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SOUTH ASIA INSTITUTE
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Neuroscience and the Development of Human Sight Podcast Transcript

Host: Ira Pundeer, Communications Manager, The Lakshmi Mittal and Family South Asia Institute. Harvard University

Guest: Pawan Sinha, Professor of Vision and Computational Neuroscience, Department of Brain and Cognitive Sciences, MIT

Professor Sinha details his groundbreaking research into how the brain's visual system develops. Professor Sinha and his team at Project Prakash provide free vision-restoring treatment to children born blind, and study how their brains learn to interpret visual data.

BEGIN TRANSCRIPT

Ira Pundeer: Welcome to the India in Focus podcast. I'm Ira Pundeer, the Communications Manager at Harvard's Lakshmi Mittal and Family South Asia Institute. For this episode, we are joined by Pawan Sinha, who is the professor of vision and computational neuroscience in the Department of Brain and Cognitive Sciences at the MIT.

His work among the visually impaired children in India received the US Presidential Award in 2012. Pawan, welcome to this podcast.

Pawan Sinha: Thank you very much, Ira. A pleasure.

Ira Pundeer: Let us begin with the Project Prakash and the idea behind it.

Pawan Sinha: Project Prakash is an effort that's very close to my heart. It's a dual themed project, it allows me to feel useful in an immediate way to society and it also allows me to be true to my scientific roots and to pursue basic scientific questions.

So, there are two goals for Project Prakash: One is to identify children who have been born blind in India and typically these children have been born in remote villages. Their parents do not know that the child's condition is treatable or even if they suspect that the child's condition is treatable, they're often so poor and so far removed from any sophisticated medical facility that the child does not receive any treatment.

So, one goal of Project Prakash is to find these children and bring them to New Delhi to provide them with the very best surgical care possible to treat their blindness. Embedded in this humanitarian goal, is an unprecedented scientific opportunity and that is to try to understand how a child who has been born blind and then who gains sight, say several years after birth, how this child begins to learn to see, and how the brain changes with the onset of sight. These are big questions for neuroscientists and with Project Prakash, we have the unprecedented opportunity to make some headway on the questions.

Ira Pundeer: So, how are the ways in which these children will learn to see compared with how infants learn to see?

Pawan Sinha: That's a great question, and I don't think we have a very definitive answer to that yet. It may as well be the case that the details of the developmental trajectory in Prakash children are quite different from the developmental trajectory of a newborn. But what we are finding is that there seems to be some similarities. The data that collected with the newborn normally sighted children seem to suggest that there are some cues about the visual world that a baby is very sensitive to. And we are finding that the Prakash children also show sensitivity to similar cues. So, there seem to be some similarities but because vision is so complicated, there are so many aspects to vision, we cannot at the moment say that the two developmental trajectories are identical.

Ira Pundeer: Could you maybe explain a little more about the outreach process?

Pawan Sinha: Yeah, the outreach part of Project Prakash, it's the very first component of our three-part effort. The three parts being outreach, treatment and scientific research. Outreach by far is the most logistically complex aspect of the work. What we do over the course of the year is organize screening camps in remote villages and the selection of those villages is guided by governmental statistics, like from the Sarva Shiksha Abhiyan, which has some guidelines about the prevalence of the individual impairment in a given district or cluster of villages. Based on those data as a starting point, we organize eye camps, we are, our teams comprising primary healthcare workers, optometrists, ophthalmologist, they go and screen children to determine who are the children who can actually benefit from surgery.

A lot of our outreach is concentrated in the Gangetic plains, the Gangetic plains are of course the most densely populated part of India. But they also suffer from not enough medical resources, so we find that as we go deeper into the Gangetic plains, more towards the east side of UP, we find more and more cases of untreated childhood blindness. We are also venturing into Madhya Pradesh, we have also conducted eye camps in Rajasthan and Haryana. So, it's a fairly broad-based outreach effort.

Ira Pundeer: Okay, and given that you are a neuroscientist, what are the insights that you have gained from this research and what are the applications of those insights?

Pawan Sinha: Yeah, a great question. The first and perhaps the most critical insight that we have gained is that the brain maintains significant elasticity even late into childhood, perhaps even in early adulthood. So, this was a concern for Project Prakash at the outset of our work. Essentially, are we coming too late on the scene to benefit the child. There has been a notion that as we age our capabilities become more and more difficult to acquire afresh. And certainly in the case of vision, there is a notion of critical periods of visual development suggesting that if the brain does not receive normal visual input in the critical "first few years of life," then forevermore it would be compromised undoing vision perhaps so substantially that there's no point in correcting the eye past the age of seven or eight years.

So, we were worried that maybe this dogma is strictly true, and we would not be serving the beneficial purpose by operating the children's eyes. But what we're finding through the data collected so far is that children gain significant visual proficiencies, almost irrespective of the age at which they are treated. So, their behavioral proficiencies increase, their ability to use vision, for instance, to walk around the world without bumping into things, their ability to recognize objects, their ability to recognize each other, that takes a significant improvement. But also, using neuroimaging, through a functional magnetic resonance imaging or fMRI for short, we are able to get a glimpse of changes in the brain directly from before to

after surgery. And what we are finding with FMRI is there's significant dividend of plasticity. So, that's been one of the most important results from Prakash and it has essentially served as a gateway result. And by that I mean, once we know that some measure of visual function acquisition is possible, even in later childhood, then we can get to the question of how that function acquisition happens. So that we can begin to get our questions of process rather than just possibility.

So, many of our experiments at the moment are looking at how it is that children are acquiring capabilities on a variety of tasks.

Ira Pundeer: Okay, so you mostly talked about Prakash children and about how you can learn to see after a certain age. So, have you worked with adults and have the results tallied?

Pawan Sinha: Yeah, so we have, the age range that we have had the opportunity to work with is very broad. The youngest child I believe we've worked with is either four or five and the oldest we've worked with is 29 years of age, a young adult. And what we are finding to our pleasant surprise, is that despite this advanced age in developmental timelines, even the young adults gain significant function. So, even if you are 20-year-old and you've had severe visual compromise for the first couple of decades, you'll still be able to acquire significant visual function.

So, that suggests to me that brain maintains significant stores of plasticity even that late in life.

Ira Pundeer: Once the Prakash children acquire sight, what are the steps that should be taken to maybe have them go back to education or?

Pawan Sinha: That's a very important point. At the outset of Prakash, I had this Pollyannaish view that once the child gains vision, even though they have lived a very difficult life until that point because of their blindness they typically stay out of the schooling system, my thinking was that with the onset of sight, the world of opportunities would open up to them, they would for sure be able to get admission in regular schools and begin progressing towards a financially independent life.

But in following up with many of the children a few years after we had treated them, I was dismayed to find that many of these children had not joined an educational program. And the reasons were typically that they were too old to be starting their educational journey. Say, at the age of 10, a child who has had no schooling, would be considered too old to be starting grade one, sometimes the children are even older. And, because of these just learning to see, they typically need some accommodations on part of the schools in order to help facilitate their acquisition of the classroom instruction. Very few schools are actually willing or equipped to provide that kind of help.

So, what we have realized is that there is a critical need to not just provide medical care to the Prakash children, but also to provide them the rudiments of a scholastic education to bring them to some age-appropriate level in their preparations, after which they can be mainstreamed. So, your question is very appropriate that we can't just rest with thinking of Project Prakash as purely a medical intervention, we have to also provide some educational intervention, and we have taken some baby steps along those lines.

We have started a residential program for the Prakash girls at the moment it's not co-ed, it's just Prakash girls and the small cohort that we have of six young girls, they have shown remarkable progress in very little time and that gives us hope and faith that this is the right thing to do and we would like to expand

this program.

Ira Pundeer: And I think it was in last year in October when we heard about Prakash vision centres team opened up in two blocks in Gorakhpur district of Uttar Pradesh. Could you tell us a little more about the vision centers and what is the vision behind?

Pawan Sinha: Yes, so the Prakash vision centers are youngest initiative of Project Prakash, and they are borne out of the realizations and observation that there is a significant need for providing basic eye care in the rural communities. Things that we take for granted in the cities that if we ever have say blurry vision, we can go to an optical store and get glasses.

And without the glasses, our lives are quite difficult, we are at risk of falling, getting run down by traffic. So, this basic level of eye care is often not available in villages and we felt that to be true to its name of bringing light into lives, we ought to provide this service in the rural communities from where people often have a hard time coming to cities. So, we wanted to have a presence of Prakash in the rural communities, this would provide care to the villagers but it would also serve as a way us to screen on an ongoing basis, children in that community so that if any child needs more extensive care, more extensive than what can be provided in the Prakash vision centre, they could be referred to us in New Delhi.

So, with that thinking of providing immediate care to the rural community and also to act as a permanent referral centre, we have started the Prakash vision centers in two communities in New Gorakhpur: Pali and Brahmapur.

One slightly longer term goal with the Prakash Vision Centers is to begin to serve as destinations for the children that we are treating as part of Project Prakash. So, I talked about how education is important for the Prakash children, but we perhaps need to think even beyond education. What happens after a child gets through grade 12 or maybe even does some college work? Can we provide one possible destination for them to apply their learning, their vision and having Prakash Vision Centers be the places that the Prakash children or Prakash young adults eventually go to and begin providing eye care services to the community. I think that would be really beautiful and really poetic completion of the circle, that a child who was initially visually impaired himself or herself is now in a position to improve the vision of others.

Ira Pundeer: That sounds like a great idea and I know that it's been 15 years since the setup of Project Prakash. So, you've been tracking the earliest children that you treated, have you been tracking their progress throughout or after a while it becomes difficult to manage the tracking?

Pawan Sinha: Yeah, tracking is an interesting challenge. We try to track the children as long as possible, often it's several years but sometimes, I would say more than sometimes, children move away, their families move away, or they get a new cellphone and we lose touch. But I would say that for a majority of children, we have maintained contact with them over several years. And it's, and we have in fact, a couple of years ago, conducted a quality of life survey with about 70 of the Prakash children, some of whom had been treated several years ago. And what's very gratifying to find is that across many indicators of quality of life, be it general safety, be it a sense of independence, the aspirations for the future and people's attitudes towards them and their families, the Prakash children all report a significant improvement in their life and that I think is the greatest joy that we can derive as Prakash

team members. Getting good scientific data is certainly nice but to be able to see that we have positively impacted lives, that's much, much better.

Ira Pundeer: For anyone listening to this podcast, who has never interacted with someone who is visually impaired because you don't see them in the public that much because of limited accessibility, so do you have a message for them, how they can get involved maybe or how we can help?

Pawan Sinha: So, I would first mention our website that people should feel free to visit and see, learn more about our work. It's projectprakash.org. In terms of getting involved, please get in touch with you, if you are a student who's interested in the science of Project Prakash, we may have a possible internship opportunity for you. If you are a person who is running an outreach effort in rural communities, please get in touch with us, we may be able to benefit from your understanding of the rural landscape and if you know any person who has significant visual impairment who you think can benefit from a second look, who might benefit from a medical examination, please get in touch with us and we would be happy to be of service.

Ira Pundeer: Excellent. Pawan Sinha, thank you so much for joining us for this podcast and it's a pleasure to host you.

Pawan Sinha: Thank you very much, Ira. Such a pleasure.