Restoring Vision through “Project Prakash”: The Opportunities for Merging Science and Service

The MIT Faculty has made this article openly available. Please share how this access benefits you. Your story matters.

| Citation          | Sinha, Pawan, Garga Chatterjee, Tapan Gandhi, and Amy Kalia. “Restoring Vision through ‘Project Prakash’: The Opportunities for Merging Science and Service.” PLoS Biology 11, no. 12 (December 17, 2013): e1001741. |
|-------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| As Published      | http://dx.doi.org/10.1371/journal.pbio.1001741                                                                                                                                                        |
| Publisher         | Public Library of Science                                                                                                                                                                             |
| Version           | Final published version                                                                                                                                                                               |
| Accessed          | Wed Oct 28 18:45:01 EDT 2015                                                                                                                                                                            |
| Citable Link      | http://hdl.handle.net/1721.1/86004                                                                                                                                                                     |
| Terms of Use      | Creative Commons Attribution                                                                                                                                                                           |
| Detailed Terms    | http://creativecommons.org/licenses/by/4.0/                                                                                                                                                            |
Restoring Vision through “Project Prakash”: The Opportunities for Merging Science and Service

Pawan Sinha*, Garga Chatterjee, Tapan Gandhi, Amy Kalia

Department of Brain and Cognitive Sciences, Massachusetts Institute of Technology, Cambridge, Massachusetts, United States of America

“So how does this help society?” is a question we are often asked as scientists. The lack of immediate and tangible results cannot be held against a scientific project but statements of future promise in broad and inchoate terms can sometimes pass the benefit-buck indefinitely. There is no incentive against over-stating the benefits, especially when they are hypothetical and lie in the distant future. Few scientists will say their science is not designed to serve society. Yet the proliferation of “potential benefits” in grant proposals and the Discussion sections of research papers, in the absence of tangible translations, can make the service element of science seem like a clichéd ritual. Its repetition hollows out its meaning, breeding cynicism about the idea that basic science can be of service.

Expanding human knowledge can be tied intrinsically to betterment of the human condition. Our personal desire to be good Samaritans and our professional desire to be good students and researchers are not necessarily at odds. This aspiration to merge science and service can only come to fruition, however, if we actively identify opportunities that merge the two—the kind of science that necessitates service, but not at the cost of trivializing either. Here, we present Project Prakash as a prototype of such initiatives might look like.

Project Prakash

The Prakash initiative [1] identifies congenitally but curably blind children in India who have so far remained untreated due to poor medical access. Figure 1 shows two major kinds of treatable childhood blindness in India—cataracts and corneal opacities. By providing such children corrective surgery (Figure 1, lower panels), Project Prakash is creating a population of children across a wide age range who are just learning how to see. Longitudinal studies of these unique children offer insights into how they develop visual skills. This approach combines the best of both worlds: it directly addresses the pressing humanitarian need to treat curably blind children and, in the process, illuminates fundamental questions regarding brain plasticity and learning. Hence the name “Prakash,” the Sanskrit word for light. To date, Project Prakash has screened over 40,000 children and provided surgical treatment to over 400 of them as well as non-surgical care to over 1,400.

Scientific Outcomes from Project Prakash

The Prakash studies have yielded evidence of significant adverse effects of congenital blindness on some aspects of post-operative vision, but also impressive visual skill acquisition by those who gain their sight even after several years of blindness [2–5]. We have investigated how patients acquire many aspects of visual function, including low-level attributes such as acuity and contrast sensitivity as well as high-level functions such as object and face recognition and spatial imagery. This work has also demonstrated how motion information plays a crucial role in parsing the world into distinct objects and, more importantly, in helping the visual system learn heuristics that can be used even with static images. The results have guided our studies of normally sighted individuals, as well as our computational modeling efforts [6–8]. Complementing our behavioral studies, we have begun to employ non-invasive brain imaging technology, specifically functional magnetic resonance imaging (fMRI), to examine the kinds of cortical changes that accompany the very initial stages of human sensory development. These neuroimaging studies so far have revealed that the onset of patterned visual information results in rapid modification of the visual cortex even in individuals who have been congenitally blind for the first two decades of their lives [9].

Recently, Project Prakash also helped answer a long-standing philosophical question about the mind. The onset of sight challenges the brain to correlate visual information with that from other senses such as touch and audition. What is the genesis of such cross-modal mapping? Is the ability to relate information from distinct senses available innately, or is this something that needs to be learned through experience? This fundamental question, which was framed over three centuries ago by philosophers John Locke and William Molyneux, is relevant to understanding how the brain encodes an object’s shape and also the “nature versus nurture” debate [10–12]. Project Prakash has finally allowed us to provide an answer to this tantalizing question [5]. Immediately after the onset of sight, the Prakash children could not recognize by sight an object they had felt with their hands (i.e., there was no evidence of an innate link between vision and touch), however, they

Citation: Sinha P, Chatterjee G, Gandhi T, Kalia A (2013) Restoring Vision through “Project Prakash”: The Opportunities for Merging Science and Service. PLoS Biol 11(12): e1001741. doi:10.1371/journal.pbio.1001741
Published: December 17, 2013
Copyright: © 2013 Sinha et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.
Funding: Project Prakash is supported by National Eye Institute (NIH) grant R01EY020517 (www.nei.nih.gov), by a Scholar Award from the James McDonnell Foundation (www.jsmf.org), and by the Nick Simons Foundation (www.simonsfoundation.org). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.
Competing Interests: The authors have declared that no competing interests exist.

* E-mail: psinha@mit.edu
Figure 1. Top row: Two major kinds of childhood blindness in India. The left panel shows cataracts, and the right shows corneal opacities. Many cases of pediatric cataracts are congenital. The lower row shows, from left to right, cataract surgery in progress, a dilated pupil revealing a dense cataract, and the eye after excision of the cataract and implantation of an intra-ocular lens.

doi:10.1371/journal.pbio.1001741.g001

Box 1. Other “Prakash” Opportunities

We believe that Project Prakash is just one instance of many compelling opportunities to merge science and service. These “Prakash” Opportunities promise to bring light into people’s lives and simultaneously illuminate fundamental questions in science. Here are a few examples.

Educating illiterate individuals and seeing effects on brain

A third of the global population is illiterate [13]. Illiteracy affects not only the individual but also society. Providing education to illiterate individuals will help improve their life prospects while also presenting an opportunity to study changes in various aspects of cognition and their neural substrates.

Providing treatments for other childhood disabilities and studying outcomes

The prevalence of childhood disability has increased significantly in the last few decades [14]. Rudimentary interventions are available for some disabilities, such as sensory impairments, speech impediments, epilepsy, and autism, which improve children’s ability to interact with their world. Nevertheless, they are far from perfect. Providing children the best available treatments is a great opportunity to study treatment outcomes as well as learning and plasticity mechanisms in the brain. Such studies can help determine how the interventions themselves can be improved.

Feeding malnourished children and probing effects on brain structure and function

Severe malnourishment is responsible for the deaths of 5 million children every year [15]. Infants born underweight are at risk for learning disabilities, mental retardation, blindness, and even premature death [16]. By providing nutrition to chronically malnourished individuals, we have the opportunity to improve their lives while also examining how the brain responds to this intervention at different points in the developmental trajectory. For instance, imaging techniques can be used to determine if improved nutrition results in changes in brain volume and connectivity. The inclusion of scientific assays can, in turn, enhance the ability to monitor the effectiveness of nutritional interventions.

Providing medical screening and detecting low-penetrance disease susceptibility genes

Many conditions, like various kinds of cancer, are likely to arise from several low-penetrance genes rather than a single high-penetrance mutation [17,18]. The discovery of these genes requires large numbers of well-characterized patients. This scientific need is perfectly complementary to the humanitarian need for increased disease screening in densely populated developing nations. The large family structures in many of these societies, and hence the availability of genetic data across many relatives, can greatly facilitate gene discovery.
became proficient in as little as a week. The development of this ability points to the existence of rapid learning processes for detecting relationships across senses.

Our findings paint a picture of a brain that remains impressively adaptable well into life and that can reorganize itself quite rapidly to allow a newly sighted child to make use of the novel sensory information received from its eyes. These early findings provide a launch pad for studies that are sure to enrich our understanding of the theoretical neuroscience, this project is also yielding more pragmatic benefits.

Service Outcomes from Project Prakash

Besides providing novel insights regarding basic questions in experimental and theoretical neuroscience, this project is also unraveling brain mechanisms of visual neuroscience generated by Project Prakash, which has treated not only congenitally blind children but also those with late-onset visual impairment. Also, independent institutional review boards must provide oversight to ensure participant welfare.

Support from society at large: A project that merges science and service risks being misinterpreted as exploitative or disrespectful of cultural and religious traditions, especially in developing countries where there is greater resistance to science-based interventions due to competing religious, cultural, or community beliefs. This very real danger must be countered with clear communication between scientists and society. In Project Prakash, we find that counseling parents, a frank description of the project’s objectives, and a few local non-scientist champions whom the patient population can relate to, are often necessary and sufficient to address this concern.

Draining resources from other deserving avenues of research: The desire to tie research to societal benefits should not diminish our ability to pursue more “blue-sky” projects. The scientific value of any project must be evaluated dispassionately. Are the likely scientific advances significant enough to merit the investment into the project? If the answer is affirmative, then all else being equal, a project that has a simultaneous beneficial impact on society may be more deserving of support than one that does not.

Maintaining ethical standards: Linking the provision of service to scientific gains may result in a conflict of interest, transforming service into exploitation. Safeguards against exploitation include avoiding a quid-pro-quo arrangement between service provision and study enrollment. All individuals who need intervention, not only those who fit the scientific inclusion criteria, should be treated. This has been a guiding principle for Project Prakash, which has treated not only congenitally blind children but also those with late-onset visual impairment. Also, independent institutional review boards must provide oversight to ensure participant welfare.

Financial support: A project based in a foreign country, whose immediate beneficiaries are individuals of that country, might be seen as beyond the ambit of a national funding body. We find that, on the contrary, funding agencies are very supportive of Project Prakash because they see that the results are likely to transcend national boundaries. More generally, funding risks are ameliorated if the anticipated scientific gains are likely to be significant and not geographically specific.

Support from the research community: A project with a service component might be seen as a distraction from our obligations to publish papers, obtain grants, and fulfill the requirements for tenure. Our experience with Project Prakash has been overwhelmingly positive, however: researchers generally share a desire to affect people’s lives, even though this motivator can be lost in the shuffle of grant deadlines and paper submissions. We feel that there is widespread support for research programs tailored to a humanitarian cause that also addresses important scientific questions.

Maintaining high quality of research: Many researchers can attest to the challenges of working with children and patients. For instance, densely sampled longitudinal studies are logistically complex. The histories of the participants are highly variable, sometimes making group level analyses difficult. Such hurdles may be exacerbated in a developing country but can provide a useful spur to designing experimental protocols that are resilient to the circumstances. Some unavoidable experimental compromises may be tolerable as long as they are accurately reported and do not hinder the interpretation of the results.

Enhancing social acceptability and awareness of childhood blindness. In Indian society, childhood blindness carries grave stigma and is poorly understood, leading to superstitions, dangerous non-medical “remedies,” or, often, no treatment at all for the affected children. Project Prakash has begun to increase awareness in India of this condition and the available treatment options, removing misconceptions from parents’ minds and inducing them to seek proper treatment for their children. Furthermore, by highlighting the problem of childhood blindness in prominent international forums and journals, the project is helping to catalyze further initiatives by philanthropic and government agencies to counter the problem of childhood blindness in India and elsewhere.

Facilitating education. For the formerly blind children, the onset of sight makes it possible to enter the educational mainstream and thus to better their prospects for employment and independence. The reports, audio/visual material, and papers on basic issues in visual neuroscience generated by Project Prakash also aid education in this domain.

The magnitude of the problem of childhood blindness in the developing world is daunting, and the challenge of unraveling brain mechanisms of visual learning is amongst the hardest in science. But, we are encouraged that Project Prakash has begun to serve as a nucleus for bringing together the resources, expertise, and commitment needed to mount appropriate responses. In undertaking this
effort, we have a unique and unprecedented opportunity to address issues of
great humanitarian, health, and scientific
significance.

Aligning service and science can be a
powerful approach for our community.
Initiatives like Project Prakash can provide
resources and directions to talented peo-
ple, channeling their skills, passions, and
scientific abilities to solve important prob-
lems in society. In Box 1, we outline some
other examples akin to Project Prakash,
where biomedical research might be
combined with service to the community.

Such approaches have the effect of
bringing science and society closer—pro-
viding the public with a strong reason to
continue funding science. Developing pro-
jects along the lines of Project Prakash
requires actively searching for scientific
questions whose answers require interven-
tions that improve lives, society, or the
environment as a constitutive part of
the research protocol. Obviously, not all
scientific questions can meet this criterion
and, when they can, there are potential
hurdles to overcome in combining science
and service (Box 2). Implementing this
model may well require more effort than
usual to achieve successful outcomes;
however, the dramatic improvements in
the lives of those who are helped, the
scientific advances, as well as the personal
satisfaction make the effort worthwhile.

Acknowledgments

We thank Richard Held, Sidney Diamond, and
Kailash Sinha for discussions related to ideas
presented here.

References

1. Sinha P (2013) Once blind and now they see. Sci
Am 309: 48–55.
2. Ostrovsky Y, Andalman A, Sinha P (2006) Vision
following extended congenital blindness. Psychol
Sci 17: 1009–1014.
3. Bouvrie JV, Sinha P (2007) Object concept
learning: observations in congenitally blind chil-
dren and a computational model. Neurocomput-
ing 70: 2210–2233.
4. Ostrovsky Y, Meyers E, Ganesh S, Mathur U,
Sinha P (2009) Visual parsing after recovery from
blindness. Psychol Sci 20: 1484–1491.
5. Held R, Ostrovsky Y, deGelder B, Gandhi T,
Ganesh S, et al. (2011) Newly sighted cannot
match seen with felt. Nature Neuroscience 14: 551–553.
6. Balas B, Sinha P (2009) The role of sequence
order in determining view-canonicality for novel
wire-frame objects. Atten Percept Psychophys 71:
712–723.
7. Sinha P, Balas BJ, Ostrovsky Y (2009)
Visual object discovery. Object categorization:
computer and human vision perspectives. Dick-
inson S, Tarr M, editors. Cambridge: Cam-
bridge University Press.
8. Sinha P (2011) The analysis of dynamic faces:
key computational challenges. Dynamic faces: insights
from experiments and computation. Cambridge:
MIT Press.
9. Sinha P, Gorlin S, Gandhi T (2011) Changes in
cortical functional organization after imitation of
sight in the congenitally blind. Journal of Vision
11: 427.
10. Locke J (1690) An essay concerning human
understanding. London.
11. Moggan M (1977) Molyneux’s question. Cam-
bridge: Cambridge University Press.
12. Degenaar MJL (1996) Molyneux’s problem: three
centuries of discussion on the perception of forms.
Dordrecht: Kluwer Academic Publishers.
13. Vagenshtein YF (2008) How illiterate people
learn: case study of Ethiopian adults in Israel.
Journal of Literacy and Technology 9: 1535–0975.
14. (2013) Childhood disability rate jumps 16 percent
over past decade. Available: http://www.
sciencedaily.com/releases/2013/05/130505073733.
hni.
15. (2010) Causes of hunger are related to poverty. Available:
http://www.globalissues.org/article/
7/cause-of-hunger-are-related-to-poverty.
16. Martorell R (1996) Undernutrition during preg-
nancy and early childhood and its consequences
for behavioral development. World Bank Con-
ference on Early Child Development: Investing in
the Future, April 8–9, 1996.
17. Houlston RS, Peto J (2004) The search for low-
penetrance cancer susceptibility alleles. Oncogene
23: 6471–6476.
18. Niittymaki I, Kaasinen E, Tuupanen S, Karhu A,
Jarvinen H, et al. (2010) Low-penetrance suscep-
tibility variants in familial colorectal cancer.
Cancer Epidemiol Biomarkers Prev 19; 1478–
1483.