

# Disability is not Inability

## IFP Alumni Advocates in the Disability Field



More than one billion people—15 percent of the world's population—live with some form of disability.<sup>1</sup> This large number belies the fact that people with disabilities are often among the most marginalized, neglected, and invisible members of society, particularly in developing countries, which are home to 80 percent of the world's disabled population.<sup>2</sup>

As part of its aim to provide higher education opportunities to disadvantaged groups from around the developing world, the Ford Foundation International Fellowships Program (IFP) provided graduate fellowships to nearly 175 emerging social justice leaders who have disabilities and/or work in areas of disability rights, advocacy, and service provision.<sup>3</sup> Since IFP's conclusion in 2013—and with support from the Ford Foundation—the Institute of International Education (IIE) has led a 10-year IFP Alumni Tracking Study that seeks to document the personal trajectories of these and other IFP alumni, as well as the impacts they are having on their home communities more broadly.

We asked IFP alumni who work in the disability field a simple question: What challenges do individuals with disabilities face in your country and how are you working to find solutions? Alumni from around the world engaged with disability issues in various capacities responded, describing the myriad difficulties faced by people with disabilities in their home countries, as well as the efforts being made to improve their lives.

This brief shares examples and common themes that emerged from the stories of alumni disability advocates in five IFP countries: Chile, India, Kenya, Russia, and Uganda. Their responses indicate that regardless of their location or impairment, people with disabilities face similar challenges at the individual, community, and national levels. Beyond these common challenges, IFP alumni are also united by the fact that their fellowship experience gave them new tools and perspectives to promote disability rights, improve services, and advance inclusive policies in the developing world.

The **IFP Alumni Tracking Study Issue Brief Series** explores thematic issues related to the Ford Foundation International Fellowships Program and its alumni, including social justice, leadership, community development, equity in education, and economic development. Part of the IFP Alumni Tracking Study being carried out by IIE, the series examines IFP through various research and analytical lenses, and provides practitioners, scholars, and the IFP community with points of discussion and debate.

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Learn more at [www.iie.org/IFP-Alumni-Tracking-Study](http://www.iie.org/IFP-Alumni-Tracking-Study)

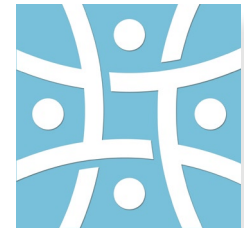
## Defining Disability

The term “disability” is difficult to define, not only because it encompasses such a wide range of conditions and experiences, but because disability is ultimately context-dependent. According to the United Nations, the term refers to individuals who have “physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others.”

What is central to the UN’s conception of disability is the idea that “disability resides in the society, not the person.”<sup>4</sup> An individual who is regarded as having a disability in one setting may not be viewed this way in another, depending on the technologies and services available, as well as prevailing attitudes and beliefs.

### IFP Alumni and Disability Advocacy

IFP alumni from around the world are working to improve the welfare of people with disabilities in developing countries by promoting equality at the individual, community, and national levels. The work of the five alumni who contributed to this brief represents some of the collective efforts of IFP alumni to promote social justice for people with disabilities.



#### Abdul Busuulwa, Uganda (2009 cohort)

**Doctorate in Enhancing Productivity of Blind Persons,  
University of Twente, the Netherlands**

Abdul’s efforts to address challenges for people with disabilities in Uganda are encapsulated in one word: advocacy. He has helped people with disabilities realize their right to representation in local governments, the national parliament, and constitutional bodies like the Equal Opportunities Commission. Blind from birth himself, Abdul also mentors and supports those with visual disabilities by helping them download free screen reading software and learn to use information and communications technology.

#### Veronika E. Ivanova, Russia (2004 cohort)

**Master’s in Rehabilitation Counseling, University of Pittsburgh, U.S.**

After completing her Master’s degree, Veronika returned to her home country and lent her expertise to a European Union-funded project to analyze disability legislation in Russia, laying the groundwork for the future Russian Disability Treaty, ratified in 2012. A wheelchair user, she currently serves as an in-house translator and disability counsel for the Walt Disney Company and is actively involved in company volunteer activities on both a global and local scale. Last year she volunteered with the global Disney team to assist athletes with Down syndrome at the World Special Olympics.





### **Bikram Keshari Mohapatra, India (2011 cohort)**

**Master's in Disability and Global Development, University of Leeds, UK**

Bikram promotes inclusive development for people with disabilities in India by advocating for improved access to services such as healthcare, education, and employment through a rights-based framework. He also works with national and international organizations to promote barrier-free environments and the inclusion of disability protocols for humanitarian response and disaster risk programs. His sister and her elder son, who both had disabilities, ignited his passion for disability rights.

### **Joyce Achieng Ogogo, Kenya (2010 cohort)**

**Master's in Special Education, University of Texas at Austin, U.S.**

Joyce's interest in the disability field is deeply personal: her brother was epileptic, and she observed first-hand how misconceptions about the causes of epilepsy and other conditions and disabilities can have detrimental consequences. Joyce now serves as a resource and a role model for her community. As part of her advocacy and community development work, she has implemented initiatives that promote independence, such as an income-generating poultry project for local youth with disabilities. She has also volunteered with the Special Olympics.



### **Daniela Valdebenito Prado, Chile (2011 cohort)**

**Master's in Employment and Labor Market Intervention, Universitat de Valencia, Spain**

An expert on inclusive employment, Daniela is a founding partner of Inclusive Consultants, an organization that places people with disabilities that have professional and technical backgrounds into strategic and decision-making roles within organizations. This year Inclusive Consultants drafted a report for the International Labor Organization-Chile, highlighting economic gains such as increased innovation and lower absenteeism that are associated with hiring people with disabilities.

## **About the IFP Fellowship**

Between 2001 and 2013, the Ford Foundation International Fellowships Program provided advanced study opportunities to over 4,300 emerging social justice leaders from 22 countries in Asia, Africa, Latin America, and the Middle East. The Ford Foundation provided \$420 million in funding resources for IFP, the single largest program commitment in its history.

From its inception, IFP was intended to be much more than a fellowship program. The program not only sought to provide opportunities to individuals who had traditionally been excluded from higher education, it sought to select fellows that would serve as agents of change and advance social justice in their home communities.

## Multilayered Obstacles and Inequities

### Challenges at the Individual Level

At the individual level, people with disabilities in IFP countries face issues common to people with disabilities anywhere.

In Chile and Russia, for example, IFP alumni reported that people with disabilities often struggle with low self-esteem, a lack of independence, and a reduced ability to make individual decisions about their lifestyle if they need to rely on others for support.

Challenges for people with disabilities in the developing world can be further compounded by factors such as poverty and a lack of trained medical staff. In Uganda, Abdul notes that a lack of early intervention and preventative care leaves many individuals with disabilities that could be avoided or better managed with effective medical attention. Disabilities such as clubfeet or cataracts can be easily corrected by medical procedures, and the effects of cerebral palsy and polio can be reduced through physical or occupational therapy. Similarly, Veronika notes limited access to rehabilitation services and facilities in Russia, particularly in rural areas. Because of pervasive superstitions about the causes of disability, preference is sometimes given to traditional healers over Western medicine, which, Joyce notes, is true in parts of Kenya.

Although the use of assistive devices improves quality of life and independence for people with disabilities, their availability is often limited in the developing world. In Uganda and India, for example, people with disabilities frequently encounter barriers to accessing and affording assistive technologies such as screen readers and magnifiers (for those who are visually impaired) or mobility aids such as wheelchairs and crutches. Bikram notes that in India only 18.6 percent of persons with disabilities have access to assistive devices.<sup>5</sup> Assistive reading devices and mobility aids are also critical for people with disabilities to have full access to education, as these technologies allow individuals to read print and electronic sources independently or physically access schools and other educational sites.

Several IFP alumni contributors also highlighted the fact that women with disabilities face “double discrimination” in the developing world due to the already unequal status of women in society. Bikram noted that in India women with disabilities are discriminated against as a result of limited political power and employment opportunities. Women with disabilities are also particularly vulnerable to educational inequalities in

countries where “historical gender roles don’t allow much room for primary school, let alone an advanced degree.”<sup>4</sup> Moreover, Daniela notes that gender is just one of many additional exclusionary factors that can further disadvantage people with disabilities in the developing world.

### Challenges at the Community Level

All five IFP alumni shared examples of persistent attitudinal barriers to the inclusion of people with disabilities at the community level. These barriers range from pejorative local terms for people with disabilities (“the handicapped,” “the weak,” and “the helpless,”) to outright exclusion by fellow community members. In Chile, Daniela describes attitudinal challenges in the form of myths, prejudices, and stereotypes about people with disabilities. In Kenya, Joyce says families of children with disabilities face rejection from members of the neighborhood who rarely visit or associate with them, and children with disabilities are “not allowed to play with typically developing peers, leading to stigmatization.” In Uganda, Abdul describes how marriages between people with disabilities and non-disabled people are often deemed socially unacceptable.

Other barriers at the community level manifest themselves through misunderstandings about the causes and treatment of disability. For example, Joyce notes that within the Luo ethnic group of Kenya, disabilities are sometimes thought to be caused by witchcraft, evil spirits, curses, or even food products like milk, eggs and wheat.

A student feeding poultry at Ngere Special School for Intellectual Disabilities in Rongo Sub-County, Kenya. Located in the county of Migori, Rongo is about 50 miles from the shores of Lake Victoria, and not far from Kenya’s border with Tanzania.





Veronika with fellow Disney volunteers.

Across contexts, integration of people with disabilities into the larger community can be difficult, resulting in gaps between people with disabilities and others in terms of access to services and the protection of basic rights. IFP alumni also attested to the fact that community attitudes towards disability exacerbate the environmental barriers already faced by people with disabilities, denying them, as Abdul says, the “full membership enjoyed by others in society.” While in many parts of the world disability and other forms of diversity have come to be seen as an asset, this conception of disability stands in contrast with the prevailing view in many developing countries that people with disabilities do not have anything to contribute, and should instead be considered “objects of charity, pity, and ridicule.”

### Challenges at the National Level

At the national level, even when laws to protect people with disabilities exist, they are often inadequate or poorly enforced. In his home state of Odisha, India, Bikram lists corruption and administrative complications among other factors that prevent people with disabilities from obtaining access and services. In Russia, Veronika cites a “lack of disability law enforcement mechanisms” and notes that job discrimination claims have yet to receive judicial consideration.

*“I performed a benchmarking analysis of the disability legislation that laid the groundwork for future adoption of the Disabilities Treaty, which was then ratified in Russia in 2012. Serving as an expert to the project allowed me to apply both my analytical and research skills I acquired during the 2-year Master’s program at University of Pittsburgh.”*

— Veronika Ivanova, Russia

These examples indicate a need for national governments to take greater responsibility in ensuring the equal inclusion of people with disabilities and the enforcement of national disability laws.

Unemployment or underemployment is another major challenge for people with disabilities worldwide. In the developing world, it is estimated that 80 to 90 percent of working age people with disabilities are unemployed.<sup>6</sup> Even when they are employed, they often struggle to earn fair wages and benefits.<sup>7</sup> Indeed, Daniela notes that even when people with disabilities do enter the labor market, they must contend with barriers such as



Participants of a Bamboo Craft Training program in the northeastern Indian state of Assam (July 2013). In 2012, more than 300,000 people were displaced in Assam as a result of riots between tribal groups and Muslim settlers. As part of his work as a programme coordinator for the Danish humanitarian organization DanChurchAid, Bikram advocated expanding the training to include people with disabilities.

unequal pay, workplace segregation, low quality employment opportunities, and a lack of people with disabilities in strategic decision-making roles within organizations. Similarly, Abdul describes “severe attitudinal and infrastructural barriers...for reasonable accommodation at the workplace” in Uganda. Both Daniela and Abdul also indicate a need for organizations and governments to promote affirmative action policies in order to facilitate equality in the workforce.

Finally, IFP alumni described how national education systems are failing to meet the needs of students with disabilities, despite the UN’s longstanding recognition that access to education is a fundamental human right. In addition to

inaccessible school sites, many educational systems suffer from severe shortages of educators trained to teach learners with disabilities. The dearth of educational opportunities further hampers people with disabilities’ potential for upward mobility, employment opportunities, and the ability to live an independent life. For example, Bikram notes that while 60 percent of people with disabilities in his home state of Odisha are literate, only 30 percent have completed primary school, and around 78 percent remain dependent on family to support their livelihood.<sup>8</sup> Statistics such as these highlight the need for improved educational access and illuminate the links between education and independence for people with disabilities.

## Overcoming Barriers and Changing Perceptions

Given their severity and complexity, the challenges faced by people with disabilities in the developing world may seem insurmountable. But while much remains to be done, the work being carried out by IFP alumni shows that there are at least four key ways to promote progress on various fronts.

### Empowering Individuals

One of the key ways that alumni described supporting people with disabilities is through efforts that build self-confidence

and promote independence. Sports and employment are two excellent vehicles for achieving this, as evidenced by the work of Joyce, Veronika, and Daniela. Both Veronika and Joyce have worked with the Special Olympics, Veronika with athletes with Down syndrome and Joyce with athletes with autism. Joyce notes that several of the individuals she supported in Kenya went on to receive medals and awards in the Special Olympics, which, in addition to promoting a healthy lifestyle and bolstering their self-esteem, made them role models for the community.

Full participation in the labor market is another key way for people with disabilities to achieve inclusion and independence. Joyce and Daniela's work shows that there are many ways for people with disabilities to participate in the economy. Started in 2013 and based at local schools for students who are hearing impaired and who have intellectual disabilities, Joyce's poultry project teaches students useful skills, allows them to earn an income and purchase school supplies, and learn self-reliance. In Chile, Daniela and her organization have worked to educate private sector companies and social service centers on creating employment opportunities for people with disabilities. In 2015 they provided training to 20 municipal job centers.

### Promoting Inclusion

In reflecting upon the lessons learned during her IFP experience, Daniela highlighted the "nothing about us without us" ethos, which speaks to the idea that people with disabilities are "the best experts on their lives"<sup>9</sup> and should drive and vet interventions that will affect them. As an advocate who does not have a disability herself but who works to advance rights and access for those that do, she is mindful of the fact that people with disabilities have "much to say about their needs" and do not need others to speak for them or assume what will be most effective or desired. People with disabilities should be directly, fully, and authentically involved in any decisions about their welfare.

As part of his efforts to implement inclusive disaster management and response projects in his home state of Odisha, Bikram has worked not only to identify people with disabilities in order to provide them with rehabilitation and other services, he has made sure to involve them in the decision-making process by including them in disaster management committees and task forces.

### Altering Attitudes

Almost all IFP alumni contributors touched upon the fact that attitudinal barriers are, in many ways, the biggest obstacles to increasing access and equity for people with disabilities on other fronts. Much of the work to break down attitudinal barriers involves changing the mindset that disability is a deficit or a disadvantage as opposed to a strength. In an effort to mainstream people with disabilities, Daniela advocates for changes to the way Chilean society views them, emphasizing a "comprehensive model of disability" based on the idea that, as a form of diversity, disability is an asset. To that end, in 2016 her organization drafted a report that highlights economic gains

*"As a result of the IFP fellowship, I learned that disability is not because of witchcraft or a curse, but the result of several other factors ranging from genetics to environmental factors. I have therefore tried to remove the cultural notion of disability, and I am a resource in my community, especially to families with children with disabilities."*

— Joyce Ogogo, Kenya

associated with hiring people with disabilities, relying on data that shows employing people with disabilities can result in lower turnover and absenteeism and increased innovation.

Joyce also works to counter pervasive misconceptions about disability through community workshops and seminars she conducts with learners with disabilities and their parents. She notes that the workshops have led to greater awareness and understanding of the causes of disability, which in turn has helped improve educational identification, assessment and intervention for learners with disabilities.

### Applying Research, Education, and Training

The World Health Organization and the World Bank note the importance of improved data collection and research to better capture useful and reliable data about people with disabilities and their needs as well as improve public understanding. They also note the importance of increasing the number of trained researchers on disability, as well as the benefit of "international learning" opportunities that link individuals in the developing world with institutions in high and middle-income countries.<sup>1</sup>

The skills and training IFP alumni gained as a result of the fellowship speak to these recommendations. Veronika had practical skills going into her fellowship, but was able to gain "fundamental theoretical knowledge of disability issues" which has helped her with her subsequent work analyzing disability legislation in Russia. Bikram was able to enhance his knowledge of inclusive development as a result of his graduate training. And Joyce notes that the fellowship helped her acquire evidence-based skills that can be used to manage many conditions in learners with disabilities, in particular those with developmental disabilities and autism.

*"I realized that no action or intervention can be carried out without people with disabilities. They are the main managers and mobilizers of cultural change."*

— Daniela Valdebenito Prado, Chile

Daniela and her organization, Inclusive Consultants, at a gathering of Acción RSE, an organization that convenes social enterprises and other entities committed to corporate social responsibility and sustainable development in Chile (October 2015).



## Conclusion

As evidenced by the challenges described in this brief, improving access and equity for people with disabilities in the developing world is a highly complex undertaking, one that requires the work of many individuals across all levels of society.

But while the challenges are great, the rewards are greater. The one billion people around the world with a disability represent enormous opportunity and potential—potential that we all stand to gain from, and that can only be realized by removing barriers and fundamentally changing the way we conceive of disability. The many IFP alumni who are themselves living and working with disabilities are testament to the fact that individuals with disabilities can live productive and fulfilling lives that impart benefits to all of us. They are sought after professionals, they have spouses and children, and they are working at all levels—locally, nationally, and internationally—to remove barriers for others.

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