is important from day zero to their hundred for example, we then have the action plan and the stakeholders. And the stakeholders are absolutely, every single one of us. Everyone who is in a possession of a brain, and that's absolutely every single one of us, is a stakeholder to ensure that this action plan reaches provision. And when we approach it that way, no one is not important, everybody's important and we can gain traction and move forward.

- Professor Mayow...: Absolutely. That's actually the grand plan. If you have a brain, you need brain health. You must be part of this.
- Dr Tina Charway...: You're interested in it.
- Professor Mayow...: And even from the point of view of those who are only interested in economics or politics, without brain health there is no brain capital. Without brain capital, there is no human capital, there is no economy.
- Dr Tina Charway...: And the most precious resource our governments have is their human resource.
- Professor Mayow...: Absolutely.
- Dr Tina Charway...: It's not the gold, it's not the diamonds, it's the human resource.
- Professor Mayow...: Absolutely, we know that. We're in a global economy that is driven by knowledge and knowledge is taught in the brain. If people didn't know that health was important, covid-19 taught us that health is more important than any other thing. It can disrupt the economy, politics, and every other thing upside down. So same way, brain health is very important. It can also improve everything.
- Dr Tina Charway...: Let me just jump in because we've talked longer than we were going to. And that's fine because it's just been such a great conversation. But I just wanted to start to summarize it really. Words like complex, intertwined, challenging, all those words you've been using today about the different challenges that are facing Africa, if there's one thing that has to be started with, where do we start and is that brain health?
- Professor Mayow...: Absolutely. I think the entry point, the key to unlock everybody's energy in synergy is brain health. It'll ring a bell with everybody and I think that's the way to go. It's to talk about brain health. That way we're able to get the support of everyone, policy actors, policy makers. And not only to promote brain health, but to also preserve brain health and to promote recovery. That's the way to win the support of everyone that brain health is worth investing in. And it's not only the future, but it's also the present for all of mankind.
- Sam Pauly: Tina?
- Dr Tina Charway...: Totally. We can't not talk about brain health. And the way to get us on the path that we need to be traveling and understanding the value of our brain health is through education. And from education, all the other things that are needed come. So it's education on different levels, education about different things, education about the value of brain health and everything will follow after that.

- Sam Pauly: Given what we've discussed, all the big, big challenges that there are, and the solutions that you've been talking about, and the adoption of the I-GAP, how hopeful are you feeling for the future, Mayowa?
- Professor Mayow...: I'm very hopeful, because just like Tina said, and just like Mandela said, education is the most powerful weapon to change the world. And I'm hopeful that's possible because we have a young population in Africa and they're not fossilized, they can easily be changed through education. So education is the key and I'm sure that with that we'll be able to attract the resources that is required and get everybody to work together in the ecosystem that can actually make Africa the capital for improvement of brain health.
- Sam Pauly: Tina?
- Dr Tina Charway...: Totally. You ask whether or not we are optimistic, whether I am optimistic, we don't have a choice. We have to do this, so we have to be optimistic because there is no alternative. So yes, we will do it.
- Sam Pauly: Well thank you both so much for joining us today and for that really vibrant and interesting discussion. So many thoughts and ideas to take away with us today and I'm sure all of our listeners have really enjoyed it. Thank you both.
- Professor Mayow...: Thank you so much Sam and thank you so much Tina. I think the neurology revolution will start in Africa. And I think it's beginning already through education.
- Dr Tina Charway...: Thank you so much. And Mayowa, we will now move on from preaching to the choir and speak to everybody else and get everyone all the stakers involved in the process. As long as we all remember that there's no health without brain health, we're already on the right track.
- Sam Pauly: Thank you both.
- Sam Pauly: Still to come on our episode today we'll be hearing from Florence Baingana from the WHO and we'll also be hearing from a stroke survivor. But first we have time for a couple of messages.
- Speaker 5: Hello, you've reached the voicemail of the One Voice for Neurology Podcast, please leave your message after the tone.
- Dr Temitope Far...: Hi, my name is Dr. Temitope Farombi. I'm a neurologist at the University College of [inaudible 00:27:29]. The burden of neurological disorders in Africa is expected to triple in the next 15 years, which resultant effect on disability life here. However, with this projection is the gross deficit of skills with neurologists to population ratio of one to 10 million. Other challenges include near total lack of government policies on brain health and neurological disease management, poor funding and debt of appropriate data for future planning. With the

growing concern, there is need for timely intervention in policy prioritization, health promotion and prevention, funding for research and innovative approach to care.

Rania Kaouech G...: Hello, my name is Rania and I represent the Tunisian MS organization. [inaudible 00:28:23] has always been the stroller that we lean on in several occasion, such as when you encounter some event concerning the patients with MS. Also, we are working consistently together especially about this lack of medicines. I raise my voice for patients with MS and I face it to the policymaker. Please, we need all the help needed. The national registry is a necessity. Sometimes thing became hard in my country for our patient, but we need to know how to handle it because life will eventually go on. And as they say, life is not about waiting for the storm to pass, it's about learning to dance in the rain. Thank you.

Sam Pauly: You're listening to the One Voice for Neurology Podcast with me, Sam Pauly.

Sam Pauly: Now earlier in the episode we heard about the challenges faced by neurologists and patients in Africa from two neurologists. Now joining us to tell us more about the goals of the Intersectoral Global Action Plan, the challenges across the region and the role that policymakers can play, I'm delighted to be joined by Florence Baingana. Florence lives in the Republic of Congo and is Regional Advisor at the World Health Organization on neurologic, mental and substance disorders. Florence, thank you so much for joining the One Voice for Neurology Podcast today.

Florence Bainga...: Thank you. Glad to be here.

Sam Pauly: Florence. As I just mentioned earlier, we looked at the current situation in Africa on the ground from two neurologist perspectives in terms of access. They were talking particularly about the importance of awareness, education, and also the problems of the brain drain. Now with your regional perspective, why would you say there is such a problem in terms of access in Africa to services?

Florence Bainga...: First of all, it's not just for neurological disorders that we have a challenge of access. Our health systems generally are weakened. We have a weak healthcare system with services much more focused in the cities and very little happening at the community level, at the primary care level. And human resources are a big challenge. So the reason for this is, first of all, our governments are poor. So if you look at the GDP, how much is the government collecting and what do they have to allocate to health?

Florence Bainga...: Most governments in the African region, according to the WHO Mental Health Atlas in 2020 found that they allocated 46 US cents per capita per year. It is very low. So you can imagine if that goes to mental health and within that we may have to also cover neurological disorders, the most unfortunate thing is when we look at neurological disorders, how much is allocated, it shows absolutely zero. It doesn't even come up as a blip. So obviously something is allocated but

it is so low that it is 0.00, it's almost impossible to capture. So if you have such a low resource for mental health or neurological disorders, it becomes impossible to have services that are strong enough.

Sam Pauly: Understanding that the budget is so low, but within that though, as you said, it's such a small amount that goes towards neurological disorders. Why is it so low in terms of the prioritization that it's being given by policymakers?

Florence Bainga...: It has to do with the burden of disorders that we have in our region. We have maybe triple or even quadruple burden of disorders. We have children under five years dying of preventable conditions. We have mothers dying as they are giving birth, no mother should die while they're giving birth. We also have a big rise in non-communicable disorders, which would include neurological disorders, but all the other disorders like cardiovascular disorder, cancer, and other conditions like that, governments have a challenge, where should the funding go. And often we opt to strengthening of services because we don't focus on providing for a single disorder. The idea is to see how can we strengthen the health system so that anybody who walks into a health center is able to get the care that they need. So we are focused on health systems strengthening.

Sam Pauly: So we have talked about the Intersectional Global Action Plan before and I'll ask you more about some of the solutions and the ways that could work in a minute. But maybe first you could just remind anyone listening, in one or two sentences, what the plan is and what it aims to achieve.

Florence Bainga...: Well, in a very simple language, I would say that the Intersectional Global Action Plan on epilepsy and other neurological disorders is a global level instrument that was endorsed by all member states to strengthen the way that we would all respond or how we would want to provide for epilepsy under other neurological disorders. It outlines different actions that can be taken by member states, by WHO, as well as by other partners.

Sam Pauly: So in Africa, Florence, then how can the Intersectional Global Action Plan or the I-GAP, how can it support and help policy makers with this goal that you were talking about of strengthening the health system? And maybe if you have an example of that as well.

Florence Bainga...: The I-GAP is a global instrument. And as a global instrument it may not be relevant or applicable to all regions of the world. So each region then has to take it, and contextualize it, and see which pieces of it are applicable. In this way, the African region in partnership with One Neurology and IBE, the International Bureau for Epilepsy, the African chapter as well as the global one, have been working together, first of all, to carry out a situation analysis on epilepsy and other neurological disorder in the African region. And we are part of the committee that is operationalizing I-GAP in the African region. So this global instrument would be contextualized to the African region. And we did

this framework to implement a comprehensive global action plan in the African region and both by the regional committee in August of 2022. At the same time, IBE Africa is also working with individual countries to actually get them to disseminate and operationalize I-GAP at the country level.

Sam Pauly: And is there an appetite or enthusiasm for countries to work together and support each other?

Florence Bainga...: Yes, yes, definitely, definitely there's enthusiasm for countries to work together because they do learn from each other. And I believe that's the strength of the WHO, the convening power that we have. So we do hold regular regional meetings. We could bring together different countries working on a specific area. As an example, there are three countries right now working on a specific project on epilepsy. So they meet regularly to discuss, and talk, and share progress, and listen and learn. Countries are very happy to work with each other.

Sam Pauly: It does seem though like a mountain of challenge given the budget funding challenges that you were talking about earlier. Where do you think policy makers should start in terms of it not being too overwhelming? And also how quickly do you think we could see improvements for the people who are actually living with neurological disorders and their carers, and even the medical community indeed?

Florence Bainga...: I think one of the biggest challenges, actually I may not have touched on is... And that's why I believe the policymakers could begin is because neurological disorders are a broad category that cuts across very many different conditions. Some are infectious just like meningitis, some are secondly to other conditions like road traffic accidents could lead to epilepsy. Or cardiovascular disorders could lead to stroke. We also have epilepsy per se, which may not be caused by any of these other conditions. We also have, it cuts across very many different age groups, from neonates all the way to the elderly.

Florence Bainga...: For these reasons because we tend to work in our silo like myself, if my label is mental neurological and substance use, I am covering mainly epilepsy and not so much the other disorders, but I do have a colleague here even in the regional office who's responsible for meningitis and it's in the communicable disorders area. And then some of the work that has to do with dementia is actually in the area of aging. So we have all these different, I would call them silos of work.

Florence Bainga...: I think one of the areas we need to improve as policy makers, how do we bring it all together and how do we all work together. We have this one instrument, the I-GAP, and it's a very good and strong instrument, but it's implementation, I think, is hindered by the different silos and the ways of working that we have, so maybe we need to begin there.

Sam Pauly: If people can work together and get out of these silos, how quickly could people start to see a difference in their own lives?

Florence Bainga...: I think the difference will come very quickly, very quickly. Because right now within MH GAP, which is a guideline for training primary healthcare workers to manage common mental disorders, we include dementia in there and we include epilepsy. So if every single healthcare worker is trained in MH GAP, then they would be able to manage epilepsy, at least at the primary care level. And this is happening all over the African region, MH GAP training being rolled out.

Florence Bainga...: We shall be meeting here in Congo, bringing together. I believe, about 14 countries from the region to develop country level plans for meningitis, to operationalize the meningitis roadmap. So already my being integrated into the meningitis work is already happening. So I will be sitting in there and contributing what I can and they're developing their roadmap, so already that's going to have an impact At the country level. I believe we are beginning to recognize the importance of working together across these different silos. I believe it'll happen within the next maybe five years. Change is slow in policy and translating it into outcomes is slow, but it'll happen.

Sam Pauly: We've discussed a number of challenges, Florence. Are there any other challenges that we haven't touched on yet, do you think?

Florence Bainga...: I think that one of the biggest ones as well is stigma and discrimination. And I believe that one was talked about. Stigma and discrimination is not just out there in the community. We tend to believe that stigma is out there, it's out there somewhere else and not within us, and yet it's within us as well as policy makers. And very many times policy makers make the decisions they make because they have that inherent, very deeply held belief that people with these conditions are not going to be productive individuals. They actually, some of them believe a lot of the negative beliefs about these conditions. So that is also a barrier.

Florence Bainga...: The other one is the myths and the misperceptions, people not understanding what the causes are and therefore seeking care from the wrong places.

Florence Bainga...: The other one is also believing that there's a magic bullet. So if somebody, a child let's say is born with a neurological disorder, that is not going to change. Or maybe at the age of three to five years a diagnosis is made of autism, there's still going to be searching for that magic cure to get that person to become, as they call it, normal. So accepting that sometimes these conditions are going to be chronic, and they're not going to go backwards, and expecting a magic bullet. That is another big challenge.

Florence Bainga...: I think also the poor linkage to social welfare and community rehabilitation. So these are chronic conditions and when people are out of the acute phase, when they're out of the hospital or a diagnosis has been made, they have to go back

into the community and live in the community. And in our systems in Africa, health gets a little budget, but social welfare gets even less than help. And we are not well linked into social welfare. So the community rehabilitation and having services available in the community or having supports for families so they can look after their people within the home, that is another big area where we have a gap. So we shouldn't see them as just a medical condition only managed in hospital, we have to think of these other areas. And again, that is an area we haven't quite strengthened.

Sam Pauly: And do you see any solutions to do that, then?

Florence Bainga...: We have a few innovations where the social welfare and the health are being combined together so that you have peer support. A lot of people are beginning to innovate in how can we provide care for people with chronic mental health conditions, but also other conditions like neurological disorders. How can we provide the care outside of the hospital? To one such project was Mental Health Beyond Facilities, which I was PI for implemented in Uganda, Liberia, Nepal funded by Grand Challenges Canada. And this one brought three pieces together, the peer support, livelihood intervention, because livelihoods are another big challenge, and then providing care at the primary care level. And so these innovations are also coming up. But they're examples that could be replicated for other neurological disorder.

Sam Pauly: So where would you like to see Africa in the next five or 10 years, in terms of the way that neurology is taken care of, and looked after, and services are accessed?

Florence Bainga...: In the next five to 10 years, I'd like to see a dramatic reduction in preventable causes of neurological disorders, those that affect children that are preventable. We often say that epilepsy in the African region is an indicator of the quality of the healthcare services. So if we are able to improve the quality of our healthcare services, we will be able to bring down the number of people living with epilepsy. I would also like to see improved daily recognition by the people themselves or their families. They need to be able themselves to recognize that this is a neurological disorder. And then if they do seek care that the healthcare provider, at the primary care level, can also make that diagnosis. Because these are the barriers that we have right now. And yet it's possible to provide a diagnosis and provide care at the primary care level, so this is what I'd like to see. I would also like to see a focus on prevention, improved access to medication that is another barrier, support for home-based care and rehabilitation.

Sam Pauly: And how realistic do you think those hopes are?

Florence Bainga...: I think they're realistic. We can do a lot together with the partners because this is not something that would be done by WHO alone or the governments alone,

but the partners like One Neurology, or IBE Africa, or our other member organizations within countries, if we all work together, I believe it can happen.

Sam Pauly: Looking ahead, do you feel optimistic then?

Florence Bainga...: Yes, I feel optimistic because things are changing. And I believe once we measure and realize how big the gap is, I think it's then much easier to begin to do something about it. So I feel very optimistic that things will change.

Sam Pauly: Well that is all we have time for Florence, but thank you so much for joining us. Lots to reflect on there, thank you.

Sam Pauly: Now we've just been discussing access to services and for our next guest from Nigeria, when he suffered a stroke, he discovered the lack of access to support groups. So he set one up. Recording from his home. Here's Michael Uchunor.

Michael Uchunor: My name is Michael Uchunor. [inaudible 00:46:33] I live in Nigeria. I am 43 years old. Occupation is advocacy. I have a big close knit family of nine siblings. My friends are stroke survivor.

Michael Uchunor: I share my story and experience because it is unique, not because my sharing can begin to our perspective and stroke and we can inspire more people to share their stories.

Michael Uchunor: My experience started 17 years ago when my head had a stroke in London. I did. I had my stroke [inaudible 00:47:10]. I used to drink a lot of alcohol, I smoke. I was rushed to the hospital, [inaudible 00:47:15] time for emergency and I got a good medical response and treatment. Then I couldn't talk or walk. They took me to many years to realize that recovery is a long process and money is involved. Every day I have to take my drugs, eat well, and exercise my body just to keep life.

Michael Uchunor: After my experience, I know what it not to be able to do things to for yourself. And I will [inaudible 00:47:51] is well pronounced. People talk to me in my community. Most my friends is [inaudible 00:47:59], they don't call or text. I once was asked, my fiance left me, she said that I am handicapped. I can't take care of her. I thank God for today. I'm a survivor.

Michael Uchunor: My condition today is better than yesterday. For 11 years I'm still recovering and my speech is getting better. When I had my stroke, there was nothing like a stroke support group. But I know that my recovery would've been easier if I had connected in social group, a group where I could meet other stroke survivors with similar injuries. Get to know and communicate with one another. [inaudible 00:48:49] Treatment and Research these are both void. Today [inaudible 00:48:58] Foundation, which is stroke support group in a place where stroke survivors [inaudible 00:49:10]. We need [inaudible 00:49:13] Nigeria. We need education for the growing population of stroke survivors and their

caregivers. A lot of the stroke survivors does not think that the disease is ordinary, they believe that someone is responsible for them to have stroke. My hope and dreams for the future is looking forward to a world where there is no stroke. [inaudible 00:49:46] to quality care, we need support of the government, organizations, privileged individuals to assist us in our city, tools, food, drugs and also our health care needs including education, neurologists, doctors, and [inaudible 00:50:12]. Thank you.

Speaker 14: [inaudible 00:50:20] Bye bye.

Sam Pauly: What an inspiring story. Thank you so much, Michael, for sharing it with us. Well that brings us to the end of this podcast on Africa. It's been a real honor to talk with our guests and I'm left feeling hopeful for people in Africa who are living with neurological disorders, they're carers, and the dedicated neurologists. If you haven't already, then I do hope you'll have a listen to some of our other podcasts, especially our other new one on India. Until next time, bye-bye.

Sam Pauly: You've been listening to the One Voice for Neurology Podcast, produced on behalf of One Neurology, a global partnership conceived by the European Federation of Neurological Associations, FNA, and the European Academy of Neurology, EAN. The podcast was produced and hosted by Sam Pauly. Thank you for listening and join us again soon.