



CREATING CHANGE

Innovations in the World of Disability



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CREATING CHANGE

Innovations in the World of Disability





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POLAND



ARGENTINA



ARGENTINA



NEPAL



SENEGAL



MEXICO



BRAZIL

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THE MOST POWERFUL

A Preface by Bill Drayton, Ashoka's First Entrepreneur



What is the most powerful force in the world?

It is always a big, pattern change idea... But only if it is in the hands of a great entrepreneur.

That is what has launched every major historic change.

Can those with disabilities be amongst these most powerful people? Of course! Many of Ashoka's leading social entrepreneur Fellows are.

Every such social entrepreneur makes a mockery of the term "disability". How can one even begin to think that a social entrepreneur is "disabled"?

Ashoka's central purpose is to help the world make the transition from the long millennia during which there were only a few players to a far happier "everyone a changemaker" society. The Agricultural Revolution produced only a very small surplus, which meant that only a tiny portion of the population could engage in anything more than creating the small agricultural surplus needed to support an elite. With change escalating logarithmically, and with change coming from more and more vectors and combinations of vectors, the "few players" system simply is no longer viable.

The key factor for success for any organization or society increasingly will be measured in terms of what proportion of the population are changemakers, and what level of this skill they bring, and how well they are connected. (Why did Detroit and Calcutta wither while San Jose and Bangalore took off?)

What counts in this new world? It is not physical brawn. Instead, it is a very complex set of social skills that every child and young person must learn empathy, teamwork, leadership, and changemaking. Plus the confidence to acquire these skills and to define oneself as a changemaker.

In the "everyone a changemaker" world, virtually everyone can be a changemaker.

The disability movement has been intuitively moving in this direction. It seeks to ensure that the 10 percent of the population who have disabilities live full lives – which ultimately means contributing importantly to society.

The movement's ultimate gift is that of enabling those it serves to be givers. And that can only mean helping them become changemakers in a world defined by change.

This end goal is clear and clearly right. Getting there requires brilliant social entrepreneurship. This volume will give you a sense of the way forward – and also of the magic of social entrepreneurship.



◀ Photo: Yusuke Abe

CREATING CHANGE: INNOVATION IN THE WORLD OF DISABILITY



Eddie Bartnik, March 18, 2009

Having a disability places a person in the world's largest minority group. The World Health Organization (WHO) estimates 10% of the world's population – approximately 650 million people, of which 200 million are children – experience some form of disability. This figure will increase as the population ages. WHO also reports that "Disability is both a cause and consequence of poverty and that about 80% of the world's population of people with disabilities live in low income countries and experience social and economic disadvantages and denial of rights."


The time is ripe for a global book on creative social solutions in the field of disability. The global economic crisis casts an even darker shadow on the ravaging handicap of poverty. The thinking that got us into this profound challenge is not the thinking that will get us out. Societal response has not been sufficient during a worldwide period of economic growth, and if history is an accurate predictor then shrinking government resources will lead to rationing even further the scarce allocation of resources and services, with disastrous consequences. We need to do much better. New thinking, new partnerships and new solutions are desperately needed.

Fortunately amidst this economic gloom, *Creating Change* is a shining light. *Creating Change* presents a unique and inspiring set of stories of Ashoka Fellows across the world, whose work not only changes the lives of individuals with disabilities and their families, but also how communities, business and governments welcome and include people with disabilities as valued and contributing citizens. The sixteen Ashoka Fellows are all recognized leaders and social innovators in the field of disability. Together these pioneers are creating a new paradigm of disability that has the potential for domestic and global impact.

Creating Change is the outcome of a Global Ashoka Fellows Collaboration which began in 2007. The Collaboration understands that "the interaction between 'abled' and 'disabled' is often hindered by stereotypes, fears, avoidance and prejudices."

Creating Change has three main aims: firstly, to challenge, inspire and change our thinking about what is possible in the field of disability; secondly to engage social leaders, business, governments and global organizations as strategic partners and supporters of the work of the Fellows; and thirdly to foster the international dissemination of these social innovations and influence global public policy.

The global scale of the Ashoka Fellows' work presented in this book covers 15 countries and a wide range of thematic areas including: education, employment, human rights, financial independence, empowerment of women with disabilities, access to computer skills, creating social support networks, social enterprise production of affordable health care products, development of mobility aids and equipment, recreation, arts and media.



The thinking behind the Ashoka Fellows' work reflects a strong move away from the pity or charity model to a framework based on citizenship rights and the capacity of each person with a disability to contribute to their community. Rather than a focus on what people with disabilities can't do (i.e. their deficits), the emphasis is on the inherent worth and dignity of each person as an individual and their gifts and capacity for contribution and self sufficiency. There is also an inherent belief in the concept of equal value partnerships between people with disabilities, their supporters, and a range of community, business and government organizations. A strong social enterprise approach is emerging that powerfully demonstrates a positive "can do" approach that links creative economic activity and generation of social benefit. New pathways are created that are positive and empowering, rather than being focused on negativity and waiting.

Each story is intensely personal and is a wonderful gift to the reader with profound examples of courage, innovative thinking, collaboration with business, and structural change. Each story charts the passage from a small scale local initiative, right through to a larger scale "social movement" that contributes to changing the structures and culture of society.


Creating Change shows us that modest amounts of investment have been multiplied to create substantial outcomes and knowledge value.

Creating Change calls each of us to action. We can create welcoming and inclusive communities. We can spread our local solutions. We can take our grand ideas to scale. We can conquer the two most persistent handicaps faced by people with disabilities – their poverty and isolation.

Heartfelt thanks to each Ashoka Fellow from all the people who will be fortunate enough to read this book and from those who have benefited or will benefit from your pioneering innovation. It is my fervent hope that your work will attract national and global institutions willing to match your commitment and assist you to implement your vision.

Photo: Greg Keating
/Keating Photography ►





Eddie Bartnik is the Director of Metropolitan Community Support with the Disability Services Commission in Western Australia and is a Fellow of the Australasian Society for the Study of Intellectual Disability. He has a 30-year perspective on supporting people with disabilities and their families, having held a range of senior government positions in policy, funding and service delivery and in recent years has also worked in the social services sector as well as an independent consultant. Eddie has had a major leadership role with the pioneering statewide Local Area Co-ordination Program, which now supports more than 8000 people with disabilities and their families throughout Western Australia and has also been a leader in the reform of services in Western Australia, focusing on personalization and individualized funding mechanisms to increase choice and control, as well as initiatives to strengthen individual and family leadership and community engagement. Since 1999, Eddie has also presented conference papers and consulted with families, community groups and governments across Australia as well as in the United Kingdom, the Netherlands, Poland, the US, Canada and New Zealand in order to bring to scale the Local Area Coordination approach and influence systems change. He has worked closely with Ashoka Fellow Al Etmanski from British Columbia on a series of reciprocal social enterprise collaborations between British Columbia and Western Australia and in 2006 met with Ashoka Fellows in Poland, which became the connection for this important book project.



ABOUT ASHOKA'S (DIS)ABILITY INITIATIVE

Anna Obem, Ashoka Poland (Dis)Ability Initiative Coordinator

The (Dis)Ability Initiative was launched in 2007. However, the idea of international collaboration between Ashoka Fellows working in the field of disability has a longer history. Indeed, in 2004 Piotr Pawłowski (Ashoka Fellow from Poland and one of the leaders presented in this book) and Ewa Konczal (Ashoka Representative in Poland) invited a group of Fellows to discuss ideas for future cooperation. Their collaboration took formal shape 3 years later, when the Fellows decided to meet to develop a strategy for their collective work. That meeting took place in Warsaw in March 2008.

The initial group of eight Fellows met in Warsaw and worked out a concept for a Global Social Campaign on (Dis)Ability issues. The idea combines three projects: the book on best practices featuring the work of Ashoka Fellows; an interactive website sharing stories of their work; and an international celebration of Inclusion Week. The concept weds the knowledge and experience of every member of the group, at the same time providing them with an opportunity to develop new creative ideas parallel to their everyday work.

Since the meeting in March 2008 the (Dis)Ability Initiative has become truly global. It currently embraces 24 Ashoka Fellows from 18 countries on five continents. The work of the group has been recognized by Ashoka headquarters as a perfect example of international collaboration between Ashoka Fellows, and as a platform where the Fellows' individual impact can be multiplied through collective work.

The (Dis)Ability Initiative is about to enter its next stage. Fellows from the group will now work on transferring their ideas to the global level to influence thinking in the field. They possess all the necessary skills, knowledge, and international recognition to be successful in this ambitious effort.



Javed Abidi

NCPEDP, India

Ashoka Fellow since 1998

The Path of Advocacy to Empowerment

by Rama Chari

"First, the nation was forced to recognize that we existed. Then it was made to realize that we did not merely exist, but that we were citizens too!" Thus did Javed Abidi quite aptly describe the journey of the disability rights movement in India, i.e., that of people with disabilities struggling to assert their rights and have their voices heard. This is a strategy Abidi has tirelessly pursued for almost 16 years now.

The condition of people with disabilities in India in the 1990s was grim. Their numbers were estimated at about 60 million, which is 5-6% of India's population. Though this vast number of people with disabilities is as great as that of many of India's states, they were largely unseen and unheard. Less than 2% of children with disabilities were receiving education of any kind. There were segregated arrangements for education. Even so, the number of "special schools" catering to disabled children was very few. As far as employment was concerned, less than 1% of people with disability were employed. Since the establishment of the first Special Employment Exchange by the Indian government in 1959, only about 100,000 persons with disabilities had obtained employment. There was job reservation in government departments and public sector undertakings, something that was initiated in 1977, but it was only for very low-ranking posts, something which clearly indicated the mindset of policy makers and of the sector as a whole – namely, that people with disabilities were not expected to be in high positions.

Thus, after over four decades of independence, there was still no legal protection of the rights of people with disabilities in India. Roads, buildings, and transportation were inaccessible to people with disabilities. Indeed, the term "accessibility" itself was unheard of! The disability sector was divided into various segments, such as those for the blind, for the deaf, spastic societies, associations of parents with mentally retarded children, and so on. Many of these organizations were "islands of excellence", but there was no cohesive action. Moreover, non-disabled people dominated the sector – and their focus was mainly on providing services for children. Nonetheless, these services did not address the rights of people with disabilities or ensure accessible facilities. Furthermore, most of these services were based in cities and had a limited reach. The government's role was restricted to providing welfare, which included providing grants to NGOs and distributing disability aids and appliances. The ministries focusing on development, like those dealing with education, employment, transportation, urban development, women & children, and so on did not address disability. There was hardly any awareness of disability issues. This was the context in which Javed Abidi envisioned a broad-based disability rights movement targeted at bringing about a change in the way disability was perceived in India.

Abidi was born to a middle-class family on June 11, 1965 in Aligarh, Uttar Pradesh. At the time of his birth he was diagnosed with a congenital impairment affecting the spine

called Spina bifida. When he was fifteen years of age he became a wheelchair user. In 1985 he went on a scholarship to the US to study mass communication. Four years later Abidi returned to India with the dream of becoming a successful journalist. He thought that, given his credentials, it would be very easy for him to get a job with any big newspaper company. However, that was not the case. He remained jobless for six months. Recalling this experience, he says, “Employers refused to look at my degree credentials. Instead, they would only stare at my wheelchair!” But he didn’t give up. He started freelancing. He began with small city magazines and worked his way up. He interviewed politicians, actors, industrialists, ministers, and even the Prime Minister. Then by an interesting twist of fate in 1991, at an unplanned meeting with Sonia Gandhi, the widow of Rajiv Gandhi, the deceased Prime Minister of India, he was asked if he would like to set up the disability wing of the newly established Rajiv Gandhi Foundation (RGF). He accepted the offer because, “quitting journalism would not harm that sector, but refusing Sonia Gandhi’s offer would mean turning my back on so many things that I was angry about – and I don’t mean my disability, but the attitude of people to my disability.” He joined RGF in May 1992.

The Birth of the Disability Rights Movement

On March 17, 1994, Abidi was invited to lead the Indian Panel of a satellite discussion between Washington and

New Delhi. The discussion was on the book *No Pity* by Joseph P. Shapiro, which is a story of the political awakening of Americans with disability. Many senior leaders of the Indian disability sector were present. After the satellite discussion, a very spirited discussion took place amongst the Indian audience, whom Abidi passionately asked: “Could we not give birth to an Indian disability rights movement here and now? Is this not the call of the hour?” Senior leaders of the disability sector endorsed the idea. Finally, they endorsed the idea and thus, on April 3, 1994, the Disabled Rights Group (DRG) was formed as the first broad-based disability advocacy group in India.

Passage of the Persons with Disability Act, 1995

One of the major issues that the Disabled Rights Group first took up was to get disability legislation passed in the Parliament. They did intense lobbying, organized press conferences, meetings, protests, sit-ins, and street demonstrations. They even faced opposition from people within the disability sector who did not want the bill to be passed. However, DRG’s efforts paid off and the **Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation)** was passed by the Indian Parliament in December 1995 and enacted on February 7, 1996. This was the first time in India that integration, equality, and rights were emphasized with regard to the disabled.



The Establishment of the Advocacy Organization, NCPEDP

It was at a discussion at the Rajiv Gandhi Foundation that the idea to set up an organization focusing on employment was conceptualized. Abidi felt that employment was the point of leverage that would set the implementation of the Act into motion. Pressing an employment agenda would also change the perception of disability from charity and welfare to that of economics, development, and equal rights. Abidi then established the National Centre for Promotion of Employment for Disabled People (NCPEDP). Senior representatives from industry, government, and the NGO sector were invited to serve on the board. Abidi later joined NCPEDP as the Executive Director in 1997.

Innovative Approaches and Strategies

When NCPEDP was inaugurated, many had assumed that it would work like a job placement agency. Abidi was absolutely clear that it would not do service delivery, which at the time was being done by most of the other disability organizations. He felt that it was **policy intervention and advocacy** that would have the most impact and bring about greater change.

Abidi was also quite clear that employment could not be looked at in isolation. As he argued: "Access is the absolute and basic foundation needed for the empowerment of people with disabilities in India. Without access, neither education nor employment is possible. And none of the three are possible without adequate legislation and policy. Thus, for all the above four to materialize, awareness is essential". This is why NCPEDP worked simultaneously on five core issues – namely, **Awareness, Access, Education, Employment, and Legislation**.

NCPEDP decided to take the **networking route** to spread its vision. First, the country was divided into five zones – North, South, East, West, and North-East. Coordinators were appointed for each of the zones. Then, in 1999, NCPEDP created a network of disability organizations, with a partner in every state and union territory of the country to promote advocacy. This was called the National Disability Network (NDN). NDN has now expanded to 320 districts of India. NCPEDP also developed cross-sectoral partnerships, particularly with apex organizations in the

areas of education, employment, architecture, information & technology, human rights, and law, not only to spread awareness through their networks, but also to integrate disability into their policies and systems.

NCPEDP has held that **information is power**. The NDN was primarily used for disseminating information to people with disabilities. The information sent included policy documents, research reports, information about any development that had taken place, and regular updates on campaigns. It was due to this that the winds of change began to blow: reports of campaigns, rallies, and even litigation started coming in from all over the country. In 2003, when the Internet had become more popular, NCPEDP launched the Disability News & Information Service, a web-based news service designed to ensure larger scale dissemination of information.

NCPEDP has treated the **media as an equal partner** in all their campaigns. Special care has always been taken to sensitize the media to issues that affect people with disabilities. As a consequence, newspapers and media channels around the country have covered all the issues raised by NCPEDP. This not only provides visibility, but also builds pressure on policy makers.

Many of the advocacy campaigns undertaken by NCPEDP were spontaneous. They emerged from news items, complaints received, and were sometimes instigated by letters and phone calls. The approach adopted in these campaigns, however, was quite systematic. NCPEDP staff would first gather all the information and data related to the issue and put together a very concise report. Focused research became the biggest strength of NCPEDP. Thereafter the tactics resorted to in order to obtain the desired outcome followed a systematic plan. First a letter was sent to the concerned authorities. Failure on their part to respond led the campaign to its second stage: that of mobilizing the disability community, the media, and signature campaigns. If this also failed to yield any result, it was then intensified in the form of a non-violent dharna and rallies. The ultimate tactic was resorting to hunger strikes or fast-unto-death protests. For some campaigns, lawsuits were filed. But for most, it was the relevant minister or the Prime Minister who took the final decision to accede to NCPEDP's demands.





Some of NCPEDP's key achievements:

Equipping disabled people with educational opportunities. In 1998, NCPEDP took up the issue of access to higher education with the University Grants Commission, an apex body for all universities in India. As a result, two landmark schemes were drafted. The first is 'Teacher Preparation in Special Education', which was introduced to prepare teachers to cater to disabled students. The second is 'Higher Education for Persons with Special Needs', which included establishment of Disability Units at universities and colleges and the provision for access and special equipment for students with disabilities. In 2004, NCPEDP undertook a nation-wide survey of regular schools and colleges to study the situation vis-à-vis the education of disabled people. Based on those findings, NCPEDP submitted a Blue Print to the Minister of Human Resource Development (HRD). As a consequence, on March 21, 2005, he tabled a Vision Statement in Parliament, which stated clearly that education would be made disabled-friendly by 2020. This policy-level integration of disability education in the Ministry of HRD was a very significant step.

Promoting employment of people with disabilities. NCPEDP targeted the business associations to effect a larger change in the employment of people with disabilities. In 1998, the Confederation of Indian Industry promptly responded by adding disability to their social agenda. In 2000, NCPEDP organized Roundtables for CEOs of some prominent IT Companies. As a result, many of these are now proactively employing people with disabilities. In 2004, a campaign was undertaken to address the blatant discrimination practiced against people with disabilities in the Civil Service. People with disabilities were either being denied a job or were being forced to take up positions for which they were overqualified. NCPEDP demanded justice and a clear policy of non-discrimination. As a result, the identified job list was reviewed and more services were identified as suitable for people with disabilities.

Ensuring easy access to public places. In 1999, NCPEDP convinced the Council of Architecture to include disability in the architectural curriculum. The issue of accessibility received a boost when Prof. Stephen Hawking visited India in 2001. NCPEDP raised the issue of access for people with disability in a major way, which resulted in ramps being

built overnight at all the historical monuments that Prof. Hawking wanted to visit. Afterwards, the Archaeological Survey of India announced a policy to make all historic places disabled-friendly. In 2004, NCPEDP fought and won an important battle for accessible polling booths. On April 19, 2004, the Supreme Court ordered construction of ramps at polling booths in the 2004 general elections. On October 1, 2004 electronic voting machines with Braille were tested and finally accepted.

Empowering through appropriate legislation and implementation. One of the major national-level campaigns organized by NCPEDP was aimed at getting a question on disability included in the Census 2001. Another landmark achievement was the inclusion of disability concerns in the Union Budget for 2003-04, wherein the income tax exemption limit was raised and the customs duty on aids & appliances for the disabled was reduced. Even better, in the next budget it was completely waived. Two other major policy initiatives that NCPEDP brought about were the inclusion of the rights of disabled people in the agenda of the National Human Rights Commission and in drafting the relevant recommendations vis-à-vis disability for India's X and the XI Five-Year Plans. Very recently, as a direct result of NCPEDP's pressure, India ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) on October 1, 2007.

Increasing public awareness. The third of December is observed every year as World Disability Day (WDD). NCPEDP gave WDD new meaning in 1997 by introducing a program entitled, "Walk to Freedom", a symbolic event signifying the distance people with disabilities had to travel to get their freedom. NCPEDP encouraged NGOs to organize similar walkathons across the country. The Walk to Freedom has now become a feature-event each year. World Disability Day is seen as an opportunity for the sector to come together to celebrate, have fun, express pride, and showcase their collective strength. WDD was given further thrust in 1999, when every state and union territory started celebrating it with a common theme and logo. Each year a new theme is taken up and NCPEDP makes sure that the message of the theme reaches far and wide through posters, films, TV spots, and by getting celebrities to promote the cause.



◀ ▲ Photos:
NCPEDP archives

NCPEDP faced many challenges along the way. Most of the issues raised so far were met with tough opposition from the authorities and have required prolonged protests to get voices heard. Disability is still not the priority of the Indian government and the majority of the ministries do not have disability on their agenda. There is still a lot of work to be done in order to integrate the disabled into the mainstream.

Abidi is now building up a national force for ensuring the implementation of UNCRPD and Xth Five-Year Plan in order to move disability further up the national agenda. Thus, NCPEDP continues to be a force to reckon with. There are many young leaders who have been directly or indirectly influenced by NCPEDP and who are pressing ahead with the agenda of the broad-based disability rights movement.

Javed Abidi, age 43, Ashoka Fellow in India since 1998, is the Honorary Director and Founder Trustee of the National Centre for Promotion of Employment for Disabled People (NCPEDP). Affected at birth with Spina bifida, he became a wheelchair user by medical neglect. Nonetheless, he has been effective in giving political visibility and economic opportunities for over 60 million disabled people in India.

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Ola Abu Al Ghaib

Stars of Hope Society, Palestine

Ashoka Fellow since 2007

A Source Of Hope For Women With Disabilities by Khetam Malkawi

Disability in the modern and developed countries is not necessarily a problem in itself, since it is addressed by adapting the surrounding environment in order to accommodate disabled persons.

However disability in the developing countries is generally considered a problem, as so much remains to be done to reach a stage where the disabled person can function in the community.

This problem derives from both cultural patterns that still deny the rights of persons with disabilities and the lack of social awareness of the challenges the disabled face.

Disability is doubly problematic when the disabled person is a woman, since women with disabilities are faced with discrimination based on both gender and their disability.

The situation of women with disabilities is an issue that requires urgent attention at the national level, since these people find it immensely difficult to receive a good education. Moreover, some families feel embarrassed to admit having a disabled daughter. Some even hide their daughters, considering them a shame to the family.

Despite all this, some women have refused to accept the fact of discrimination and have fought to bring about positive change and awareness of their rights to be productive members of their communities. Their aim was not to become well-known figures in the disabled community, but

to be accepted, to obtain their basic rights in education, and to have the right to love and be loved – as these are basic needs for all humanity.

One of the most prominent figures in this world (in fact, in two worlds – the Middle East and world of the disabled) is a woman who leaves positive change wherever she goes.

She is Ola Abu Al Ghaib, and hers is a name that shines like a star in the sky over Palestine. This physically disabled woman, who has used her disability as a source of strength rather than weakness, has become a prominent leader in the movement to empower women with disabilities in her homeland.

Ola: “Disability encouraged me to achieve my dreams”

Ola has recently established the Stars of Hope organization in Ramallah, one of Palestine’s major cities, in order to help achieve her goal of serving disabled women.

Having a wealth of first-hand experience, Ola says: “I have suffered a lot, learned a lot, and will learn more. My experience is not only mine... I have to share it with women who need help and want to enjoy their rights”.

Ola, born in the Palestinian town of Naples, was only twelve when she had to deal with a dramatic change in her life and accept a permanent disability that has confined her to a wheelchair. This forced her to stay at home for almost

three years without being able to go to school, because her city's schools were not prepared to enroll students with disabilities. But Ola refused to accept the situation and kept looking for alternatives to pursue her education.

The best solution for her was to move to Bethlehem, another city in Palestine, where she enrolled at a private school and lived with an English woman. Such a step was highly unusual for an Arab girl – let alone a disabled one.

"Convincing a traditional Arab family to let their daughter leave their hometown to get schooling at such a young age is never an easy job, especially if she is disabled", explains Ola. "Nevertheless, my determination and desire to have a better life through education was strong enough to convince my family", she adds.

The private school in Bethlehem initially enrolled her as a listener only, but after the first semester, when she got the highest grades among all the school's students, Ola was admitted as a regular student. But her tuition fees were too high for her family, and this jeopardized her dream to continue her education. Fighting for her rights, she went to the Palestinian Ministry of Social Affairs and asked for a scholarship on the grounds that she was an A student. Since she also needed non-tuition fees (as she lived away from home) Ola had to find further funding. Working with disabled students during her school years,

Ola got involved with a German organization for the disabled. The Germans were eager to grant her a full scholarship, as they recognized her brilliance and admired her activism on behalf of the disabled students' community in Palestine, especially her fight for accessible school facilities for the disabled. During her high school years Ola also worked with the physiotherapy department at Bethlehem University to include disabled characters in some of the well-known children's stories.

Those years were the most challenging period in Ola's life, as she had to deal with her disability and fight for her rights at the same time. However, she was able to achieve a lot. She gained her independence, adapted to her new physical limitations, and learned about what her new conditions entail and accepted them. This changed the attitudes of the people in her close circle about the abilities of women with disabilities.

Continuing with the same passion for success, in 2003 Ola obtained her Master's degree from Beirzeit University in Ramallah for a thesis on project management.

During her university years Ola again had to face the problem of the university campus's inaccessibility for the disabled, so she started to campaign for the right to an accessible campus. Her advocacy efforts won her a place on the campus construction committee. Ola was appointed



by the administration to work with engineers to adapt the campus to the needs of the disabled, something which involved a lot of planning and supervision.

"It wasn't easy for me to reach that stage. Facing many obstacles, whether related to accessibility or community barriers, has forced me to fight wherever I go", Ola said.

While working at the rehabilitation center, the disability advocate showed very good fundraising skills and proved to be a dedicated employee whose physical disability never stopped her from doing the required fieldwork.

Commenting on this Ola says: "I was born a warrior... a warrior for my rights and the rights of all women with disabilities. I started with empowering myself and I am moving now towards empowering others".

"It's no shame to ask for what you deserve... and this is the reason why I kept knocking on every possible door to ask for what I deserve. I will continue in following the same approach if I am deprived of anything related to my rights", Ola adds.

The problem

As in other Arab societies, discrimination against women still thrives in Palestinian society in spite of the efforts exerted over the last decades on behalf of equality for women. And discrimination against women with disabilities is even more profound. In fact, women with disabilities in Palestine carry a triple burden: one is being a woman, the second is being disabled, and the third in living under armed conflict. According to the Palestinian National Information Center, the total number of handicapped is 107,700, of which 52,200 are females. Despite their significant number, they are the most vulnerable among disabled people and the least protected. Many of them are kept hidden and silenced, their concerns unknown and their voices unheard.

The lack of statistics and unenforced law

According to the Palestinian Bureau of Statistics Report in 2007, 5.2% in Palestine are disabled. However, attitudes towards men with disabilities (especially those resulting from injury during the Intifada years) are less discriminatory. Disabled women in Palestine are subjected to prejudice and daily

discrimination on every level, for example, as regards educational opportunities, work, marriage, and social status.

Most people and societies are inclined to believe that disabled people are genderless. In patriarchal societies, women with disabilities are at a greater disadvantage. Some communities are known to value women above all for their child-bearing and child-rearing role, meaning that their social status is derived from being wives and mothers. In such communities and societies, women with disabilities are of very little value, as they are assumed unable to bear and rear children. Sometimes they are even considered asexual.

Disabled people experience high levels of abuse of all kinds: physical, emotional, and sexual. Statistics indicate that disabled women are more likely to be sexually abused than non-disabled women are. Because of the strong emphasis on physical appearance in every society, disabled women are made to feel less worthy than non-disabled women. This negative self-image, along with the silencing of or refusal to believe victims and the lack of prosecution of alleged abusers, increase the risk of sexual abuse. Physical and sexual violence against disabled girls and women occurs at alarming rates within families, in institutions, and through out society.


Moreover, none of the existing programs or organizations take into consideration the rights of women with disabilities. Some of them provide limited medical care services, although this usually stops after a certain age and does not reach to all the parts of Palestine.

Ola confirms that there are no programs in Palestine that focus mainly on disabled women: "I have been a physically disabled female for 20 years, and if there were any such systems I would know about it".

Above all, Palestine is a country under occupation. Laws, albeit on the books, are not enforced for a range of political, financial, and social reasons. The Palestinian law for individuals with special needs was issued in 1999, but it is still not enforced. There is great need for all local organizations to work together in order to change this. Unfortunately, few are ready to do so – or even admit that the problem really exists.

The above issues and the lack of services provided for disabled women are the main reasons Ola cited in establishing





the Stars of Hope and working towards building a community free of discrimination against women with disabilities.

However, despite all that Ola has struggled to attain, she is still encountering problems that require her to exert more effort. The lack of census data on the actual number of women with disabilities and their needs is the main one, along with the lack of financial resources to cover the basic medical and rehabilitation requirements of disabled women.

"Finding funding is a difficult task", says Ola, explaining that she seeks funds through networking with international disability organizations that she has established links with over her professional career.

Another problem is that of the environmental barriers that compound disability and limit opportunities. Lack of environmental adaptations and the absence of accessible buildings hinder disabled women from enjoying the freedom of movement. Transport for all the disabled is an important key to the exercise of citizenship and participation in society. Women in general, and disabled women in particular, are less mobile than men. They are less likely to have access to cars and are more confined to home because of cultural and social patterns. In Palestine, public transportation does not accommodate the needs of the disabled. And private transportation, if any, is usually used by the male members of the family.

Ola explains that the main problem facing women with disabilities is the lack of community awareness of the rights of disabled women and the nonexistence of support systems that work for lasting positive change. The Palestinian community is still not prepared socially to accept change regarding attitudes towards women with disabilities. Thus, most of them are marginalized, isolated within their own homes, or locked up in institutions.

Methodology

Ola's objectives are to actively promote and advocate the integration of women with disabilities in all aspects of social, economic, political, and cultural life. She is seeking to have her organization become the national representative of women with disabilities in Palestine through undertaking systemic advocacy, lobbying policy makers, and providing disabled women in Palestine with services, support, infor-

mation, and education. Networking with like-minded Civil Society Organizations (CSO) is also one of her tools to ensure support for her mission on the community level.

Strategy

In striving for her objectives Ola has pursued a dual-thrust strategy.

The first thrust is to provide holistic services to Palestine's disabled women. The second thrust is to campaign for disabled women's human and civil rights through national and regional advocacy and awareness-raising campaigns. Ola's institutional framework for the implementation of her strategy and the propagation of her idea is that of the CSO established and managed primarily by disabled women – Stars of Hope. This is the first and only CSO for disabled women managed by them – not only in the Levant, but across the entire Arab world.

Ola's CSO proposes solutions for the plight of disabled women in a very realistic and practical manner based on the actual experiences of disabled women themselves, who, led by Ola, are both a role model for empowering disabled women and living proof that change is possible. Ola is convinced that the common suffering, commitment, experience, and skills of the board members are cornerstones supporting her to achieve her mission.

Through her organization, Ola intends to establish the first resource center in Palestine to survey the number and real needs of women with disabilities. This will be a cornerstone in working towards the elimination of the causes and far-reaching consequences of disability among women.

Stars of Hope Services

Stars of Hope has created a comprehensive package of services for disabled women that is tailored-made to the individual type of disability, need, and interest. The services include psychological consultation, capacity-building, skills enhancement, and self-advocacy training. This teaches women with disabilities to push for their own needs. Stars of Hope is working on the grass-roots level to generate knowledge, information, and skills to secure the inclusion of women and girls with disabilities in society's mainstream. In addition to that, she is developing inclusive outreach strategies to reduce the social isolation experienced in communi-

ties where women are marginalized. Additionally, Ola and her organization are providing training services to women with disabilities to help them develop their abilities to take up socially responsible and productive roles in civil society, just like their male counterparts and others.

Consistent advocacy and lobbying are effective tools for achieving the required pressure to enforce legal amendments and influence policymakers to acknowledge the rights of women with disabilities and to promote their integration in society. Accordingly, Ola has geared her advocacy campaign toward raising societal awareness and changing the predominant attitude toward women with disabilities.

Ola's achievements

Stars of Hope is the first disability organization in Palestine that promotes the rights of disabled women. Already it has succeeded in improving the lives of a number of women, all of whom attribute this change to the vision of its leader Ola Abu Al Ghaib.

"Working with Stars of Hope improved my self-esteem", says Shatah Abu Sroor, an employee at Stars of Hope who is visually impaired. "My job has given me a wonderful opportunity to prove myself and my capabilities. It has also given me deeper knowledge on the art of cooperation and dealing with challenges. Ola has been the most inspiring and flexible manager, a person who has increased both my respect at work and my achievements", Abu Sroor concludes.



▲ Photo:
Ola Abu Al Ghaib's
archive

Ola, who is married to Mohammad Abu Al Ghaib – and with whom she has a five-year-old son – describes her life as a battle with her community that will have no truce until the rights of disabled women are honored.

"I will fight day in and day out...I will not stop my battle until I achieve my life's calling", Ola declares. "I am a woman with a disability who carries a message. And this message will be conveyed to the world through the support of my family, colleagues, Stars of Hope, and all advocates in the field of disability".

Ola Abu Al Ghaib,

born in Nablus, Palestine. Ashoka Fellow since 2007. Founder and chairwoman of the first DPO for women with disabilities in Palestine. She was only twelve when she became disabled and her life dramatically changed. She earned her degree through the strong determination to continuously upgrade her qualifications no matter what. She has over 14 years experience in initiating and managing projects related to disability, development, and rehabilitation services. She has participated in many programs working on behalf of the development of disability management on the national and regional level.

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Caroline Casey

Kanchi, Ireland

Ashoka Fellow since 2006

The Elephant In The Room

by Alanna Gallagher

The Irish Context

"Disability is the elephant in the room of society," says Caroline Casey, an Irishwoman dedicated to enhancing the relationship between disability and society. Caroline is the founding CEO of Kanchi, a social enterprise whose name comes from that of the elephant Caroline once rode on a trek across India.

There are more than 700 million people living and working with a disability throughout the world. In Ireland today, over 10% of the population live with a disability.

"Disability cannot be fixed or eliminated like poverty or AIDS," Caroline Casey explains. "It is not about getting rid of it. It is about changing society's attitude towards disability. If society will not change its attitude and begin to accommodate and to value difference, then it is society that becomes disabling."

One European in four declares having a family member who is affected by disability. This, coupled with the fact that 85% of people who are disabled have acquired their disability during their lifetime, indicates that a great portion of society has important contact with disability.

"Outside the UN Convention on Disability, there is no visible global leadership. We don't have a Bono or Nelson Mandela," Casey points out. Why? Because disability is a broad, complicated issue that is avoided due to fear of difference, lack of knowledge, and misconception. It has

no cure, poses no clear inspiring goal to work towards, and therefore becomes an uncomfortable topic.

These misconceptions are magnified and reinforced by the media's inaccurate and unbalanced representation of disability. Yet without proper representation, the world's largest marginalized group will remain invisible and discrimination will continue.

The exclusion and invisibility of people with disabilities is never more obvious than in the area of employment. Despite the fact that the levels of people with disabilities are rising, employment figures for them remain frighteningly low. Indeed, seventy-percent of people with disabilities in Ireland are unemployed. In 2006, the employment rate of working-age people with disabilities in the US was 37.7%, compared to the 77.9% of working-age people without disabilities.

These statistics are frightening because the effect is so far-reaching. Employment is not merely about a job: it's about inclusively contributing to society, something which increases self value. If a person with a disability remains unemployed, they are more likely to seek assistance from the state. This in turn diminishes their self esteem, excludes them from society, and reinforces the thinking that a person with a disability is incapacitated and a burden to society.

The Kanchi Approach

With a vision that differences should be valued and re-

spected, Kanchi aims to change the way society behaves by changing the way it thinks. This involves the most positive, solution-based thinking. Kanchi works with business and media leadership to push disability up the global agenda and shift focus from charity to valuing people with disabilities for the contributions they make when given proper opportunity. It has two programs: Ability Business, which drives change concerning disability in the business world; and Visibility, which promotes change through media, communications, and visual arts.

A New Idea

In 2004 Kanchi developed an innovative solution, the Ability Awards, to engage business leadership in changing the reality of employment for persons with disabilities. The Awards provide a unique audit tool coupled with an intensive communications campaign aimed at establishing examples of excellence that can be replicated, role models that can be followed, and leaders that can be emulated. Kanchi interprets the key benefits for business in opening up to those with disabilities as access to markets, access to talent, retention of staff, and reputation management. This is the disability business case.

It is undeniable that the global business environment presents a case for change in relation to people with disabilities. Such factors as decreasing skill replacement rates, a continuously aging workforce, higher consumer

demand, and intensive competition for market share supports a global business case for hiring, developing, and retaining the talent and potential of people with disabilities.

The Ability Awards are the first Irish business awards for best practice in the employment and inclusion of people with disabilities. The awards are not disability awards. They are a highly successful business awards scheme with the proven ability to drive social change for people with disabilities.

The awards are open to all businesses – Irish, international, small firms, non-profit, public, corporate, and social business. Each has a role to play in influencing positive change.

The O2 Ability Awards lead companies through an intensive seven-stage learning process:

1. submission of completed on-line application forms by interested organizations
2. initial assessment; 75 most successful organizations selected; qualifying organizations notified of next stage
3. one day on-site assessment for 75 organizations; Assessment Reports compiled for the Judges
4. the Preliminary Judging Panel selects 50 organizations that demonstrate best practice



5. the Final Judging Panel selects overall winners in the private sector, the non-private sector, and the best small company
6. winners announced at televised Awards Ceremony followed by a celebratory evening
7. feedback given to organizations on areas for improvement.

Best Practice is examined in six categories:

- Leadership
- Environmental Accessibility
- Customer Service
- Recruitment & Selection
- Learning, Development, & Progression
- Retention and Well-Being

The Ability Awards employ an intensive commutation campaign:

- dedicated news supplement with Ireland's daily newspaper, The Irish Times
- live, televised awards shown primetime on the major Irish network, RTE
- extensive radio coverage

The Ability Awards have sought to provide business with a methodology for change, but they have also aimed for something far greater: namely, to enable business to lead societal change on behalf of people with disabilities. If disabled people are valued as consumers, commentators, and employees, exclusion no longer has a place within the culture of an organization. If business recognizes the disability dividend, society will follow.

Progression and Achievements

With the Ability Awards, Kanchi has engaged business leadership in a way never done before. Speaking the language of business, the Ability Awards drives business by opportunity, making a case for business to include the disabled, that they not be dependant on handouts or charity. The Ability Awards influence the behavior of leaders so that they in turn will affect real change.

There are now more than 100 Ability Companies in Ireland, more than 100 champions of change. This makes disability visible within the business world – and not as a worthy

charitable cause, but as a solid business venture. The change was not just about corporate social responsibility, human resource policies, or diversity initiatives, but was about strategic systemic change and getting leaders to understand how disability permeates every part of their business.


The success of the awards can be picture by noting that:

- 15% of the working population has been impacted by the awards in the three years since they were launched
- 65% of the organizations involved have evidence to prove they have changed their practices, policies, and procedures in employing people with disabilities
- the audience share for the televised Ability Award programme attained 27%, creating a massive awareness raising vehicle which has contributed to changing the social landscape. The event is hosted by Ireland's President, Prime Minister, and leading media personalities and attended by key celebrities –e.g., Andrea Corr of the pop band The Corrs and footballer Roy Keane.
- the Ability Awards' companies proactively get involved in other Irish disability initiatives.
- production and both national and international dissemination of The Business of Ability book in 2008 (The book is a tool outlining collective best practice and case studies for business).

Kanchi's success as a business methodology is evident as the Ability Awards franchises outside Ireland. Through O2's parent company, Telefonica, Kanchi will bring the Ability Awards to Spain. Telefonica is one of the world's leading integrated operators in the telecommunication sector, providing communication, information, and entertainment solutions. It operates in 37 countries worldwide with over 245 million customers.

Kanchi's ambitions grew when Caroline Casey was appointed a 'Young Global Leader' of the World Economic Forum in 2006. She has since been invited yearly to Davos to make presentations on a variety of issues relating to disability. This international experience, along with Caroline becoming the first Irish Ashoka Fellow in 2006 and her 2007 Eisenhower Fellowship, gave her the opportunity to step outside Ireland and see how disability was portrayed in other countries. This also showed her how unique





Kanchi's approach is. Moreover, Caroline also realized how absent disability was from the global agenda and decided to strive to change this by using Kanchi's philosophy and ideals. The franchise of the O2 Ability Awards to Spain with Telefonica is the first step in achieving this ambition.

Lessons Learned

To be a social entrepreneur you have to be ready for anything and everything, Caroline believes. You can't be afraid of failure – it is just part of the process. "It is how you handle failure that matters," she says.

As with any human rights issue, working to change the social landscape of disability comes with its own complex set of challenges. "It is very frustrating when businesses or foundations simply say, We don't do disability," Caroline admits. Finding adequate time, resources, and funding is a constant battle. Scaling up and developing your organization into a sustainable entity is also challenging.

The success of bringing an idea from a national platform to a global stage is both Kanchi's biggest success to date and its greatest challenge, Caroline admits.

Partnerships in business are massively important in driving social change. Caroline explains that, "As a social entrepreneur the most important thing for me personally is having people believe in us."

- Doreen McNerney, Denis O'Brien, founder of CommuniCorp Group, Danuta Gray, Chief Executive of Telefonica O2 Ireland and Dermot Desmond, whose investment holdings include London City airport and Barbados' Sandy Lane Hotel, have been the most influential people in Kanchi's history.
- Kanchi uses mentors and advisory boards to identify where it is lacking. "As we grow, we need to reach out and work with people who have the skills and influence we don't have."
- The Sounding Board, a group composed of people who either have a disability or are in close association with disability, advises Kanchi on their current and future projects.
- The disability sector is notably political and very disjointed. Through the creation of partnerships Kanchi has worked hard to act as a cohesive force within the disability sector to make change have greater impact.
- The Kanchi Team is essential to our success.

Caroline's story

Caroline's success as a social entrepreneur began with her trek across India on an elephant named "Kanchi", but the culture and philosophy of her organization derived from her unique background. Growing up, Caroline perceived herself to be as normal as any other kid in school, just a bit more clumsy. On her 17th birthday she discovered that she had an incurable eye disorder that has decreased her visual acuity to the point of becoming registered as legally blind.

Her parents had chosen not to tell Caroline about her vision, hoping to give her a chance at a normal childhood. With her dreams of racing cars, you can imagine Caroline's frustration when the eye doctor told her, "You can't". The word "can't" isn't in her vocabulary. "There is always a way," she explains.

Caroline chose to ignore her visual impairment for as long as she could, earning an archaeology degree from UCD. A diploma in Business Studies from the Michael Smurfit Graduate School of Business, and a Masters in Organizational Human Performance and Design followed. Thereafter Caroline landed a job as Management Consultant with Accenture. However, Caroline did not provide the full picture of her visual impairment to her employer.

Two years into her job, at the age of 28, Caroline hit a wall. Due to an intensive workload, her sight had temporarily deteriorated so badly that she was left with no choice but to finally accept that her eyes were just not good enough. She had to do something else with her life.

Inspired by Mark Shand's *Travels on My Elephant*, Caroline chose to go back to her childhood dream and planned a journey across India on an elephant, learning how to become a trained mahout. This was something no Western woman had ever done before.

Realizing the fundraising potential of the adventure, in 2000 she established the Aisling Foundation (today called Kanchi) as a vehicle for the IR£250,000 she had raised for various disability organizations.

Caroline's own experiences in the workplace have given her unique insight into disability and the way it is perceived. Disability is utterly misunderstood. It is invisible,



makes people uncomfortable, and garners pity. This is what Caroline wanted to change and this is what Kanchi does today. In effect, it works to remarket disability, to change the way society thinks so that society will change the way it behaves.

"I sometimes wonder now, if only I had accepted earlier that my difference was my greatest asset, what more could we have achieved?" she says. "I don't want anybody, anywhere in the world, to be left out, excluded or be invisible because they have a disability or because they are different. I want everyone to have the same chance and opportunity. For that to happen, we have to see that people with disabilities are people first".

"The success of Kanchi has been achieved by their unique ability to engage critical leadership to think differently about disability. We need maverick organizations like Kanchi to bring creative entrepreneurial thinking to such a complex issue to drive the profound change required.

◀ ▲ Photos: Meek

Kanchi has put Ireland on the map in terms of setting the first and only business standard for enhancing the relationship between business and disability through the O2 Ability Awards.

I wish the team the best of luck as they continue to push boundaries, challenge the norm, and extend their ambitions. We all need to think differently".

Mr. Brian Cowan, An Taoiseach
(Prime Minister of Ireland)

Caroline Casey became the first Ashoka Fellow and Eisenhower Fellow from Ireland in 2007. A social entrepreneur and adventurer, she is the Founding CEO of Kanchi, which encourages society to think differently about disability. Creator of the O2 Ability Awards, Caroline is 37 and visually impaired. Additionally, Caroline is a Young Global Leader of the World Economic Forum.

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Ndèye Dagué Gueye Dieye

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Ashoka Fellow since 2002

Reproductive Health Care For Women With Disabilities. The Logic Of Survival

by Guédel Mbodj,

translated by Valerie Wilson

The Senegali Context

Senegal's constitution recognizes equal rights for all citizens. But the reality is that many economic, physical, and psychological obstacles hinder the integration of persons with disabilities.

The Family Ministry, in partnership with organizations of persons with disabilities and all other actors operating in the disability field, have drawn up an important bill that takes into account all the concerns of people with disabilities. This bill has been approved and we expect it to be ratified by the National Assembly.

According to the World Health Organization (WHO), people with disabilities represent 10% of Senegal's population of about 11,000,000 people, 49% of whom are female. Eighty-percent of those with disabilities live in rural areas, and more than 70% do not have access to basic social services. Among the population of people with disabilities, 16% have visually disabilities, a quarter have motor skill disabilities, and 51% have some other sort of disability – including auditory disabilities, albinism, etc.

The situation of Senegalese women in general remains marked by a number of hostile and discriminating factors.

Sadly, this is even more the case for women with disabilities. These factors include:

- socio-cultural standards;
- feminization of poverty, with social consequences even more dramatic for disabled women;
- sometimes discrimination and exclusion of access to education, basic social services, and work;
- weak representation in the decision-making sphere and the low presence of women with disabilities.

Women with disabilities are therefore doubly vulnerable at each stage of their lives. Because of their disabilities they are constantly confronted with difficulties concerning their physiological state and their precarious economic situation.

Education and Training

In terms of education and training, the school and university systems currently in place do not favor women with disabilities. Structures and infrastructures are insufficient and often inaccessible. Students are not always aware of the need to welcome and assist students with disabilities.

All these factors engender the high illiteracy rate for women with disabilities (50%).

Work

Access to salaried jobs for women with disabilities is very restricted. Indeed, the rejection rate is hair-raising. The private sector rarely recruits people with disabilities because of strong prejudices concerning their productivity. The Senegalese administration follows the same logic.

Women with disabilities are excluded from many job sectors – tourism, hotel service, and the legal system. Those who have the opportunity to work often suffer from discrimination within the workplace. They hardly ever get promoted to jobs carrying significant responsibility.

Senegal has not yet ratified Convention 159 of the International Labour Organization (ILO) regarding work.

Nevertheless, advances in this realm are discernable. One major landmark is that the government of Senegal has reserved 15% of public jobs for people with disabilities. Women with disabilities are attaining more and more jobs that carry significant responsibility. At this point, the goal of the National Committee for Women is to allow women with disabilities who have the right skill level to attain the work they merit while retaining their dignity.

Training constitutes the key to success for our endeavor. We are giving our members qualified training in emerging sectors (like Information Technology). For those without much

education, we have moved forward with functional literacy training to place them in promising and innovative sectors in conjunction with the Italian International Cooperation and other non-governmental organizations. These training modules have contributed to the emergence of women leaders with disabilities throughout the nation.

Social Innovation: the reproductive health of women with motor skill disabilities

The effective socioeconomic integration of people with disabilities, particularly women, is a major feat. It necessitates a change in behavior and awareness at all levels of society. Another challenge concerns the reproductive health of women with motor skill disabilities. It is rare to find specific programs targeting the health care, and particularly reproductive health care of these women.

According to a study in Senegal, 78% of people with disabilities live in a state of complete poverty and are dependant on their families for their basic health needs, clothing, and education. This specificity of women with motor skill disabilities in large part is due to poliomyelitis, which attacks the grey matter of the central nervous system up to and including the pelvis, which of course is important in the process of childbirth. The lack of information in this area on the part of women with disabilities and the parents engenders grave, even mortal risks for them. Women with disabilities



often give birth by Cesarean section because of the asymmetry of their pelvis. Moreover, the most basic of precautions are neglected. This type of operation is very costly and unrealistic in rural areas. Usually women need a letter of guarantee from the Director of Social Action. We are striving to make them aware of this issue to assure pregnant women with disabilities medical care in large hospitals.

The National Committee for Women in Senegal lobbies the state and its partners for guaranteed free basic health care for women with motor skill disabilities. In fact, this is a global battle, as it concerns all women with motor skill disabilities, particularly in developing nations.

The US Agency for International Development (USAID) has a program for women with disabilities.

Childbirth is fundamental for women with disabilities because, like all women, they have a need to start a family, and their children play a large role in their lives. A baby becomes a friend and confidante. These children will understand more than anyone else the problems of their mothers.

"Personally, as a woman afflicted with polio, I had my two children by Cesarean section. My job as a civil servant and my education level allowed me to benefit from excellent medical care right up to childbirth. Unfortunately, this is not the case for the majority of women with motor disabilities".

A case example

"The first case on this subject concerns a woman with disabilities who believed she could give birth normally and by consequence did not take any particular precautions. It was necessary for her to have a Cesarean section.

I ran into enormous problems trying to fill out the letter of guarantee for her admission into the hospital Le Dantec. The birth was trying and risky, but in the end the baby was saved.

I've known other dramatic cases where the concerned women or their babies lost their lives before birth. The surviving women compelled me to take on this battle".

Achievements

The committee for women achieved marked success in several important socio-economic programs with the support

of many partners. The women with disabilities on this committee use several lines of credit for financing its members. The project's beneficiaries have started to take charge and rediscover a normal life. Women with disabilities are present in a variety of sectors, like gastronomy, information technology, fashion, etc.

Social awareness of disabilities was another challenge unto itself, because most women with motor skill disabilities have undergone degrading situations, namely having to crawl. We have provided them with wheelchairs and prosthetic supports. They need to be clean and beautiful, and to maintain their femininity and dignity. In this way we have fought their ingrained inferiority complexes. At the very least, they now have models that they can use as reference.

State takeover of the caesarean for women with disabilities. As it stands, the standard of life for those concerned has greatly increased. Women with disabilities are more and more often promoted to jobs carrying significant responsibility. "As proof, the ministerial cabinet has twice offered me the position of technical advisor. We have already provided opportunities for almost six hundred (600) women with disabilities. They no longer sit on the sidelines in public demonstrations, but now prove their leadership capabilities by defending their causes".

Lessons Learned

In African countries like ours, there are many obstacles to our integration. They include physical, sociological, structural, psychological, and prejudicial barriers.

Moreover, the number of women with disabilities who are single is very high, as it is very difficult for them to find husbands. This prevailing situation stems from certain socio-cultural constraints and prejudices. The majority of the time, parents do not accept a son who marries a woman with disabilities. They argue that these women cannot fulfill their household duties (laundry, cooking), and, worse, because of their physical state, they are considered to be bearers of bad luck in the house.

All these matters reinforce our determination to combat injustice and inequity. We are not alone in this challenge. Even so, much remains to be done.





Failures

The effective application of social legislation favorable to the socio-economic integration of women with disabilities is not yet in full swing. For example, the relevant convention is not being applied. Another issue involves persistent cases where women with disabilities are forced to beg, despite our efforts to eradicate this blight. For begging exposes them to all kinds of abuse and atrocities.

Resources

Recognized personalities in Senegal's civil society have joined our fight for social justice. Mrs. Annette Mbaye d'Erneville, a journalist, has substantially contributed to the social readjustment and recognition of women with disabilities. She is present in all of our lobbying and advocacy efforts. Moreover, Mrs. d'Erneville has hired women with disabilities.

Recommendations

Our commitment and determination alone are not sufficient, for the issue of disabilities requires a comprehensive approach. It concerns everyone.

Therefore, we encourage research and work in this domain. A policy of communication and shared information would remove ignorance and prejudices recurrent in the lives of people with disabilities. Furthermore, education from an early age on the value of mutual assistance and of solidarity and diversity will no doubt participate in the awakening of social awareness.

Ndèye Dagué's story

Today in her forties, Mrs. Dieye, born Ndèye Dagué Gueye, carries the stigma of a disability. "I had polio when I was one year-old and I have had crutches and a brace my whole life", she says. Nonetheless, she spent a happy childhood thanks to motherly love and the selfless efforts of her father, who contributed greatly to her success in society. He never gave up fighting against the socio-cultural constraints limiting the promotion of people with disabilities, particularly women. "At school, I endured many struggles that strengthened my will to succeed. My father always reminded me, whenever someone mocks your disability, you have to prove to him your worth."

Ndèye has been a teacher for more than two decades and is an ambitious and altruistic mother. She stresses the importance of action over ideas.

Her biggest shock occurred when she was laid off from her teaching position at the Ecole Normale des Jeunes Filles (an accelerated high school for girls) after just several months of teaching, under the pretext that her disability made her unfit for the job. This unjust decision had no legal basis. She recalls how on that day "I felt awful, violated at my core." But Ndèye had fortune on her side, for although her father had died, her adoptive father Mactar Sarr succeeded, after great effort, in getting her reinstated in her original position at the Ecole Normale des Jeunes Filles, Germaine Le Goff. Since his entrance in her life, Ndèye's adoptive father has been at her side through all her struggles.

This painful event heightened her awareness of the need to fight for women with disabilities.

Thus, she joined one of the organizations within the movement for people with disabilities, namely, the National Association for Motor Disabilities of Senegal. She quickly climbed the ranks to become the representative of women for the Senegalese Federation of Associations for People with Disabilities (FSAPH), which brings together some twenty branches of organizations for women throughout the country.

Ndèye Dagué inspires anyone familiar with the world of people with disabilities. She has made herself known in the media because of her lobbying and advocacy for the social inclusion of women with disabilities.

Ndèye has participated in many international conferences devoted to the issue of women with disabilities. The supervisory ministers, who twice offered her the post of technical advisor that she ended up accepting, recognize her experience and expertise.

What is most admirable about Ndèye Dagué, though, is her unrelenting strength in the fight for the emergence of women leaders among those with disabilities, despite the adversity of social norms.

However, her activities deprive her of having both a professional career and family life. But she benefits from the understanding of her husband, Mr. Dieye, who is also very involved in the fight.

"Mrs. Ndèye Dagué Gueye is a tireless campaigner for the promotion of the rights of women and in particular of wom-



en with disabilities. She has always advocated with responsibility and courage. What fascinates me the most about her is her capacity for team work. This is most striking in her speeches for the National Advisory Committee for Women, where she has always upheld to the Minister of Family Affairs the importance of putting into place a policy of socio-economic integration for people with disabilities”.

The promotion of gender, health, and education rights form the basis of her strategy for the promotion of people with disabilities, which has made her, in my opinion, one of the most charismatic women leaders of her generation.

Ndèye Dagué is truly with the times, an age when humanists who have chosen to serve their peers often forget themselves in their single-minded pursuit on behalf of the community.

She remains an icon in the fight to promote people living with disabilities, and so it is no coincidence that the Minister of Family Affairs included her in the cabinet to draw on her vast experience and expertise. After all, her credo for the future is: “equal opportunities open to all”.

Mamadou Ndoye – Sociologist, Directorate of Family Affairs.

◀ Photos:
Ndèye Dagué
Gueye Dieye's
archive

Madame Dièye Ndéye Dague Guéye,

47 years old, married, two children. Ashoka Fellow in Senegal since 2002. Throughout her life she has led her fight with a brace and two crutches. She created the first Women's National Association of Disabled in Senegal. Her work is focused on the socio-economic status of girls and women with motor disabilities in Senegal.

A teacher by training, she has received several distinctions in Senegal: as a pioneer in the struggle for the promotion of disabled woman, by the Ministry of Women, Children and the Family in Senegal; as a women's role model in promoting the education of girls (by FAWE: Forum for African Women Educationalists); and many others.

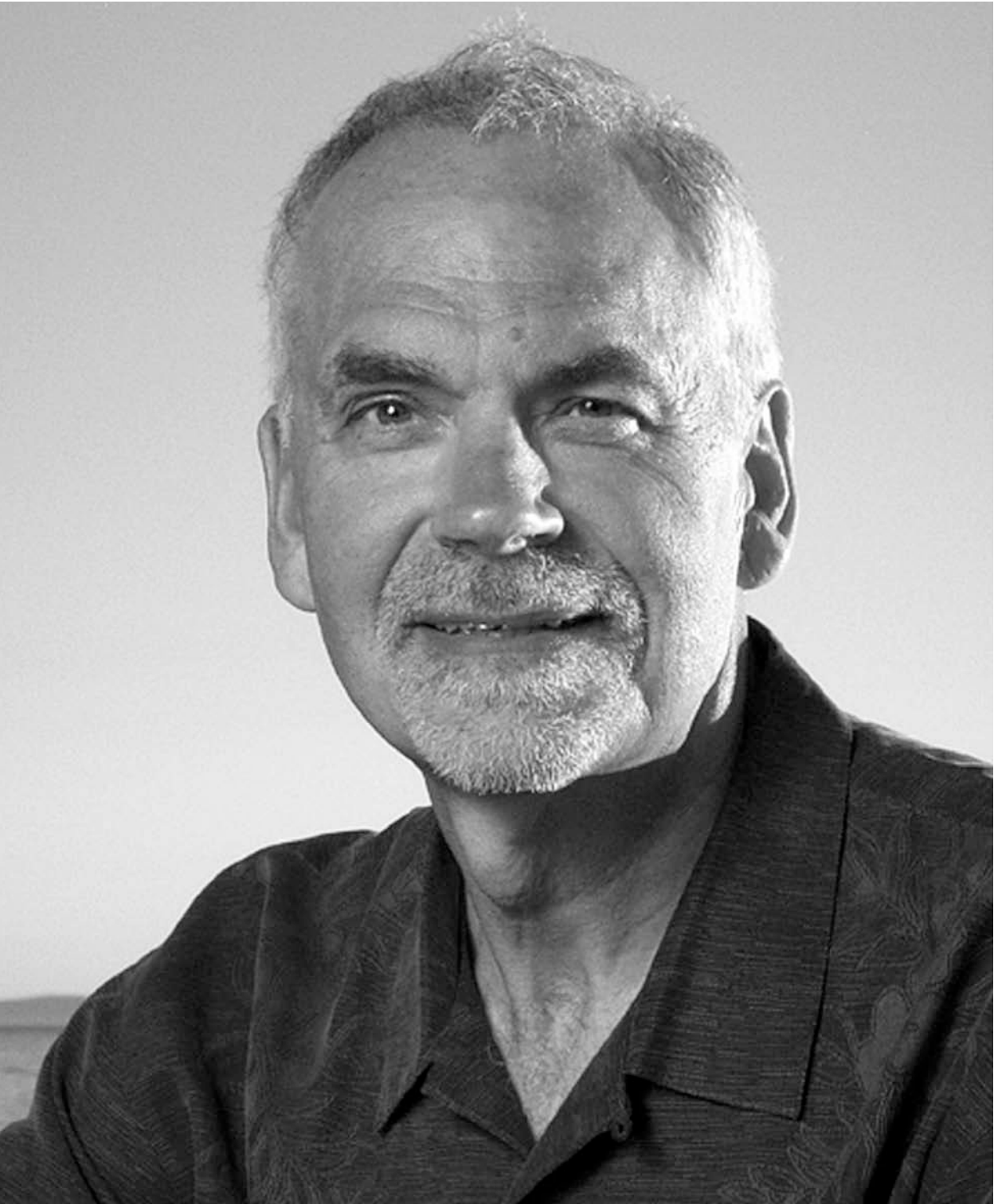
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Al Etmanski

PLAN, Canada
Ashoka Fellow since 2002

Hope For The Future by Al Etmanski

The first time I met George he told me he was afraid to die. His wife had just passed away. His son Rick was an only child and had no friends. Nor was there any extended family in the Greater Vancouver area. He was desperate.

The first time I met Rick he wouldn't talk to me, or even look me in the eye. In fact, he walked out of the room.

As I got to know him I understood why. In his career as a client of the disability services system he had been labeled uncooperative, lazy, uncommunicative, aggressive, retarded, unreliable, and incapable of working. I once saw vocational files nearly 6 inches thick chronicling everything that was supposedly wrong with him and why he couldn't be counted on. These files would destroy anyone's self esteem. He had made the rounds of a variety of programs, been in and out of lots of services, and – though he didn't express it – he had met his fair share of social workers like me. People who made promises they couldn't keep.

George, and a dozen other parents like him, was the inspiration to create the Planned Lifetime Advocacy Network (PLAN) – a resource to families who live with the persistent question: *What will happen to my child with a disability when I die?*

We soon realized we were on the leading edge of a global phenomenon. This is the first time in history a generation of people with disabilities are outliving their parents. Twenty years later we are supporting over forty family-led organizations around the world – all based on the PLAN approach.

George and Rick were also the inspiration to change our way of thinking about disability.

It was clear Rick's spirit had fled. He carried around a heavy invisible backpack laden with labels, taunts, misdiagnoses, pity, prejudice, and misunderstanding.

Rick believed he was worthless. He was profoundly lonely. He was so lonely he hardly spoke – and when he did, he whispered.

His words had dried up. And so had his dreams.

To awaken someone's imagination, to ignite their dreams, is not easy. It takes a special person – someone who sees beyond their disability to their gifts. Someone who listens; someone who is resourceful, well connected, and infused with the spirit of abundance.

We found her – a gifted young woman named Anna. PLAN retained Anna to create a circle of friends with and for Rick.

She sat for many hours in silence waiting to hear Rick's song. She didn't offer suggestions or solutions. She just believed in him

One day she came to our office ecstatic. She said, "I've got it, I've got it! It's horses." It turned out Rick loved everything about horses. He wanted to ride them, to groom them, he even wanted to own his own horse. More than

anything he wanted to be a cowboy herding cattle on the range.

As PLAN assisted George with his will and estate plan – which is a service PLAN provides to families – Anna began creating community connections for Rick. She started by introducing Rick to a friend of hers who owned a horse in Southlands, a stable by the Fraser River in Vancouver. Rick was invited to the stable to meet her horse 'Big Bob'. He walked 'Big Bob' and even went for a little ride. It was clear he had a special connection to horses.

When you own a horse in the city two things are certain: one, horses eat a lot of hay; two you don't visit as often as you intend, and so you pay someone to ride and exercise the horse, clean the stables, and so on. Either way they cost a lot of money.

Seeing Rick's obvious comfort with 'Big Bob' his owner invited him to visit the stables anytime – with or without her. Rick, who had a lot of time on his hands, took up the offer. In fact he began to visit every day.

Soon, the owner of the stables noticed Rick's manner with horses, noticed how he enjoyed mucking out the stalls and rubbing down the horses more than anyone he had ever seen. Being a wise businessman, he offered Rick a job.

Rick still works there today – 12 years later. In fact, when the vet comes, she insists that Rick be there. She knows the horses are always calmest in Rick's gentle, quiet presence.

Others are recognizing Rick's gifts too. A couple of summers ago Rick's circle of friends organized a birthday party for him in a local park. The stables surprised Rick by parading horses at his party. As the horses and riders cantered around the park it was a beautiful testament to how loved and treasured Rick is. His circle of friends is one of PLAN's largest – over 20-people strong, 8 of whom can be counted as close and dear friends.

You can imagine the peace of mind this gives his dad.

Over time Rick has made many friends in the horse world. One of them told him about a 250-mile cattle drive in south-eastern British Columbia and asked him along. Rick went – and has gone every summer since. His dream has come true: he's been a cowboy out riding the range in the mountains of British Columbia for six years

Rick, our horse whisperer, had been transformed. The nurturing power of friendship has brought him to life. Belonging and being valued has made his heavy backpack of labels disappear.



What we have learned from Rick and the thousands of people with disabilities who now have social networks is this:

- an exclusive focus on needs and inabilities leads to isolation and loneliness
- a focus on gifts and contributions leads to inclusion and acceptance
- isolation and loneliness is one of the biggest handicaps faced by people with disabilities
- people with disabilities, like everyone else, want to make their contribution to society
- relationships are the most effective ways to discover, appreciate, and enable people to make a contribution
- it is through their contributions that people with disabilities will be accepted as full citizens who fulfill their responsibilities.

We have organized circles of friends for people with every conceivable type of disability or condition. We can state with complete assurance that no disability precludes relationships.

All Rick wants is to work at the stables, to live on the bus line close his work, to pursue his passion, to 'pull his weight', and to have the satisfaction of being counted on. In other words, Rick wants what we all want: to have meaning in his life.

All his father George wants is a society that sees what he sees – not just his son's disabilities, but his gifts, capacities, and contributions. He wants a country and a culture that doesn't place the asterisk 'needy' beside his son's name.

We've since learned George is not alone. Hundreds of thousands of parents around the world want to ensure that their sons and daughters are valued and have a good life.

We've also learned that our job at PLAN is not to create Rick's good life – how foolish of us to think we could. For one thing we don't know the first thing about horses!

Rather, our job is to figure out how to support George and other parents ensure that their sons and daughters have a good life. Our job is to tap into the considerable connections, creativity, dedication, and resources of families who have a relative with a disability. Our job is also to tap into the natural hospitality of all citizens.

Amory Lovins in his book *Natural Capitalism* (www.rmi.org) asserts that what we count is what we value. Or to put it another way, if we don't count it we don't know it and we don't value it.

If we apply Lovins' analysis to the disability sector (both individuals and their families) we soon learn the only things the system counts are needs – individual needs and family needs. We also learn that financial resources are allocated by the government only on the basis of needs – that is, you only get the money if you are needy and stay needy. We think this is a 'search and destroy' mission to keep people needy. For in so doing, governments ignore the considerable assets of the Ricks and Georges of the world. Instead of nurturing their resilience, this approach breeds dependency. And yet friendships are created around gifts and passions, not needs.


As one mother told me recently: in order for me to get funding for my daughter I have to describe her in the most horrible terms, and that is the opposite of how I see her, what I know about her, and how I want her to be seen.

By and large the Canadian disability system is counting the wrong things about Rick and George. I think it has to learn what we've learned at PLAN – how to tap into the resilient, adaptive capacity of people with disabilities and their families. To see the glass as half full, not half empty.

Individuals with disabilities and their families and friends face three big challenges:

One: a new 'worthiness agenda' is emerging. We are constantly reminded of how fragile society's support for people with disabilities can be. Debates about mercy killing, right to die legislation, and a reverence for technology and genetic engineering reflect a quest for perfection and implicitly a belief that some lives are not worth living or not as worthy. With every new tragedy or scientific breakthrough, fears surface that ambiguous terms like 'quality of life' will be used within a re-emerging eugenics movement. History suggests economic downturns precipitate cutbacks in support for people deemed not as worthy. Because they are not valued as contributors or producers they are seen as unworthy to receive society's limited resources.





Two: we see an epidemic of isolation and loneliness. The biggest handicap faced by people with disabilities is often their isolation and loneliness. “Loneliness is a most terrible poverty”, said Mother Theresa. When we belong life has meaning. Friendships bring forth our gifts and bring meaning to our lives.

Despite widespread agreement on the importance of relationships and friendships, there is no concerted effort made to address this challenge. Government budgets are focused exclusively on programs and services which often unwittingly further isolate vulnerable individuals.

Three: we worry about the impact of the financial crisis and demographic change on funding social support.

Population aging will be a key challenge facing our national economies over the next 15 years. Here are some Canadian statistics. In 2005 there were 44 children and seniors for every 100 Canadians of working age. By 2030 there will be 61 children and seniors. The impact is twofold. One, there will be increased health care expenditures (one source suggests that if current trends continue, health care costs in my home province of British Columbia will account for more than 70% of the provincial budget by 2017). Two, there will be fewer taxpayers and therefore smaller government budgets.

Regardless of how future governments respond to these demographic trends, all projections suggest increased pressure on fewer resources, something that will leave a much smaller slice of the fiscal pie for social expenditures.

After two decades of learning from the Georges and Ricks of this world we’ve come to appreciate we’re sitting on a treasure chest of unaccounted for and untapped resources. There’s a lot we weren’t counting.

We’ve learned for example that welcoming people with disabilities into community life serves as a catalyst for belonging, for everyone. Members of Rick’s network declare he has brought meaning to their lives.

One day we started counting something else, which in retrospect is so obvious I’m almost embarrassed to admit

it. We started counting the number of wills families were making; the number of trusts families were establishing for their sons and daughters, and their accumulated dollar total; the total worth of families’ life insurance; in fact all the funds, deposits, investments, and mortgages of individuals with disabilities and their families which were under administration in financial institutions.

We began to recognize the potential power of the disability market. The numbers are staggering.

We learned Canadian families, rich and poor combined, are establishing \$80 billion in special needs trust funds for their relatives with a disability.

Then we researched the additional funds families were prepared to set aside for their family members. Conservatively the estimate was \$250 million annually. We used this research to propose the establishment of a Registered Disability Savings Plan (RDSP). After eight years of hard work we were successful.

On December 1, 2008 Canada’s financial institutions will offer the world’s first disability savings plan for people with disabilities. The RDSP also offers generous matching grants from the national government and a Disability Savings Bond worth \$1000 a year. The estimated size of the RDSP market in Canada is \$80 billion! This will impact 800,000 Canadians with disabilities and their families!

The establishment of the RDSP has inspired us to think big. We want to mobilize the collective economic power of people with disabilities and their families. When you combine the RDSP \$80 billion and the \$80 billion in special needs trusts, we have \$160 Billion in untapped economic resources to harness.

We want to use these funds to lever government resources to address vital issues affecting people with disabilities and their families – like housing; employment; adaptive equipment and mobility devices; isolation and loneliness.

We are partnering with financial institutions and provincial governments to disseminate information to all families in Canada. We are a vast country and this is hard to do ourselves.



◀ ▲ Photos: PLAN

We want to establish a No One Alone Fund to systematically and strategically address isolation and loneliness in our country.

We are developing a strategy to create a pooled disability investment fund to invest in social enterprise.

No longer do we see ourselves as victims dependent on charity or government handouts. Like the Ricks and Georges of this world we are counting all our assets, moral, social, and economic. Pity is not enough. Pity was never enough. We are convinced the future is based on claiming our economic power.

Al Etmanski, Ashoka Fellow in Canada since 2002, is President and Co-founder of the Planned Lifetime Advocacy Network PLAN. He is the author of two best selling books: *A Good Life – For you and your Relative with a Disability* and *Safe and Secure*. He is a founding member of Social Innovation Generation (SiG), focused on scaling social innovations and social enterprises to have impact and durability.

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Other websites: www.plan.ca connections to PLAN's services and resources

www.planinstitute.ca PLAN's companion Institute for Caring Citizenship providing resources to families including on-line courses, books DVD's and training in Circles of Friends

www.philia.ca devoted to a new theory of disability based on contributing citizenship

[www.tiestthatbind.ca](http://www.tiesthatbind.ca) companion website to an inspirational film based on PLAN's work

www.socialaudit.ca what families think – independent audit of PLAN's services

www.tyze.com web-based platform offering personal networks for people with disabilities based on PLAN's approach

www.rdsp.com up-to-date information on the world's first Registered Disability Savings Plan (RDSP)

www.sigationeration.ca devoted to values, practices, and methodologies which accelerate the impact of social innovations and social enterprises.



Isabel Guirao

A Toda Vela, Spain

Ashoka Fellow since 2006

The Story Of A Journey

by Elena Sevillano

(translated by Peter Dowdy)

At the age of 11, Puri had no friends – at 24, she does. The difference that has made this change possible is an association called A Toda Vela – Full Sails Ahead – which is dedicated to developing inclusive free-time and recreation options for children and youth with intellectual disabilities in Spain. Puri has gone from being alone to filling her free-time with a schedule that many would wish for themselves. She decides what she wants, where, how, when, and with whom. And when you talk about her, you are also talking about Vanesa, who is in a wheelchair. Or Simon, who helps her. Or Sonia, who had a crowd of people comforting her at her father's funeral. They are all friends with Isabel Guirao, the technical director and alma mater of A Toda Vela.

Isabel, psychologist and school counselor, saw that the support offered by educational centers to people with disabilities ended on weekends or during vacations. "You leave, but we are still here", many families explained to the professionals. Isabel's two children, who have no disabilities, played around, stayed over at their friends' houses, etc. "The children I looked after didn't do that", Isabel says. In the summer of 1996 she visited Cambodia and the projects of the NGO La Casa del Agua de Coco, run by her brother José Luis. She returned thinking that there had to be more that she could do in the field of disability.

"When you look for something, you pay close attention and seize opportunities on the fly", she notes. In her case, it came in the form of a newspaper clipping María Victo-

ria gave her, one of the mothers at her school. A group in Madrid was working with recreation time for people with intellectual disabilities. "That was it! To use recreation as a tool for integration! Creating an organization that would fill the hole in the lives of people with intellectual disabilities in Almería with friends and plans". The idea first got off the ground under the name A Toda Vela – Full Sails Ahead – in January 1997, with Isabel, María Victoria, Ina, Cati and Antoñita, five women as founders. The Chair of Recreation and Disability at the University of Deusto in Bilbao, and the Chair of Disability Psychology at the University of Salamanca provided theoretical support for the undertaking. There was much to do in this field. For no laws, administrative support, or subsidies were available to cover free-time for a group of people that amounts to 9% of Spain's population or some three and a half million people, of whom approximately one-fifth are people with intellectual disabilities.

Ask any young person which three things are most important to him/her, and at the top of the list, along with family or work, is leisure. A Toda Vela surveyed 200 kids with disabilities and found that 92% did not have friends. The majority never celebrated their birthdays with anyone else outside family members. 98% were not free to move around outside of their home or the care center. 61.3% were not members of any clubs or associations. 85% had never spent the night outside of their home. 40% had never been to a movie theatre. 20% did not use the tele-

phone. 77% did not know how to swim – and this in a coastal city with six months of good weather each year! 25% suffered from pathological isolation, depression, and social phobias.

“The associative movement working with disabilities does not consider free-time activities a transformative service for this group of people. For that reason the associations do not demand, request, or design programs in this area, which is so important for personal and social development. People with disabilities are an invisible group, one that does not exist”, Guirao wrote in a report in 2007. And when they do not exist, the community does not offer “inclusive sporting, cultural or recreational programs, and when it does, because the community does not fully understand the real needs, the activities offered do not include all the support required to attend to these people with dignity. Our welfare society is unaware; it is incomplete...”

A Toda Vela outlined and then perfected an inclusive recreation project that avoided the term ‘welfare’ and refused to confine itself within the four walls of an office. From its very beginning it reached out and raised awareness in the city, trying to involve the community. Boys and girls started to use public spaces and services such as pools, sporting centers, and parks, as well as becoming frequent visitors of the boardwalk, where they practice archery, or the beach of El Zapillo, where they mingle and talk to peo-

ple in the beach. Inclusion and equality were approached through visibility and awareness. Getting to know Puri, for example, was impossible until she turned 11 for the simple reason that she never crossed the threshold of her own door. “School was a kind of hell. I told my parents that I was more relaxed at home, but that was a lie. In fact, I was simply petrified of being outside”, she now recalls. She had to be almost dragged out by her sister, who was then a volunteer for A Toda Vela. Thanks to word-of-mouth, many others now enjoy their free-time just like any other kid: “Hey, there is an association where our children can play sports, go camping, and have fun as equals”.

Around 1,000 youth from 10 to 30 years of age, with and without disabilities, have participated in the activities of A Toda Vela. The group has produced a CD, *The Heart as a Flag*, filled with video clips by the choreographer and stage director Danni Pannullo, as well as a monthly program on Spanish National Radio. They sign up for whatever event is celebrated in the area, ranging from carnivals to caroling. A Toda Vela offers a Daytime Care Center and a recreation service which takes care of the club where youth come to hang out. The association also offers a support service for families by providing babysitters that help families take a break. Additional services include support for disabilities, with a group of autonomous individuals: people with disabilities who work and give ideas to the group. In 2008 there were 345 associates, 175 youth, 144 families, and five organiza-



tions running youth shelters. There were also 60 professionals and, as the fundamental pillar of this organization, 115 volunteers offering their own support and training.

Pepe has Ondine's (CCHS) and can neither speak, chew, eat, nor even breathe, for which he needs assisted breathing. It would be easy to give him up as a lost cause based on the long list of ailments that limit him. But in A Toda Vela the only list that counts is that of his virtues. What can Pepe do? Swim – and he loves it. Even though he needs three rubber rings, two for his 20-year-old body and a third for his oxygen tank. The pool at the Euro-Latin American Youth Center of Mollina, in the province of Málaga (southern Spain), is where trips for very needy children are planned for summer afternoons.

One enormous advantage of using community facilities is that you always meet interesting neighbors, such as members of the Youth Council of Melilla, who have invited us to their workshops on laughter therapy, salsa, or masked balls; an association for the disabled in Guadix, with which we share trips, a cafeteria, and restrooms. Those who want to travel around town, and those who prefer to stay at the center are both in complete control over how they use their free time. This is something that parents greatly value, i.e., that their children are treated like people whose opinion must be taken into account. This means dignity, respect, and emphasis being placed, not on their disabilities, but on their abilities.

"My son has friends, goes to birthday parties... this has changed our lives", offers Lola, Antonia's mother. "Improving his quality of life has improved his entire surroundings", say Martirio and Ricardo, Pepe's parents. "His friends kiss him, they hug him, they care for him..." adds Martirio. Personal stories are the greatest testament to the changes that have been achieved: Vanesa's journey to Istanbul; Sonia riding a camel in Tenerife; Isabel, who was taken away as a problem child, returning to live with her family, supported by the group... Ricardo and Martirio confessed that at the beginning they were not confident that strangers could handle Pepe. "Now we trust A Toda Vela, the volunteers are marvelous".

Without its volunteers A Toda Vela would not even exist, insists Isabel, who came to Mollina at the head of a group


of six or seven volunteers. Among them is her son Nacho and the daughter of some friends, Teresa, who is trying it for the first time. Teresa recently cried talking to her mother on the telephone, as she was simply so moved. "The first thing I remember from A Toda Vela is a canoe, going through some rapids. I was by far the slowest, and this made me wonder, who's the one with disabilities here?" interjects María Ángeles, another volunteer. This has made it clear that the group also changes the lives of the people who work for it.

Isabel says that, even though she cannot explain why, if she went to Mars tomorrow she would go find a Martian with a disability, grab him by the antenna, and drag him into the light. She has not gotten that far yet, but having become an Ashoka Social Entrepreneur in 2006 has allowed her to transplant the A Toda Vela model to Madagascar. In May 2007, again with her brother José Luis and his NGO Bel Avenir, they explored the southern half of the island to find people with disabilities and set up a small center where they gathered 30 boys and girls with visual problems. They were joined by youths without disabilities at an integration camp and knocked down the walls between them with games and music. "The change there was immediate. Within 24 hours almost everyone had laughed themselves silly. We hugged, we shared".

These blind children sang like angels, and just a year later A Toda Vela presented them in Spain as the group Malagasy Gospel – "An inclusive cultural event that communicates the richness of inclusion and the power that vision has for the abilities of people to surpass any other condition". Guirao sees the enormous possibility of Ashoka as a loudspeaker, through which she can give voice to her plans for inclusive recreation. Along with Ashoka, she works with the Spanish Confederation for Persons with Mental Disability, FEAPS, to export this model of service and inclusive recreation to all of Spain.

"12 years ago I took a step forward", and that was the foundation of A Toda Vela, for which she retired from her job as a school counselor. "I tried to split my time between both endeavors during the first few years, until a colleague told me, 'Isabelita, you will kill yourself. Ask the delegate of Education to let you go'. I thought, 'let's go, it's all or nothing'. And it worked. Now she splits her time





between the technical direction of the association and the promotion of national and international projects. Ricardo, representing parents at A Toda Vela's Board of Directors, considers the project to have become sufficiently consolidated to expand the model and provide coverage to many more people. "I always say to families outside our present reach: 'if only you had an A Toda Vela nearby'".

Meanwhile, the association is immersed in its own process of change. A year ago A Toda Vela began a campaign of demanding that the rights of the disabled be honored. The campaign has especially focused on ensuring that recreation services be inclusive – and when they are not, official protests are lodged. "We have rights, but until now we haven't demanded them. We need to fix that". The association will also resume working towards autonomy, something that does not figure in its founding objectives. However, A Toda Vela is based on active participation, and the children with disabilities are reclaiming their homes and jobs through their two representatives on the Board of Directors. "Will this mean a change to our philosophy? No, it simply represents progress towards fulfilling our demands and dreams. We have arrived at this point because we have become personally involved with people". They have seen that Vanesa wants to work, and Puri wants to become independent and live with her boyfriend, Salva. These are their challenges. "We've got to move forward".

Who Is Isabel Guirao?

When she was a psychology student at the University of Granada, Isabel Guirao rarely attended classes. Her memories of the university are those of a young woman from a socially-involved family who was taking part in a research team studying disability. She was first an intern at a school of girls with intellectual disabilities. After finishing her degree she worked at another school in Guadix. "I fell in love with the work, built bonds with the individuals there, and committed myself for life to them". After that, everything went smoothly: "You notice that you like people with disabilities, want to do something to improve their quality of life, and make friends with their mothers. You observe them".

Isabel affirms that these people constantly make her doubt her own abilities, "and I love that". They have made her face her fears, feel panic in the face of responsibility,

and develop emotionally: "I laugh and cry very easily. I hug, kiss, yell, and I am moved daily". Her choice in life, she assures those who ask, has given her rich rewards: "This is what I wanted to do and I did it, even if some relationships have been left by the roadside due to my personal unavailability. But I have not lost. On the contrary, I have gained". The contact with young people motivates and revitalizes her. "I have a unique relationship with my children and their friends" who participate in A Toda Vela, and with whom Isabel shares projects besides the family-related ones. "These are experiences that bind me to them in a special way".

Her Advice

- 1) See the person, not the disability. Based on the potentials and abilities of each person, give her/him support to help her/him develop and grow.
- 2) Include them in the community, so that the latter participates. Bring both worlds closer together, so that they are not seen simply from a physical viewpoint, but through activities that involve them emotionally.
- 3) Use the language of emotion. People with intellectual disabilities communicate through emotions, feelings, impulses, glances, smiles. Get down off your professional pedestal and put yourself in their shoes, speak their language. Get close to them, open their doors with options, opportunities, and defense of their rights.

Change Through Emotions

Abel La Calle, professor at the University of Almería, believes that living with A Toda Vela changes values, perceptions, and opinions both about people with disabilities and about oneself. "They create a sincere emotional space that attracts you and, in some way, transforms you". He realized this at a Work Camp for adolescents with and without disabilities: "Although I formally went there to lecture about human rights, from the moment I arrived until my departure – that is, during the couple of days of living with them – the learning experience was mutual". This experience posed him some challenges: "They asked me how to share the values that make up human rights... I decided to do so through photographs and chose images that showed the reality that we, in general, hide. When I showed them on the projector and we spoke about the



feelings that those images produced in us, we all wanted to change the world. There, among us, it seemed this dream could be made reality". The second challenge was "to learn to relate to people with disabilities. Observing Isabel, Javier, Eo, Silvia, and the rest of the volunteers resulted in sincerely wanting to connect with those people. And I think I learned how'.

In his opinion, A Toda Vela is "a caring space where there is only one essential rule: empathy, feel what the other person is feeling. Even if you don't always succeed, they know that you're really trying. It's about a socially contagious percep-

tion that has given more autonomy to people with disabilities but, above all, has changed perceptions about them and has made them visible. If you meet one of them, you find yourself with someone who recognizes you, greets you cordially by name, and expects that you'll recognize them and return their smile". He remembers how the association began, "focused on the sphere of recreation. The only thing you had to do was have fun. I believe that this was a great hunch or guess – I don't know. The point is that now A Toda Vela has brought this solution to every sphere of life of people with disabilities. For the disabled sincerely want what all people do: dignity, love, autonomy..."

◀ ▲ Photos:
OjoFotográfico

Isabel Guirao Piñeyro,

50 years old, two sons.

Psychologist and Master in Advisory and Management of organizational development processes. Member of FEAPS Advisory Network and Ashoka Fellow since 2006.

After 20 years working as a school counselor, in 1997 she founded A Toda Vela.

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Andreas Heinecke

Dialogue in the Dark, Germany

Ashoka Fellow since 2005

Dialogue In The Dark by Andreas Heinecke

The German context

The interaction between “abled” and “disabled” people is very often hindered by stereotypes, fears, avoidance, and prejudice. Statistics talk about 610 million disabled people worldwide, of whom 400 million live in the developing world, and 38 million in Europe. But research shows that while they are all labeled “disabled”, only some 5% of them regard themselves as such. In Germany approximately 8 million disabled people are registered. One million are visually impaired and around 100,000 are legally blind.

Different levels of understanding, different levels of support, and different levels of access for the disabled are to be found in different countries. In Germany the physical needs of disabled people are generally well met by government welfare programs. We do have an anti-discrimination law meant to guarantee people with disabilities the same legal rights and responsibilities as those who are not disabled. But reality paints another picture. Indeed, only about 15% of the disabled have jobs, and the majority do not enjoy equal rights in terms of education, transportation, and access.

The situation of disabled people

The uneasiness many people feel around blind and handicapped people leads to an “avoidance strategy” – something that leads to marginalization and discrimination.

Simulations of blindness already exist in Germany and other countries, but they are usually done for classes

teaching people how to approach the blind, how to help the blind. In part, these experiences are to show how difficult the life of a disabled person is. They tend to elicit compassion rather more than understanding and only very few people participate in this type of experience, which is most often part of educational programs in social work.

The new idea

The concept is simple: visitors are led by blind guides in groups through specially constructed dark rooms in which scents, sounds, wind, temperatures, and textures convey the characteristics of daily environments – for example, a park, a city, or a bar. The daily routine becomes a new experience. A reversal of roles is created: people who can see are taken out of their familiar environment. Blind people provide them with security and a sense of orientation by transmitting to them a world without pictures.

The concept has proved quite effective. Over the last years Dialogue in the Dark has been presented in 28 countries throughout Europe, Asia, and America. More than six million visitors have been led through our exhibitions by 6,000 blind staff members. And although it's been over 20 years, the demand is still growing. In 2006 alone 17 exhibitions were opened in 10 countries, giving 380 blind people all over the world the chance to have a job and to show 480,000 visitors that being blind is another interesting form of sense perception and a way of life.

The aim

Dialogue in the Dark is not supposed to convey what it is like to be blind. To say “blind means black” would be a gross oversimplification and would not at all correspond to the real life situation of blind people. Only 5% of all blind people in the world see only black. The others have extremely different forms of blindness and impaired vision. Hence, the darkness has to be understood as a metaphor referring to the social reality of blind people, who are not spared discrimination, social exclusion, prejudice, and unequal opportunities in society, education, and the labor market even in the 21st century. Thus, they are also a representative example for other fringe groups who “stand in the dark” for various reasons or are connected to each other by a “dark episode”. Darkness however is also an ideal medium for communication. In the darkness pleasant appearance and status symbols do not count, and this makes room for unprejudiced encounters. Dialogue in the Dark’s visitors are also connected through the strong emotionality of the experience, something which gives rise to mutual support and a shared basis for conversation. And dialogue is of utmost importance, for whoever does not speak does not exist. Social distance disappears and solidarity is born: people are not judged and labeled so quickly, but are given the chance to express themselves and their values during conversation. This naturally happens first and foremost with blind people, as they are the people

you most talk with in these surroundings. Empathy and understanding are developed for handicapped people, and awareness of human variety is expanded.

Apart from this social dialogue, Dialogue in the Dark strives to stimulate reflection on identity and perception. Dialogue with one’s self starts no later than when you enter the complete darkness and you experience limitations and leave familiar ground. Frustrations arise, and this makes room for new assessments, whether of the experience of strong emotional feelings, of one’s own limitations, or the discovery of other senses. There is also the humbling joy of fresh appreciation of one’s eyesight. A mere one-hour visit is often enough to discover several unexpected things inside you.

The effect

The numerous guest books powerfully demonstrate that after the visit to the exhibition people feel the urge to give expression to their thoughts and feelings. Perhaps especially noteworthy is that 98% of the comments are positive. Three general categories of the comments may be discerned:

- 32% express their gratitude for the experience,
- 37% are satisfied with the experiences gained,
- 31% invest some time in analyzing these experiences and reflecting on them.



One effect which is achieved by Dialogue in the Dark is especially important: the feeling of gratitude towards the blind companion. The blind person is seen as the person who helped to overcome anxiety and insecurity during the journey through the darkness. Gratitude and admiration evolves from that: social distance changes into interest, and pity into respect.

Thus it is clear that Dialogue in the Dark gives a fresh impetus, one that alters thinking patterns, makes stereotypes disappear, and creates a new accessibility to the unique world of blind people. One's own values and ideas are questioned, limitations are experienced, and through the encounter with people of another culture and life-reality a dialogue is developed that goes far beyond the visit to the exhibition.

A second matter proves impressively that this new awareness is not fleeting.

People who had visited the exhibition five years ago were contacted by telephone. These people were chosen randomly and asked to participate in a questionnaire that allowed particularly free and direct answers. The results are as follows:

- 100% remember the name of the exhibition,
- 100% remember the person they visited the exhibition with,
- 90% say that the exhibition is supposed to sensitize people to the world of blind people,
- 100% take the view that the exhibition achieved this aim,
- 98% had talked to friends, colleagues, and family members about their experience,
- 80% say that they now have more knowledge about blindness,
- 52% had encouraged someone to visit the exhibition,
- 34% come a second time.

Dialogue in the Dark has succeeded in establishing a place for social and emotional learning. The values of other people are taken up with interest, reflection and communication about being human begin, and empathy develops. This happens regardless of age, sex, level of education, and cultural and social background.

Furthermore, Dialogue in the Dark has a great influence on the development of the personalities and identi-

ties of the blind staff members. Being a guide changes self-perception, relations with the seeing population and increases self-esteem. Blind people gain strength in their acting and communicating competence, take responsibility, work together in a team, and learn to defend their interests. Their own income helps them to be independent and strengthens respect among family and friends. For many blind people their work for Dialogue in the Dark is their first paid job. They can gain experience and qualifications which can be useful on the labour market independently of Dialogue in the Dark. Blind people change from passive receivers of welfare to active contributors to society and are able to live a self-determined life.

The strategy

Even in the beginning there was hardly a doubt but that the concept of Dialogue in the Dark could be used effectively to create jobs for blind people and to change the general perception of blindness among the public and the media. But there were almost no financial resources or helpful networks available, so the question arose as to how to spread the message. In 1988, the year Dialogue in the Dark came into being, the franchise was not yet a widespread business model, so the idea of using only the label and know-how for building and operating arose more from need than knowledge or strategic points of view.

From today's point of view there could not have been a better way to disseminate Dialogue in the Dark worldwide. We use local structures, networks, and resources, and in addition we employ only blind people from the region where the exhibition takes place. We thereby reduce the strain on public budgets, generate local tax revenue, and increase purchasing power – moreover, we are able to establish the idea for the long term. The franchise-holders are connected via an international network and meet each other once a year to share experiences and form synergies. We cultivate an open exchange of knowledge, and reveal every bit of know-how which is necessary to make Dialogue in the Dark successful. We try to make our clients partners, and our partners friends in order to build up a long-term international cooperation based on trust and respect.



Lessons learned

I have been running Dialogue in the Dark for almost 20 years. What lessons have I learned?

- 1) Never give up
- 2) Don't count on logic
- 3) Life is change
- 4) Compensate the lack of talent with endurance
- 5) Be authentic
- 6) Trust people
- 7) Stay positive
- 8) Money never counts
- 9) Life has no handrail
- 10) Success is the most dangerous situation
- 11) Don't overestimate yourself
- 12) Stay humble
- 13) Things are becoming very simple

The most important lesson I have learned in the last years: not everything can be controlled. We have to find our place despite unknowable and unpredictable situations.

Origins

The concept of Dialogue in the Dark has gained acceptance and currency worldwide. People often forget how difficult it was to build a business model in order to pursue a social mission, and to make a living from that in the long term. Today I know it is possible to make a living from it. You devote yourself to a project. And whether because of naivety, missionary zeal, social romanticism, rebellion, a sensitivity to injustice, a lack of understanding, or a fighting spirit, you blaze a trail that will definitely not end up in early retirement and an idyllic life in terraced houses or clubhouses. Of course, the question does arise as to what drives you.

The answer to all this is obvious and short: there is no other way. Dialogue in the Dark is connected so closely

to me and my history that it has become an inextricable part of myself. The beginnings of this life task go back to the history of my family. My mother had Jewish relatives who were persecuted and murdered during the Nazi era. By contrast my father passed through the whole National Socialist educational system and grew up surrounded by both tacit supporters and perpetrators. After the war my parents found each other and started a family. Since the age of 13 I have been aware of this family constellation and I have wondered again and again what causes people to become mass murders and what compels people to abandon humanity, morality, and self-respect. Since the age of 13 I have tried to understand something which is not graspable by mere intelligence. Not even my years of studying history, literature, and philosophy helped me answer the question of how and why violence, contempt for human beings, and systematic murder arise.

After finishing my studies I started working at a broadcasting company as a documentalist and journalist. One day our supervisor asked me if I would be interested in training a journalist who had become blind after a car accident. My basic attitude was rather that of avoiding contact with handicapped people, and the idea of being blind scared me. I met this blind young man and was deeply touched by his positive personality, his potentials, his positive outlook on life, his humor, and his intelligence. I regarded my attitude, consisting of a mixture of pity, empathy, anxiety, and insecurity, as something shameful. Even my years of searching for an understanding and acceptance of being different could not keep me from judging people's lives as "worthy" or "unworthy". I trained the young man at the broadcasting company and received a life-time lesson. Though to some it may sound grandiose, a blind person had to come into my life to open my eyes.

Because of my studies I knew that the Nazis considered handicapped people as "useless". Today handicapped people are still disabled in terms of social exclusion and personal self-realization, and are shunned to the fringes of our societies. Thinking of the importance my personal encounter with a blind person had had in my life, I was motivated to create a place where blind and seeing people could come together. It was obvious that we had



◀ Photo: Arne Weychard

▲ Photo: G2 Baraniak

to do it in an unusual style and makes complete use of the potentials of blind people. Martin Buber's maxim that "the only way to learn is through encounters" is the philosophical basis for the concept of Dialogue in the Dark— one many people will be able to experience in the future.

Andreas Heinecke is the first Ashoka Fellow in Western Europe. He is the founder and CEO of Dialogue Social Enterprise, an international social franchise company to foster employment for disabled people and to change perspectives towards otherness. Andreas is a fellow of the Schwab Foundation for Social Entrepreneurship, has been nominated as a member of the World Economic Forum's Global Agenda Council on Social Entrepreneurship and has won various awards.

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Maha Helali

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Addressing Autism in Egypt

by Maha Helali

In 1993 my life was touched by autism when my son, Mostafa, was diagnosed at 28 months with regressive autism. Since that discovery of an affliction I had never heard of, nothing in our family's life has been typical.

Mostafa was born in January 1991 full-term and quite healthy. Mostafa was not easy as a baby because he did not sleep much and refused most foods except breast milk. Nevertheless, he met all the developmental milestones until he was 20 months old, when some of his abilities started regressing.

Autism's onset approaches in a subtle style and for almost the first two years of Mostafa's life, nothing seemed to be wrong. He was engaged with the world around him, progressing normally, and taking steps into language – he could even speak in small sentences. He used to sing and recite nursery rhymes, and could draw very detailed drawings – for instance, a mosque with a minaret and the crescent on top. We thought, "Wow, a gifted child!". Then, suddenly, some unknown cascade of neurological events washed it all away, and he started losing many of his previously acquired skills.

By his twentieth month, Mostafa had changed noticeably. He began talking less and less. He seemed preoccupied and tended to daydream. He withdrew into himself and lost most of his speech by 24 months. We started speech therapy, but there was not much change outside the sessions. It was heartbreaking and we did not know what

to do. It was also around that same time that I lost my greatest supporter, my mother. From then on we were on a descent, a very steep one.

By 28 months, Mostafa became hyperactive and his love of repetition became more pronounced: he would draw the same pictures or pace the same area of the room. Like most parents, I went into denial and started to switch nurseries. One of the nurseries had a very understanding owner who was also a pediatrician. She told me that Mostafa might have Attention Deficit Hyperactivity Disorder (ADHD). I asked a psychiatrist who was a family friend for help. He visited us and observed that Mostafa had certain autistic traits, such as a love of repetition, his hypersensitivity to sound, his need for routines, etc. Nonetheless, we were not ready to accept that, and did not know what it meant to have a child with autism. We shopped some more!

Mostafa's father Niall, my ex-husband, had dual nationality, Egyptian/British. So in February 1995 his British side of the family arranged for us to take Mostafa for assessment at the Center for Communication and Social Disorders, which is the diagnostic center for the National Autistic Society in the UK. Mostafa, then four, was diagnosed as atypical autistic. However, the only advice they gave us was to put him in a school for autistic children. I explained that we lived in Cairo, Egypt, where there are no such schools. We were then advised to continue with speech therapy and to add occupational therapy to it.

Returning home, I began searching for information about autism on the Internet. From the outset, Niall and I agreed to be open about our son's condition with everyone we knew. We decided that we were not going to hide him at home. Our openness helped us find therapists for Mostafa, and I formed a support group with two American women in Cairo who also had sons with autism.

We learned that autism is a mysterious developmental disorder that causes a child to turn inwards, losing interest in the outside world. Autistic people look like everyone else, but they often lack language and social skills and tend to be hyperactive. They are prone to repetitive behavior. Researchers have a theory that an autistic's senses work differently than other people's, and this may be what causes their perceptions and behavior to be different. I learned that Mostafa has "hyper-hearing", and this explained why he couldn't sleep. He was hearing beyond the walls, he was hearing his own body functions.

In 1996 we took Mostafa to Belgium for "Auditory Integration Treatment", a therapy that uses music to train the brain to tolerate and process sounds better. Mostafa started to sleep for 6 continuous hours for the first time in three years. Indeed, we all started to sleep better.

However, back in Cairo life was difficult. Mostafa's therapists kept quitting because they were moving or taking

different jobs. I was tired of traveling with Mostafa to pursue treatment programs. My support group friend Lois Huntington provided advice and encouragement. She had helped start a center in the US for special kids, and I began to consider doing the same in Cairo. Lois Huntington is one of the most amazing parents I have met, a woman who dedicated her life to ensuring adequate services for her son. She is my friend and was then my mentor.

In the midst of the turmoil in 1996, my father was dying of Leukemia and I just could not focus fully on my son. I was preoccupied with providing my father with the help and care he needed in his last days. Baba passed away in April 1996. I allowed myself a mourning period of almost 3 months, then resigned my job as an Executive Secretary at UNESCO Office in Cairo and launched the Learning Resource Center (LRC) with two partners, Mrs. Beth Novjaim, Educational Psychologist and Dr. Nasser Loza, Consultant Psychologist, and actually the friend who had diagnosed Mostafa earlier. My personal aim was ensuring therapists would continue my son's program, as I had by then come to realize that I was not doing enough, and needed to serve others in our situation. Since then, LRC has helped children with developmental delays, learning difficulties, or behavior problems, reaching out to almost 3,000 families over the last 12 years.

My first eye-opener was discovering that set-ups such as "Learning Resource Centers" do not exist in Egypt and thus



licensing became an issue. We could not apply for a license from the Ministry of Education as we were not a school. We could not apply for a license from the Ministry of Social Affairs as we were not a charity, although we did not aim for profit as our main purpose. We ended up applying for a license from the Ministry of Health, which we received on the basis that we provide medical and para-medical services to children with learning difficulties. Our heads of departments had to be physicians. The Head of SLT is a physician with a PhD in Phoniatrics, as SLT is not a separate specialization in Egypt. The head of sensory-motor had to be a physician specialized in physical medicine and oversees both physical therapy (PT) and occupational therapy (OT). OT does not exist in Egypt and I have been an active member since 2000 on the Committee for Developing Occupational Therapy in Egypt (CDOTE), which enjoys the support of the World Federation of Occupational Therapists (WFOT). We aim to establish OT as a distinct health profession in Egypt.

So, the LRC commenced operation in September 1996 as a multi-disciplinary private clinic; and in 1997, we started a diagnostic nursery, the ADVANCE Unit, under the LRC for children aged 2 to 6. Our aim was to enroll children for 4 to 6 weeks, have them diagnosed, establish an Individualized Intervention Plan (IEP) for them, and support their enrollment later in a regular nursery or kindergarten. The idea was to keep them mainstreamed and provide them with necessary therapeutic interventions. However, we found this was not possible for some of the children who had greater needs, and were thus refused by the nurseries and kindergartens. Mostafa was one of those children, and it dawned on me that these children needed a full-time structured program that would also provide them with the needed therapeutic interventions.


I got together with other parents and together we established "The Egyptian Society for Developing Skills of Children with Special Needs – ADVANCE", a non-profit organization registered with the Ministry of Social Affairs. I became the Chairperson and Executive Director of the Society and have been in that role ever since. I set up ADVANCE following the same multi-disciplinary model as LRC. All the students are assessed by a team of specialists from different professions, mainly SLT, OT, Special Education and psychology. They are then provided with an Indi-

vidualized Educational Program (IEP) to meet their special needs and build on their strengths. Each child in his/her classroom learns within a group, but is also drawn out of class to attend individual therapy sessions as per the IEP. Five out of seven of the founders of ADVANCE had children with autism, and therefore, ADVANCE focuses mainly on autism and related disorders.

The third obstacle met was finding an up-to-date intervention program in Arabic for children with autism and related disorders. So, in 1999, I searched for such a program and when I did not find one, I decided to use a Western program and then Arabize and localize it for our children. I contacted Behavior Analysts Inc. in San Francisco and arranged to send 4 of our senior staff to train there in the summer in their STARS Program, which followed the "Assessment for Basic Language and Learning Skills" (ABLLS). Later we had to add other components to ABLLS program, as it was mainly targeted at children within the cognitive age of 3 to 8. We also added a sensory-motor section, prevocational and vocational sections, arts & crafts sections, social skills, psychomotor section. Moreover, we had to completely rewrite the language, grammar, and academic sections to fit the structure and nature of Arabic. We now have a complete program for ADVANCE that was built up not only on the ABLLS, but also on other programs such as Poretge, Carolina Curriculum, and Steps to Independence.

I realize that Mostafa is among the 70 percent of persons with autism whose IQ has been affected by the condition. He is mostly non-verbal. Mostafa enjoys swimming, horseback riding, and jogging at the club. He is a happy young man, and I pray he always will be happy. I want him to have his own life at his own ability level, which I accept is going to be different than that of others. Mostafa turned 18 this January, and so he will enter ADVANCE's "Transition into Adulthood Program" to further develop his independence and functional skills. He will learn, at his own level, how to communicate more effectively, along with daily living skills (such as hygiene and grooming) and work-related skills (including following a schedule and practical tasks like cooking and gardening). So, this is my new challenge, building an adolescent and adult program for our children at ADVANCE as they reach adulthood.





I strongly believe in advocating for persons with special needs and for their acceptance in society. An estimated 10% of every population has special needs. We cannot ignore 10% of any community, and the only way to deal with those people is to upgrade their skills. We have to provide services to them because this is the right thing to do. I always say that anyone of us can become handicapped in a minute. Anyone crossing the street can be hit by a car. And then how do you want to be treated? How do you want people to look at you? Are you a priority or are you a burden? Having a special child puts a strain on the family, and this needs the understanding and help of the community.

According to the Egyptian National Agency for Public Mobilization & Statistics, persons with disabilities represent 3% to 4% of the population, yet international statistics state that persons with disabilities represent 10% to 12% of the population in the Middle East. I believe that the confusion arises from the categorization of what is to be regarded as a disability. Some families refrain from announcing that they have a disabled child, as they believe it would impact the family's social status. However, we can assume that there are some 7.5 million people with special needs in Egypt, and yet most of them continue to be legally and socially marginalized.

The Egyptian child law issued in 1996, which is currently being amended, and the first and second Decades for the Protection of Egyptian Children (1989-99 and 2000-10) have not granted the right to inclusion. As Egypt still follows the medical model of disability, children are categorized according to their IQ, which reflects on their school placement. Students with disabilities attend one of three types of specialized schools – namely, schools for the mildly retarded with IQs of 50-70; schools for the blind and visually impaired; or schools for the deaf and hearing-impaired. Those under the ministry's jurisdiction do not accept pupils with an IQ lower than 50. For those with an IQ above 50, they teach a simplified version of the curriculum, while the schools for the blind and the deaf follow the regular curricula using Braille and a mixture of sign language and visual aids, respectively. In effect the ministry caters to no more than 4% of the disabilities with which Egyptian children are afflicted. In other words, for no convincing reason, learning disabilities,

speech impediments and dyslexia, autism, social and psychological issues, physical disabilities, multiple disabilities, and brain injuries resulting from accidents are not officially addressed.

A study on the prevalence of autism among Egyptian children aged 18 to 24 months in the provinces of Cairo and Alexandria (Special Needs Unit Ministry of Health, Dr. Ibrahim El-Nekheily - 2004) found the rate to be 1:876. The statistics from the World Health Organization (WHO) show that 1:500 new born children acquire autism. Therefore, I personally believe that the rate should be more 1:500. However, this will be difficult to study, first of all because of the lack of a normalized Arabic assessment tool for autism. However there is a current study between Saudi Arabia, Qatar, and Egypt to Arabize the ADI-R and the ADOS to be used in the Arab region. In addition, there is still the social stigma in the Arab region (which causes parents to hide their children's disabilities), the awareness about autism is not very high in Egypt. Thus some children may be diagnosed as MR (if lower functioning) or as language delayed (if higher functioning).

Diagnosis of autism is possible through neurologists, ENT (Ear, Nose, & Trachea) physicians, and sometimes speech & language therapists who diagnose the children too. However, diagnosis is given to older children (5YO+) and it does not make a difference as to services. Limited services are available, and this reflects on the diagnosed child's future prognosis and chances of improvement. Finding adequate affordable assistance is quite a challenge, and the most regular and preferred forms of treatment for autism in Egypt is usually speech & language therapy in addition to cognitive development and behavior modification. However, the latter is not that common except in large cities like Cairo or Alexandria.

Thus in 2005, the ADVANCE Society launched the national campaign "April is Autism Awareness Month" to raise awareness and share our expertise and knowledge throughout Egypt. We carry out several activities such as an Art Exhibition, a Sports Gala, a Parents' Seminar, a Children's Concert, and an open conference each year in a different governorate. Last year we invited 35 active NGOs working with children and adults with autism from all the 20 governorates of Egypt to participate in those func-



tions, with the aim of creating awareness about autism, advocating for early intervention for better prognoses,

showing the children's strengths as active participants in society, and campaigning for their inclusion within the community in general.

◀ Photos: Maha Helali's family archive

Maha Helali graduated in 1982 from the Faculty of Economics & Political Sciences, Cairo University. Maha is currently studying for her Masters Degree in "Inclusion and Disability Studies" with the Institute of Education, University of London. Maha left her post at UNESCO in 1996 to establish the Learning Resource Center in Cairo. In 1997, the Egyptian Society for Developing Skills of Children with Special Needs (ADVANCE) was inaugurated and Maha was elected Chairman of the Board. In December 2004, Maha was elected as the Coordinator for the UNESCO "Education for All" Consultancy Committee meeting with NGOs concerning Special Needs Education for the Arab Region. In 2006, Maha was recognized by the American University in Cairo for her efforts in advocating special needs persons. In 2007, Maha was nominated as an Ashoka Fellow by the Ashoka Foundation to support her mission of including persons with Autism in the Egyptian Community.

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Reach-Out: A New Perspective In Empowering Persons With Disabilities by Okechukwu Ozowalu

The Nigerian Setting

Based on the 2006 census, Nigeria has a population of over 141 million. The World Health Organization estimates that over 19 million of this population lives with disabilities. This segment of the population is bedeviled by a myriad of problems:

- They are poorly rehabilitated and lack the most rudimentary mobility aids and devices to leave home independently. It is still commonplace to find Nigerians with disabilities crawling on all fours for lack of the wherewithal to purchase the appropriate equipment. They are the poorest of the poor.
- Existing rehabilitation centers/homes are poorly funded and too dependent on philanthropic organizations and individuals for cash and in-kind donations.
- Lack of maintenance facilities for aging mobility aids and other prosthetic devices.
- The majority are illiterate, unskilled, and unemployed.
- They are stigmatized, stereotyped, marginalized, disadvantaged, and discriminated against. Ill-founded socio-cultural beliefs characterize them as 'damaged goods', not worth investing resources in.
- Architectural and attitudinal barriers prevent them from being integrated into mainstream society. Society is

in denial of their existence, thus public infrastructures are inaccessible to them.

- Non-existence of adequate welfare programs or laws to alleviate their suffering or protect their rights. Discrimination in the workplace against them is more overt than covert.
- There are no adequate provisions for them to participate in sports for recreation or as professionals.
- They suffer from low self-esteem, and lack role models to look up to. With all the negative stereotyping, most resign themselves to a cruel fate, adopting a defeatist mindset.
- There is an absence of cohesive, organized Disabled Peoples Organizations (DPOs) to present a common agenda to the government to improve their lot.

Social Innovation To Solve The Problem: The Reach-Out Program

MAARDEC was founded in 1991 to address these problems by manufacturing various aid equipment for the disabled. MAARDEC conceived the Reach-Out Program in response to its operational challenges in 1994. Reach-Out was born after it was realized that no matter the subsidies put on its products to make them affordable to Nigerians with disabilities, most could still not afford them. The beneficiaries therefore of our Reach-Out Program are Nigerians with physical, visual, and hearing disabilities.

The Reach-Out Program is a partnership between MAARDEC and corporate organizations, philanthropic individuals, and governments to provide free of charge wheelchairs, leg braces, tricycles, crutches, walking frames, guide canes, braille machines, braille watches, prosthetics, and hearing aids to both needy Nigerians with disabilities as well as aging members of Nigerian society. The program affords these organizations a credible platform to discharge their corporate social responsibility. MAARDEC contributes 10% of its annual income to it.

Reach-Out started out in one location in 1994 and by 2007 had spread out to 6 locations across Nigeria. The program is based on our belief that the first step in rehabilitating anyone with a disability is to provide him/her with the most appropriate mobility aid to move about independently.

MAARDEC has a policy of recruiting and training Nigerians with disabilities in the manufacture of mobility aids and prosthetic devices (50% of our staff are persons with disabilities). But it is incapable of training and employing all of them. However, it introduced Motivational and Strategic Empowerment Summits during Reach-Out to counsel and teach them survival strategies to improve themselves.

Most Nigerians with disabilities do not get professional advice about their disabilities. Consequently, they do not know the most appropriate mobility aids they need. At

Reach-Out, they get professional help for the first time through our team of professionals.

Organizations like Rotary, Inner Wheel, and the Lion/Lioness Club etc. distribute free mobility aids occasionally; but they do so without any professional and technical support. MAARDEC's Reach-Out Program, on the other hand, is regular and backed up with professional and technical support. Reach-Out is therefore not a one-off distribution of mobility aids. We maintain a long-term relationship with beneficiaries that are valuable for our work; especially in research studies.

Reach-Out is flexible and adaptable to accommodate the budget of big or small corporations and individual sponsors desirous of helping persons with disabilities. Products sponsored are usually marked with the sponsor's name and colors.

Reach-Out is also an avenue for disabled Nigerians to interact, socialize and network with the public.

Reach-Out serves as a forum for successful disabled persons to mentor younger disabled persons; creating role models, who are in short supply in the disabled community. Accomplished persons with disabilities also serve as motivational speakers and resource persons at our Motivational and Strategic Empowerment Summits.



Changes Achieved As A Result Of The Reach-Out Program

■ Publicity received in the media resulting from the program has made MAARDEC synonymous with the empowerment of the disabled nationally. Prospective beneficiaries flock to our office to ask/demand to be given free mobility aids. Some clients learn about us through newspaper stories/interviews, TV documentaries, and radio interviews/jingles.

■ MAARDEC has developed a vast and valuable database of information about Nigerians with disabilities from interacting with them at Reach-Out.

■ It serves as an ideal recruiting ground for membership of the DPO called ASCEND which MAARDEC founded.

■ It has enabled MAARDEC to establish tremendous structures. For instance, the partnership we entered into with an American hearing aids manufacturer will utilize these structures.

Spectacular Achievements

■ There is attitudinal change toward rehabilitation as a result of our work. Members of the public, along with government and corporate donors are beginning to buy into MAARDEC's philosophy of positive empowerment of persons with disabilities to fend for themselves in the long run, rather than the short term gesture of handouts, as that fosters dependency.

■ Other organizations are borrowing from MAARDEC's approach to empowerment. 2 rehabilitation centres: Handicapped Education Foundation (HANDEF) based in Ondo State and Bwari Rehabilitation Centre based in Abuja (Federal Capital Territory) are based on the MAARDEC model.

■ There is an attitudinal change on the part of persons with disabilities for whom the Reach-Out Program serves as an outlet for socializing. This process does wonders for their self-esteem and self-perception.

■ Re-orientation of the press, which witnesses firsthand the needs of persons with disabilities, conducts interviews with them, and projects a better image of them.

■ Attracting the attention of local and international organizations to enter into partnership with MAARDEC to donate and distribute mobility aids to indigent Nigerians with disabilities. Partners donate cash, products or services.

■ Popularization of the concept of volunteerism. A total of 500 volunteers have donated their time and sometimes money. MAARDEC staff have donated over 2000 man-hours to Reach-Out since 1994.

■ In 14 years, Reach-Out has raised over N85,265,000 (over US \$710,000). This has provided over 56,000 Nigerians with disabilities with free mobility aids. Through our Motivational and Strategic Empowerment Summits, we have impacted the lives of over 1.56 million disabled Nigerians.

■ Reach-Out has empowered 203 disabled Nigerians to start new businesses or support existing ones through the donation of equipment and loans. These efforts and our Motivational and Strategic Empowerment Summits have been instrumental in changing the mindset of Nigerians with disabilities to shun begging and embrace productive endeavors.

■ A formidable DPO, ASCEND, emerged from the Reach-Out Program. It has succeeded in sensitizing Nigerian legislators, who are on the verge of enacting legislation to protect their rights.

Biggest Successes

■ The change in the Nigerian public's attitude to the rehabilitation and empowerment of persons with disabilities. The maxim it is better to teach someone how to catch fish than to give them fish now holds sway.

■ Reach-Out has created tremendous awareness for persons with disabilities to clamor for their rights under ASCEND. This clamor has led to changes in approach to rehabilitation and society's perception of persons with disabilities.

■ Reach-Out has remained highly visible in the Nigerian media and the public eye since 1994. It remains a credible platform for philanthropic individuals and corporate organizations to discharge their corporate social responsibility. For 3 years, First Bank of Nigeria Plc. sponsored 60 tricycles and other mobility aids. It also sponsored the production and broadcast of a 30-minute documentary about Reach-Out on national television.

■ After being provided with free and appropriate mobility aids, needy Nigerians with disabilities are able to move about independently and with dignity. They can socialize,



return to school, seek employment, learn vocations, and acquire skills to become productive members of society; transcending their disabilities and minimizing the discrimination they suffer.

- MAARDEC publishes a quarterly newsletter that records the Reach-Out Program in words and pictures. These newsletters contain interviews with disabled beneficiaries, articles, feedback from visitors, clients and beneficiaries etc. It is distributed free of charge to visitors, sponsors, and donors at all our events.

Challenges

- Funding
- Inadequate manpower
- Dearth of valuable data and statistics.

Recommendations On How To Be Successful In Achieving.

Passion: “As a person with disability, I am outraged at the status quo in Nigeria, where there are no concrete efforts by the authorities to empower persons with disabilities”.

Strong Drive and Commitment: “My desire to change the situation of persons with disabilities is driven by my personal experience as someone with physical disability. My belief is that if this endeavor fails, then I will have failed as a person”.

Creativity: one has to be creative and devise new ways of doing things to be able to effect change. Reach-Out is an example of such creativity.

Perseverance: To achieve social change one must overcome resistance; so to succeed one needs to persevere and remain focused.

Credibility: A driver of social change must have integrity and credibility to engender the required trust to effect change. “I have been a public servant, visible in the media for 18 years. I enjoy a lot of credibility as a result”.

“I have known MAARDEC and its founder Cosmas Okoli for over a decade. As a lawyer and human rights activist during the military era, our paths crossed at several work-

shops and seminars where he made compelling presentations on behalf of his fellow Nigerians with disabilities.

With continued government apathy to disability matters, in spite of the enthronement of democracy, MAARDEC, under Okoli’s leadership, has addressed these issues squarely by empowering Nigerians with disabilities to assume their rightful places in our society. MAARDEC has made remarkable inroads in the provision of affordable and free mobility aids, employment, re-orientation of the disabled, mentorship, promotion of disabled sports, raising awareness, public enlightenment, and advocacy.

MAARDEC’s multifaceted approach is all the more compelling because it was initiated by a concerned stake holder – a Nigerian with disability – endowed with passion and drive to change the status quo”.

Clement Nwankwo, Deputy Country Director National Democratic Institute Abuja, Nigeria

Cosmas’s story

Ikechukwu Cosmas Blaise Okoli lost the use of his legs to polio after his fourth birthday. He resolved early in life to live a full and productive life, in spite of disability. At school he crawled on all fours in the absence of appropriate mobility aids. A flair for problem solving saw him make improvements to his leg braces and develop a device that enabled him to drive conventional cars with hands only.

A passion for sports propelled him and others to participate in, organize, promote, and administer disabled sports. He played wheelchair table tennis, representing Nigeria internationally. He was the first disabled president of Special Sports Federation of Nigeria (SSFN); holding office from 1995-2001. He led the Nigerian delegation to the Atlanta ’96 and Sydney 2000 Paralympics.

A graduate of medical physiology, he has attended several executive courses and international conferences. Winner of several awards at state and federal level, he was offered automatic employment into the federal civil service on account of one of these awards.

Driven by a zeal for an outlet to share his innovations with fellow Nigerians with disabilities, he resigned his appoint-



◀ ▲ Photos: MAARDEC

ment to start up MAARDEC. Okoli is also a Schwab Foundation Social Entrepreneur. He also holds the Nigerian National Honors Award of Officer of the Order of the Niger (O.O.N.). He is married with four children.

"My social life now revolves around my work at MAARDEC. I am consumed by my work, which I consider a substitute for a social life and a hobby put together. As much as I try, I find my efforts so far as mere drops in the ocean, so I push myself to do more to empower Nigerians with disabilities".

Cosmas Okoli 46, founder/ President of Mobility Aid and Appliances Research and Development Centre (MAARDEC) and Association for Comprehensive Empowerment of Nigerians with Disability (ASCEND). Advocate for the holistic empowerment of the disabled, an Ashoka Fellow(since 1991) and Schwab Foundation social entrepreneur. Married with 4 children.

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Piotr Pawłowski

The Friends of Integration Association, Poland

Ashoka Fellow since 1996

How to change Poland on behalf of people with disability? by Piotr Stanisławski (translated by Philip Earl Steele)

Statistical data on Poland

With a population of over 38 million, Poland lies at the heart of Europe, and is a leader among the post-communist countries as concerns the social and economic transformations underway for 20 years now. Since 2004 Poland has been a member of the European Union. According to official statistics (Central Statistical Office, 2004), 16% of the population (6.2 million persons) are affected by disability. What this means is that almost one of every seven Poles struggles with a greater or lesser disability.

People with disabilities in Poland

Basic change to the world of people with disabilities in Poland began with the collapse of communism in 1989, when the Soviet bloc's first democratic government since World War Two was formed. That government introduced reforms designed to activate the disabled – notably, the Law of August 27, 1997 on Occupational and Social Rehabilitation and Employment of People with Disabilities. Thousands of disability organizations and associations have been established throughout the country, as have new laws and regulations accommodating the needs of people with disabilities, e.g., the Construction Law of August 7, 1994.

According to the statistics on the economic activity of the Polish population (BAEL), Poles with disability still figure among those with the lowest educational level. The largest portion (some 68%) is that of those who ended their education at the elementary, lower secondary or vocational level. Just over 25% complete secondary and tertiary education. Around 6% of Poland's disabled have attained higher education.

The situation on the labor market is similar. Although recently there has been slight growth in the employment of the disabled (owing, inter alia, to EU programs), the rate is half that of other European countries. According to statistics (BAEL, first quarter 2009), only 20.5% of the disabled in the 18-64 age group are employed, most of whom with relatively minor disabilities.

There has been, however, growing awareness in Poland of the situation and needs of people with disabilities. More and more cities are deciding to purchase low-floor trams and buses. Until very recently only 10% of the mass-transit vehicles operating in Poland's largest cities were handicap-friendly. Today many Polish cities may boast that a full half of their fleets are handicap-friendly – in some even 80% are. More and more Polish cities procure only low-deck buses and trams. Changes are also underway in creating an environment that is free from architectural barriers. There has been an increase in the number of employers on an open labor market offering jobs to people with disabilities. More schools have become accessible to special need students, some of them offering integration classes. While there remain many unresolved issues, the changes underway look very promising, if only to mention the construction and election laws being revised and the Parliament being adapted for disabled MPs.

Piotr's profile

When Piotr Pawłowski was 16 years-old he had no idea his life would undergo such diametrical change. But during vacation that summer he broke his spine when he dove

head-first into a river near Warsaw. He was left almost entirely paralyzed. Ever since then he has been able to move about only in a wheelchair. He undertook an individual program at his comprehensive secondary school. Following graduation he began pedagogical studies at the Academy of Catholic Theology in Warsaw (today's Cardinal Wyszyński University). Later Piotr did postgraduate work in ethics and philosophy at the University of Warsaw. He next pursued a doctoral program at the Institute of Philosophy and Sociology, Polish Academy of Sciences. Among his other pursuits was learning Japanese. In fact, he planned to become a translator in the future. However, his years of struggling with the many barriers preventing him and other disabled people from leading an independent life persuaded him in the end to devote himself to working on behalf of the full integration of disabled people in Poland.

Enabling people with disability to function normally in society became his passion and his mission. In 1994 he created the magazine *Integracja* to highlight the problems and challenges before Poland's disabled. One year later he established the Friends of Integracja Association. In the years since Piotr has discovered ever new allies and friends who wish to help him achieve the goal of full social integration for people with disabilities. Indeed, today his organization employs over 100 people and is one of the Poland's best recognized organizations working on behalf of the disabled.

Piotr Pawłowski has initiated very many nation-wide social campaigns through his organization. These campaigns rely upon the media in the endeavor to address a specific and significant problem the disabled and others must face. Virtually all of them debunk the stereotypical image of the person with a disability and lay out new standards for approaching the group. Among the best remembered campaigns are: *Płytką wyobraźnia – to kalectwo* [Shallow thinking – that's crippling] warning young people about the risk of diving into water without knowing the conditions; *Czy naprawdę chciałbyś być na naszym miejscu?* [Would you really want to be in our place?] addressing the problem of taking parking places reserved for the handicapped; *Polska bez barier* [Barrier-free Poland] promoting the accessibility of Polish cities for the disabled; and *Sprawni w Pracy* [Able at work] encouraging the disabled to take up work, and soliciting employers to hire them.

Among Piotr Pawłowski's most spectacular achievements are:

- 1) The creation of a magazine that has become the largest one in Poland to address the issues important to the disabled community (with a circulation of 40,000);
- 2) The construction of Poland's largest internet portal devoted to issues relevant to the disabled (200,000 entries per month);
- 3) Setting up a network of Integracja information and consultation centers in Poland's major cities;



- 4) The successful lobbying of Polish Public Television to broadcast a weekly program devoted to people with disabilities;
- 5) The initiation and organization of Poland's largest media campaigns concerning the challenges faced by the handicapped.

The essence of Piotr's activities

The efforts Piotr Pawłowski has undertaken are targeted at bringing about a transformation of the situation of disabled people in social and personal life, and to help enable them to lead normal lives.

These efforts have a two-fold thrust. The first includes those activities, initiatives, and campaigns that are directly addressed to the disabled, encouraging them to be active on the job market, to take part in vocational training, to pursue their educations – and to do all they can to become more self-reliant, independent, and happy. Serving to meet this set of goals is the magazine *Integracja* with its many associated publications and books, the work of the internet portal, and the five Integracja Centers in various cities of Poland – each of which conducts training, shares information, and offers legal and psychological counseling. Of great importance was a Polish Public Television's weekly program, and now – documentaries prepared by Integracja along with the various media campaigns.

The second thrust of Piotr's work embraces a range of projects addressed to the broad groups of people living close to people with disabilities: families, employers, teachers, those employed in social institutions, as well as ordinary citizens. The organization Piotr Pawłowski leads also lobbies policy-makers – especially in the fields of labor and social policy, but also in the areas of education, culture, and sport. Today the Friends of Integracja Association is working to draft a statute on equal opportunity for people with disabilities.

Some of the changes made thanks to Piotr's projects


The projects Piotr's organization has pursued have above all contributed to rising social awareness in Poland. They have enabled the disabled and their families to learn more about their rights and the possibilities of living actively. They also showed good practices and solutions to architects, officials, public facility administrators, private building owners and authorities responsible for public

transport services. The handicapped-friendly public space and mass-transit adaptations allowed a great many of Poland's disabled to leave their homes and start all sorts of activities. The local and national campaigns run by the Friends of Integracja Association have drawn Polish society's attention to the situation of people with disabilities, including their low level of employment. Just a few years ago employers on the open labor market were afraid to hire the disabled and did not create jobs for them. Today job offers addressed to this group are simply standard fare in many sectors of the economy. Integracja has also committed itself to the disabled with direct assistance in finding employment by operating five Integracja Centers in Poland (in Warsaw, Gdynia, Katowice, Kraków and Zielona Góra). They serve primarily as job preparation centers for people with disabilities. Their staff provide information, training and assistance in finding appropriate jobs. Owing to the Centers' activities, in 2008 alone, 1,000 people found employment, 2,500 received specialist training and 14,000 obtained advice on individual issues.

In many cases, Integracja's nation-wide media campaigns were the first such to draw the attention of Polish society (and local governments, as well) to the basic challenges confronting the disabled. Piotr's well-known fight against these barriers has so changed things that now a significant number of investors contact his organization seeking consultation in adapting buildings to be accessible for the handicapped. Such was also the case with the adaptation of the Polish Parliament buildings, including the historical ones. The opening of Poland's Parliament to the disabled was crowned with a full conversion of the speaker's podium to the needs of MPs moving on wheelchairs.

The Friends of Integracja Association's work is also visible in Polish law. In being the initiator and promoter of amendments to the law (and with his organization being a consultant to the government administration in planning amendments), Piotr Pawłowski has had a role in improving the law in such areas as construction and traffic. In that latter case the cooperation of Integracja and the Ministry of the Interior and Administration brought about the raising of fines for non-handicapped drivers who park in places reserved for the handicapped from a petty amount to a substantial 500 zloties. Another crucial event that happened owing to Piotr's vision and unflinching efforts was drafting the first Pol-





ish proposal of a law on equalizing opportunities for people with disabilities. The proposal, that had taken two years to prepare, was submitted to the Prime Minister in December 2008 by representatives of the All-Poland Coalition for People with Disabilities. Thies Coalition, which groups disability NGOs and today acts as a partner to the Government, had been initiated by Piotr Pawłowski.

His achievements also include unifying many institutions, companies, and private individuals around the idea of integration. These “Friends of Integracja” support Piotr’s efforts because they believe in the enormous meaning of his aims and in the benefits of integration for society as a whole.

What has Ashoka given him?

Piotr stresses that Ashoka has, above all, placed its faith in him and confirmed the rightness of the approach to integration that he began pursuing in 1994.

When he was accepted by this American organization that promotes leaders in social work and their valuable solutions, the Friends of Integration Society (known as Integracja) was still a fledgling enterprise. Ashoka membership gave him the opportunity to learn about the activities of leaders in social work around the globe, and to have closer contact with Polish Ashoka fellows. This enabled him to build this small organization based mostly on voluntary work into a 100-person team of specialists committed to carrying out a range of projects for people with handicaps.

Today Integracja is a large organization, and one that has ushered in many important changes in Poland. Piotr is therefore thankful to Ashoka for the help it offered him when his organization first came into being.

How to replicate Integracja’s achievements abroad?

The work being done by Piotr Pawłowski is designed to meet the needs of the handicapped in Poland. His premise is entirely universal, and that’s why it can be carried out in virtually any country. However, his approaches can be most readily applied in Central and Eastern Europe, where the problems and challenges before the handicapped have the most in common because of the region’s cultural affin-

ities and similar historical experience. One example is that of how to effectively conduct social campaigns directed to persons with disabilities, healthy persons, employers, and civil servants – and that of how to initiate and participate in the changes that lead to improved legal regulations for the disabled community.

Another example eminently worthy of emulation is the creation of Integracja’s Centers (Piotr intends to create one in each of Poland’s 16 provinces), as they are places that offer comprehensive services and support for the disabled.

About Piotr

“Piotr Pawłowski is an undisputed leader in the work on behalf of integrating people with disability in Poland. He has both pioneered and captained a range of campaigns that have channeled social policy toward solutions that provide the disabled with the opportunity to pursue personal development, education, and an active cultural life. In his efforts Piotr has not only had an impact on legislation, institutions, and popular attitudes – for he has also striven to help activate those with disability through improving their social skills, assuring them access to information, and encouraging them to organize. An enormous role in all this is played by Piotr’s magazine *Integracja*, his Internet portal, and the host of media events he contributes to.

Indeed, Piotr Pawłowski is living proof that even the most burdensome barriers a person’s body may create can be overcome when in that body abides a dauntless spirit. For many years I have followed Piotr’s work, ever in deep admiration for his charisma, vision, energy, and unflagging drive to bring about meaningful change.”

Professor Antonina Ostrowska, Institute of Sociology,
Polish Academy of Sciences, Warsaw, Poland.”



◀ Photos:
Integracja's archive

Piotr Pawłowski

Born 1966, lives and works in Warsaw. Married. Since 1982, when he dove into shallow water, he has been completely paralyzed and so must use a wheelchair to get around.

Graduate of the pedagogical faculty at the Academy of Catholic Theology in Warsaw (today's Cardinal Stefan Wyszyński University), Institute for Studies into the Family, and an alumnus of the postgraduate studies program in ethics and philosophy, University of Warsaw.

Piotr has founded and runs two organizations: The Friends of Integration Society and the Integration Foundation. Their objectives and mission are pursued through the magazine *Integracja*, through radio and television programs, as well as through societal campaigns and educational programs that Piotr conceives and launches. He is a member of the National Consultation Committee to the Government Plenipotentiary for People with Disabilities, Chairman of the Disability Team at the Office of the Commissioner of Civil Rights Protection, and Deputy Chairman of the Coalition for People with Disabilities. He is a laureate of many awards, including the TOTUS Award for "Advancement of the Human Person, Charity Work and Education" and the Andrzej Bączkowski Award. He has been distinguished with the Knight's Cross of the Order *Polonia Restituta* and with the Medal of the Commission of National Education awarded by the Ministry of National Education

The Friends of Integration Association

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Beatriz Pellizzari

La Usina, Argentina

Ashoka Fellow since 1999

Changing Attitudes Towards Disability In Argentina

by Carolina Heindenchain
(translated by Peter Douglass)

In 2002, Bea Pellizzari, a Fellow at Ashoka, brought together a group of citizens – with and without disabilities – concerned with changing the social prejudices that devalue differences in the community. The discussion dealt with the founding of a non-profit civic association in Argentina called La Usina, whose mission is to promote changes in the community's attitude toward disabilities, and to generate community activism in promoting those changes.

La Usina is a “generator of energy” and “motor for change” driven by Bea Pellizzari who, together with her staff, focus their efforts on breaking down the cultural barriers which impede disabled persons from interacting with their community and from enjoying every opportunity which a democratic society should offer its citizens. Thus, La Usina's mission is to help those with disabilities to become active, valued, and visible members of their communities.

The context of disability in Argentina

Some significant figures in order to demonstrate the current situation of disability in Argentina are as follows:

- 2.2 million people with disabilities live in Argentina as of the last official survey of 2003(INDEC). This affects at least 6.7 million people, when we consider the direct family of those living with disabilities.
- 40% of those living with disabilities in Argentina are unemployed. Here we need to keep in mind that according to

the International Organization of Work the rate of unemployment is 3 times higher for those with disabilities.

Day in and day out the disabled must face obstacles that often leave them excluded from the social, economic and political life of their communities. Without the ability to leave their homes, to communicate, to have access to education and community life, the disabled become invisible within the community and viewed as second-class citizens. From this seclusion stems many of the stereotypes and skewed visions of people with disabilities perpetuated throughout society. However, the government otherwise expected to fund organizations working on behalf of the disabled continues to cut its expenditure on social programs. This makes the existence of such organizations more and more difficult and leaves the disabled without the assistance and aid they desperately need. The result is often a “static” organization, that is, one which is prevented from performing the services it wishes to provide. Thus, the tendency for these organizations is to close in on themselves, and this contributes to the marginalization and “social invisibility” of those living with disabilities.

La Usina's Approach to Disability

In reliance on innovative ideas in the social sector, La Usina endeavors to offer a different vision of interaction within society. It seeks to change public opinion regarding disability by raising community awareness, strengthening social organizations, and helping to articulate their aims and goals. For it is believed that this will allow these or-

ganizations to break from their present isolation in Argentina's communities.

La Usina represents one of the few organizations of its kind in Argentina with the ability to complement and articulate the work of those social institutions already in existence, all the while with the ultimate goal of developing a profound structural change. It is a question of healing the "social tissue" by promoting connectives between existing NGOs and with other local actors, stimulating a chain of mutual effort to transform society, achieving greater visibility of the issues, and ultimately changing public opinions towards those living with disabilities.

Guided by this mission, La Usina carries its objectives to a national level utilizing three concrete strategies for operation:

1) The Program for Sustaining Organizations of and for People with Disability

To support the movement of people living with disability through their prospective organizations by promoting better practices and generating greater prominence within their communities through networking and interdisciplinary work.

2) The Program for Civic Responsibility

To build citizens' awareness of disability in environments

where the issue is normally neglected and to impact the public agenda so as to offer opportunities to the disabled in areas from which they are normally excluded. Through its Program for Civic Responsibility La Usina pursues the following initiatives among several others:

a) The Annual Awareness Campaign

La Usina is the only organization of its kind in Argentina to launch an Annual Awareness Campaign (chosen each year through a National Contest among communications students from universities around the country) directed towards educating the community on various aspects regarding disability. Each new campaign is meant to reinforce the message and to disseminate information regarding disability within the community. Each campaign relies on street ads, award-winning television spots, the radio, Internet, flyers, personal cards, newspapers, and blogs in order to spread its message.

b) The Civic Campaign "Enforce them! You can create change!"

In 2007-2008 La Usina worked to develop the Civic Campaign "Enforce them! You can create change!", with the support of the Finnish Abilis Foundation. Through this campaign, La Usina collected more than 100,000 signatures from individual citizens in order to enforce the disability laws that already exist in Argentina. This campaign was launched in order to draw public attention to the issue and foster the ac-



tive participation of persons with and without disabilities. For this is the most difficult barrier the disabled face each day of their lives: the barrier of indifference. Never before has an initiative of this nature been organized in Argentina, one in which both those with and without disabilities have worked together as the central actors. This Campaign has unified and articulated the efforts of 34 private companies, 9 governmental organizations from different regions of the country, 5 universities, and 37 NGOs (many of which had never addressed disability before).

3) The RedACTIVOS Program

RedACTIVOS is a network for the commercialization and distribution of products and services developed, under a code of ethics, by people with disabilities. This project will generate funds to be used towards supporting and sustaining productive endeavors by people with disabilities. Moreover, with the profit generated by this project, La Usina will invest in new initiatives aimed at improving the situation of those living with disabilities.

The RedACTIVOS program works within the confines of the "Protected Production Workshops", of which there are around 220 in Argentina, where approximately 8,000 people with intellectual disabilities work to make goods for sale. In its first phase of production currently underway, the RedACTIVOS program represents 10 protected workshops (with about 140 disabled workers) that help people with disabilities to overcome poverty and exclusion. Red ACTIVOS works in three capacities that are designed to facilitate the passage from a deficit situation to the self-sustainability of these protected workshops. These three capacities are:

- **Improvements to the Processes of the Protected Workshops:** training and technical support are offered in an effort to improve the workshops' productivity and to improve the quality of the final product, at the same time as providing a professional environment in the workshops and achieving a higher standard of production.
- **Commercial Operations in the Market:** RedACTIVOS works exclusively with socially responsible clients in order to achieve a stability of sales, as this ensures the sustainability of each workshop as well as the labor opportunity for those with disabilities.

- **Collective Purchase of Commodities:** RedACTIVOS works exclusively with responsible suppliers who are able to provide the volume of materials necessary in order to keep prices reasonable while maintaining the quality of the products.


The principal challenges and the strategies to overcome them

La Usina began with only \$100 dollars given by its founding members. Thus, initiating activity with neither capital nor "in kind" resources for management were the primary obstacles Bea Pellizzari faced in founding her organization. Fervent motivation, a critical look at the lack of resources, and a network of social relationships (cultivated along her professional path) were the determining factors for the way in which the structure of the organization was subsequently developed.

Presently, the main challenge continues to be financing the organization's projects, covering La Usina's operational costs in order to sustain greater economic autonomy, and generating resources for its cause by using the knowledge and training of the La Usina team. It should be noted that one of the principal difficulties faced by La Usina (paradoxically, something related to its innovative nature) is the fact that its projects are not usually considered within the scope of public financing. Because of the nature of its mission, La Usina doesn't provide services to the state, and therefore cannot receive state resources. This is why, with the exception of specific cases in the past, La Usina has not been able to work effectively with the state for any extended period of time.

The problem is exacerbated by the high visibility of La Usina in the media, something that often hinders the organization's efforts to generate funding and resources. For La Usina's media presence spawns the misconception that the organization does not need money, as it has become so prominent in Argentinean life. But this presence was forged by an enormous effort of La Usina's professional team to develop and manage "in kind" donations (that is, free airtime and donated ads in various media). Nonetheless, this team deserves appreciation for their high performance and skill managing the technology necessary to keep La Usina operating.





These limitations, stemming from the difficulties faced when attempting to finance a social organization, have driven Bea Pellizzari to diversify the sources for generating financial support and fundraising in order to achieve self-sustainability. This effort emphasizes three specific facets:

- 1) Individual donors as “investors for change”,
- 2) International cooperation (an exchange of practices as well as financial cooperation),
- 3) Sources for self-financing relating to the mission of the organization.

These last two sources of financing concern two projects:

- **Active Diversity** supports the companies that wish to take on the disability issue through a series of custom-made modules that include workshops and awareness programs, with the aim of promoting the employment of people with disabilities and improving the treatment of clients with disabilities.

- The **RedACTIVOS Program** makes up part of this strategy of resource development, given that, in addition to generating income for the Protected Workshops and their workers with disabilities, the surplus received will be completely invested in La Usina to minimize its financial vulnerability, keeping it on track with its mission.

These two forms of management are completely innovative in Argentina. Nevertheless, concern for the issue of self-sustainability and management of economic resources usually demands a lot of time and on many occasions diverts the efforts of the Fellows and staff away from the concrete implementation of the actual programs. It also often diverts the knowledge and experience of the Fellow away from his/her area of expertise. In this sense, proposals that combine both the achievement of La Usina's mission as well as the generating of funds and resources, as in the cases of RedACTIVOS and Active Diversity, seem to present a valid alternative and will contribute to future sustainability.

Lessons learned:

How to approach social change

1. Strive to develop donations in kind

One of the principal strengths of La Usina is developing resources in kind, under the motto “the worst step is the step you don't take”. This breaks from the premise “Who

has what we need?” (which in many cases does not refer only to money), to establish relations with diverse players who can contribute their products, services, and talents and are interested, because of their work, in contributing value to society by collaborating with the mission of the organization. Although the management process to achieve in kind donations requires an engaged and perseverant team in order to carry out the task, the results are usually more immediate than in the form of a monetary donation. For example, the Annual Awareness Campaign is possible thanks to wide-ranging support from many different professionals and companies that donate the production of commercials on television and radio as well as free spaces and spreads in other forms of the media.

2. Understand the importance of articulation between social actors and participants

The mission of La Usina, the projects it develops and of course the donations, would be impossible without the relations that Bea Pellizzari and her team work tirelessly to generate and cultivate. It should not be forgotten that this network of relationships is formed above all between people who, although they may be representatives of businesses, media, or other organizations, are first and foremost citizens having interests, values, and fears. The challenge consists in finding common points of interest in order to generate an alliance in which all parties feel as though they are receiving value from their partners and, for their own part, that they are contributing value and improvement to the community with their work. It is through this articulation, implementing the issue of disability in all participants, that La Usina fulfills its mission to promote a change in the social attitude towards disability.

3. Understand the social organization as a social enterprise

La Usina is faced with difficulties and concerns related to economic sustainability and financing. In part this is because Argentina remains subject to diverse political and economic disruptions, and state funding is still very much oriented towards the traditional philanthropic concept. Thus, it is advisable to gradually direct the generation of resources to diversified sources, especially towards the creation of social enterprises that can both continue working towards the organization's mission, as well as allow



the generation of resources that can offer greater independence. For this can alleviate the organization's reliance on donations from the state and private companies.

◀ Photos: La Usina's archive

Bea Pellizzari,

47 years old. Ashoka Fellow since 1999, elected for her work in the field of disability, Bea is a social psychologist and ex-scholarship holder of the Spanish MPAFRE Medicine Foundation with "Rehabilitation of employees with disability". After having survived a serious car accident, she has focused her efforts around disability issues in Argentina. In 2002 she founded La Usina – The Change in Disability, a CSO focusing on bringing strategic cultural and social changes to people with disabilities on a national scale.

Born in Uruguay, she has lived in Buenos Aires, Argentina since 1983 with her husband and daughter.

La Usina

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Victoria Shocrón

DISCAR, Argentina

Ashoka Fellow since 1994

Supporting people with intellectual disabilities to be socially active. Art as a path to inclusion by Leonardo Shocrón

People with intellectual disability in Argentina are not so numerous as those from other disability segments. Moreover, helping to bring about their social inclusion implies a broad and highly imaginative approach.

Why? What is so unique about their situation? Generally, these people have been disadvantaged and have experienced the highest levels of social, work-related, educational, and even domestic discrimination. In fact, it is not easy to measure the level of discrimination, as it is hidden by some of the relatives who are ashamed and thereby impose old cultural patterns of exclusion.

Just over 7% of Argentina's population has some kind of disability. This means nearly 2.2 million people in a population of over 36 million. Mentally disabled people represent approximately 15% of the total number of disabled, and hence some 330,000 people. But what do we understand by mental disability? Unfortunately, available studies are not very detailed – they identify only two subgroups: the mentally retarded (63%), and all the rest (37%), who range from those with child psychoses to the autistic.

Forty-percent of the mentally disabled have no health coverage, and the national health agenda has no real strategy for the disabled. Thus, each case starts as a health problem and becomes a social matter, as it usually alters family roles, i.e., cause greater work and constraints on the domestic budget. Nowadays 3% of

Argentinean homes include at least one mentally disabled person. No one knows how many of them could get a job.

Article 75 of the National Constitution gives instructions to the Congress to legislate guarantees for truly equal opportunities and treatment. We now have norms that extend from health insurance, a broad protection system, and a special regime for families, to the existence of a mandatory employment quota of 4% for disabled people in state offices and in public service companies. For private companies there is an economic incentive for them to employ the disabled and there are also production workshops reserved for the disabled. However, for the intellectually disabled person, these legal answers have traditionally been reflected in protected workshops, which have not allowed those persons to feel like simple citizens – nor to be viewed as such.

This is where DISCAR has engendered an important change, because its focus is not so much on disability, but on communication.

Communication

DISCAR was born seventeen years ago with the purpose of offering intellectually disabled people a variety of roads to communication through art, as communication can lead to better social integration. DISCAR was the first art center created in this aim, and its workshops

immediately became powerful tools for developing the capacities of the mentally disabled.

"Afterwards", DISCAR's President, Victoria Shocrón, explains, "when we got to know these people's realities, because", she confesses, "we had known very little in the beginning, we understood that there were a lot of uncovered areas, one of which was employment inclusion. That was when the options got bigger".

In 1993 the Employment with Support Program was born to include mentally disabled people in the labor market. This means real integration, as the disabled adapt to work – and not work to them.

The paradigm

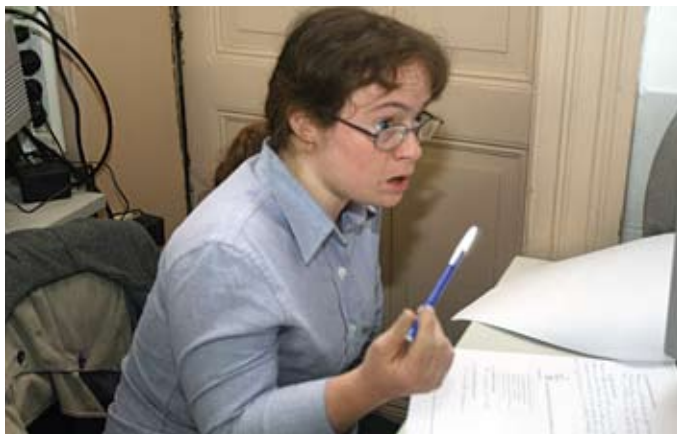
DISCAR offers workshops on art, theater, music, reading, writing (and publication of students' books), cooking (today in the Argentine Institute of Gastronomy), transition to adult life, computing, and employment. All of these workshops are significantly different from what the disabled are typically offered. After all, the traditional approach has aimed to assist the disabled with treatments, special schools, and rehabilitation. However, as Vicky's co-workers say, "rehabilitate means to habilitate something not habilitated".

How to understand DISCAR's innovation? Let's see: if DISCAR would have pursued the conventional paradigm,

many of its students would not have had a chance in the theater workshop... because they did not speak! The standard idea was: "if it's possible, let's exercise their faculty of speech whenever they are moderately ready".

That was not DISCAR's idea. DISCAR simply included them. They were allowed to act and express themselves with gestures along with other students who could not speak. For DISCAR's paradigm is: "we work with what we have. And with what we have we do music, theater, and all possible other art forms". In this way DISCAR started to overcome the "non-communication" barriers. The result was so overwhelming that, only two years after its appearance, new art centers were opened, more actors decided to teach, and the idea of working with what was possible beyond disability was no longer a crazy idea.

At DISCAR, the person with disability stops being an object for treatment or a recipient of information and teaching, and becomes a subject that interacts, a person who makes their own games, their own music, and even their own musical instruments. In so doing they change not only the way their surroundings view them, but how they view themselves. The person progresses, and their overcoming of certain disabilities ends up being a sub-product, as DISCAR's goal is not so much therapeutic, as it is to include. Above all to include.



What is the goal?

"We want to help enable the disabled person to enjoy, take advantage of, and be a part of society – just like any other citizen", Victoria explains. "The activities we provide are to be positive for them in some aspect of their lives, so that going to the workshops does not represent an imposed obligation by the doctors or the family".

Becoming professional on the run

None of DISCAR's work was born as a research theory. Victoria remembers how she started with the idea of work inclusion: she realized that some of the students knew aspects of her life that, because she was an actress, had appeared in magazines. She soon came to the conclusion that, except for their attendance at the art workshops, their lives went by with nothing to do but watch television and read entertainment magazines, as if they did not have a life of their own, but were a mere observer of other people's lives. They did nothing. They had never worked. So she decided to get them a job. The Employment with Support Program (ECA) is, simply, the professional support structure for a campaign that was born with few preambles. Today the ECA works to prepare all the matters relevant to successfully winning employment through the evaluation of working positions, training for companies, its focus on the family, training for professionals, systematized follow-up, conference presentations, and answers to questions through the Web.

Going to work implies moving from one place to another, having a certain independence... yet many of the students did not know how to travel! Another need appeared: the Transition to Adult Life workshop. Part of it was built around visits to social and cultural events, museums, etc. However, the real benefit came into view when some of the students found themselves thrilled to have discovered something new, not a drawing or a sculpture. For the first time they paid for their own bus ticket! With that simply act they were taking a bold step toward their social inclusion, a step beyond their disability.

In time Victoria and her colleagues recognized the need to improve their approach by reaching out for assistance and support from academia in their campaign. This reflected their determination to keep building while moving forward.

Today DISCAR provides companies with the opportunity to get to know a part of society they thought was alien to their reality. Company owners have learned that, with less resources and more creativity, they obtain very positive results. Day after day more company employees are involved. Some offer their help in training the included young people, and others cooperate so that DISCAR can participate in international congresses where staff can convey DISCAR's experiences to others. More than 80% of the people included over the last 12 years have kept their jobs in favorable conditions. Today we may state that there was a significant and long-lasting change in their lives.

The program has reached more than 15 institutions in different cities. DISCAR's professionals travel widely to train their people and allow its experience to be replicated both inside and outside the country.

A spectacular achievement

Nowadays there are companies that request DISCAR's people intellectually disabled to be included in their workforce. Before, such had to be patiently convinced by careful argumentation – and that did not always meet with the best reception. For company hiring policy did not include the premise that someone with a disability could produce as responsibly as other employees. Today Argentina's companies know they can.


Changes

At the beginning, DISCAR was a small project with some economic support obtained from the government of the city of Buenos Aires. When this support came to an end, it might have all shut down right there. But through facing the adversities, new ideas came up. Victoria asked the dedicated actors for help, and together with them she organized, for three consecutive years, "Soccer with the Stars", with famous soccer players, including Diego Maradona and even the President of Argentina, Carlos Menem. In this way she could raise funds to sustain a workforce for the next five years and buy an office for its own headquarters. Then came the scholarships from Ashoka and its E2E program, which links social and business entrepreneurs so that more students may attend workshops.

Correcting mistakes

Victoria admits that at the beginning she confused "non-profit" with "charity and gratuitousness", and that was why





the workshops were initially free. Facing the threat of not being able to continue, tuitions were introduced, while DISCAR's staff started searching for scholarship donors for the needier. Today there are annual plans and evaluations that allow DISCAR to flexibly adjust and consolidate the task of inclusion. DISCAR also invites apprentices from various newspapers, who act as workshop chroniclers, enriching the classes with their writings. Of course, the main goal has remained the same: what is of highest priority is work inclusion because of its positive impact on students, their family, their workmates, the company environment, and on society itself. A host of institutions have acknowledged these benefits, and the media has made them widely known in Argentina.

Victoria feels that there is an important matter yet to resolve: to make the inclusion of more people sustainable. To do that a more numerous workforce, a bigger office, and full-time workers are needed. This implies fixed resources that can guarantee continuity. Here lies the main challenge.

Being successful in social change

Victoria asserts that if someone intends to have results, one must first be sure that someone needs it, be convinced about what one wants to create or change, and feel that it is an innovative idea that will make good for others. But that is not enough: one has to have the strength to move forward when negative opinions try to block the changes, "that's not how things have been done". Do not lose courage when the nay-sayers appear at every turn. And do not believe that only one person will make social change. "I would never believe that", Vicky says – "We have to surround ourselves with people who understand what they want to do and who want to be part of it. They want to transmit the idea and trust in these people to carry it on. I always say that when I started I was the crazy one, and now we are all crazy", as if that is how we can refer to someone who dares to innovate. Her colleagues call this the "DISCAR Spirit". But it is nothing more than the universal principles for success, put in the service of what Victoria started seventeen years ago.

An unexpected beginning

Way back when Victoria did not have in mind doing anything about disability, as it was not a subject of her inter-

est. The trigger appeared during a beach vacation, when she saw a kid who was isolated, unable to communicate with the others. Something happened: he responded when instead of words he heard music, a rhythm. Vicky recounts: "When I started playing with my son, who was then 3 years-old, making music with some beach buckets, that kid came over and echoed the sounds. I at once realized that it was not that he did not want to play, but that we had not understood each other before... but then he became able to communicate!". The boy had an intellectual disability that kept him apart. A musical rhythm suddenly had included him. At that moment a feeling was born, a wish to do something more. But her work in the theater, movies, and TV did not allow her to pursue a new project. Then suddenly there was a halt in her activities, with no work in sight. So she decided to face that new challenge... and she is still doing so to this day.

Support

More than resigning from other things in life, Vicky seems to have made good profit from her time. Indeed, she enjoys dedicating each minute to her project.

She feels that her main support lies with her family, because they do not ask her to have a job or to generate income, which allows her to work for free and be focused 100% on DISCAR. "My family", she says, "is also there when things do not go right and I go home and cry".

In DISCAR, she finds a shoulder in the director, Marta Mendia, and in the workshops and classes coordinator, Jorge Billordo, as she does in all her professional colleagues who give the best of themselves to each other.

"Vicky came to me 15 years ago, at a time when we were not yet deeply involved in the community. So she gave us a great opportunity, as she had a lot of energy and leadership skills. Many people thank me for helping these kids, but the truth is that they help us. I nominated her to Ashoka because this project, through Vicky's tenacity and hardworking, has become a sustainable project".

Wood Staton, President South America Division,
McDonald's



◀ ▲ Photos:
Ignacio Puente

Victoria Shocrón

51 years-old, married, one son.

Actress, dancer, singer, social entrepreneur.

After 11 years of working in cinema, TV, and theater, she founded DISCAR in 1991.

Ashoka Fellow since 1994.

For her activity in DISCAR she has received many awards, distinctions, and nominations, among them from the United Nations for Best Practice, the Show Business Journalist Association, the City of Buenos Aires, and Very Special Arts. She was also a Visionaries finalist and was recognized by McDonald's on International Women's Day.

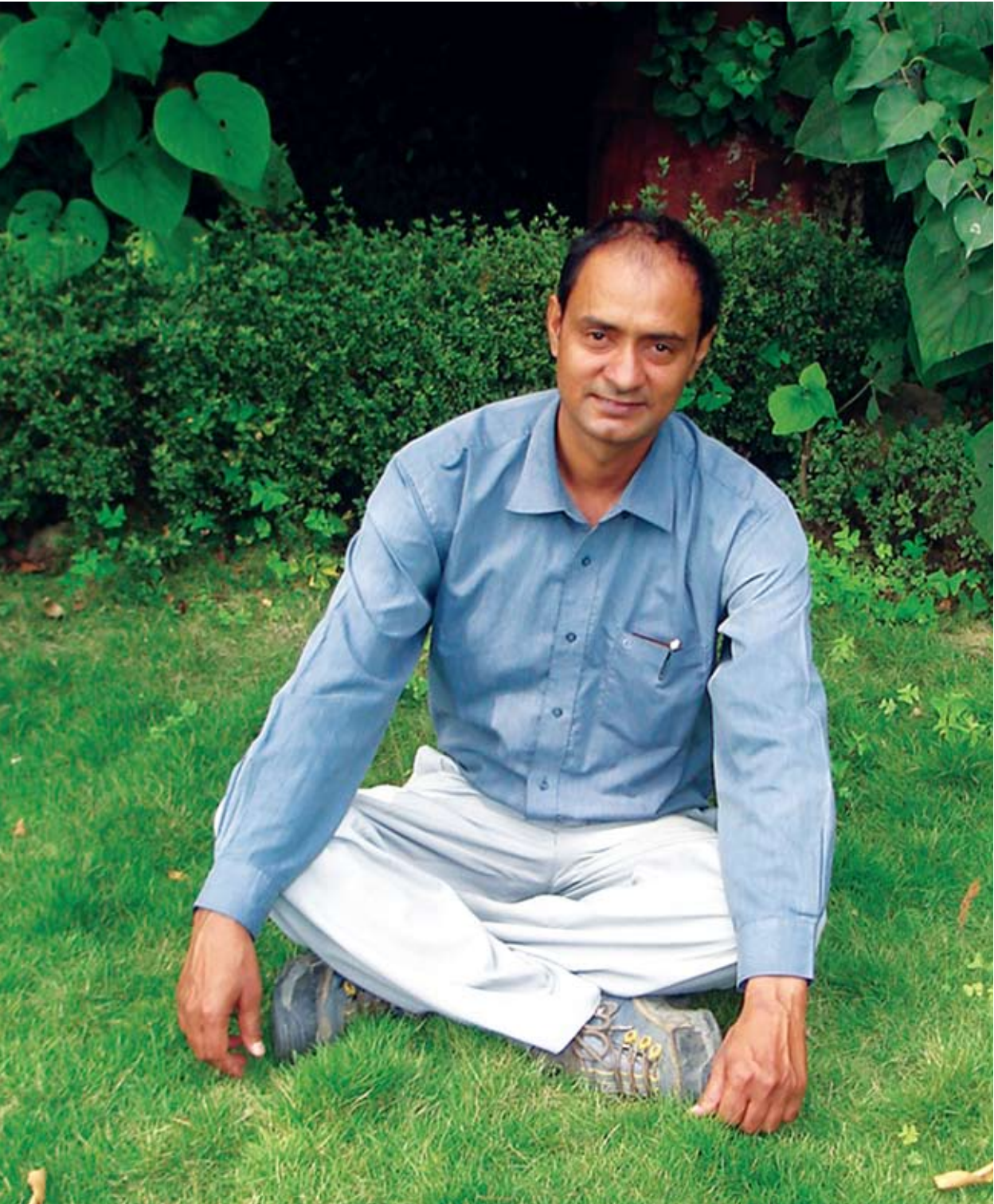
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Shudarson Subedi

DHRC, Nepal

Ashoka Fellow since 2005

Undeterred And Unafraid Leader Of The Disability Movement in Nepal by Pranab Man Singh

In 2003, Shudarson Subedi lodged a case in Nepal's highest judicial body, the Supreme Court, demanding implementation of a free education policy for people with disabilities as guaranteed by the Government of Nepal. The case was brought up by Shudarson through his organization, Nepal Disabled Human Rights Centre (DHRC-Nepal), and it marked a historic step in the fight for disability rights in Nepal. Until then, few people with disabilities were aware of their rights – and government officials themselves were either unaware of the provisions granted to people with disabilities or not keen on implementing them. More importantly, this marked the first time people with disabilities in Nepal got together to fight for their rights as equal citizens. The Supreme Court ruled in the favor of the disabled and set a historic precedence in acknowledging the rights and empowering the status of people with disabilities in Nepal.

Shudarson sees the Supreme Court ruling as a reward in itself. He finds great hope and inspiration in this victory for justice. Ever since he was one and a half years old, when he contracted polio, Shudarson has had to fight an uphill battle to prove himself an equal member of society. Fortunately, Shudarson had the advantage of having a father with a keen sense of social justice and a knack for entrepreneurship. He recalls how his father took up the initiative to establish the first community school in the village in Bardiya, West Nepal. "He did not believe

in charity. I remember going to the forest and collecting vegetables for him to sell in the local market. That's how he raised money for the school," Shudarson relates. His father was also the local village judge. "The idea of justice never really hit me until villagers started coming to my house seeking justice," shares Shudarson. This exposure to social justice and moral integrity played a significant part in shaping his own fight for justice. He says, "I used to cringe at the thought of social situations in fear of being ridiculed." However, with the support of his family and an increasing awareness of the injustice he was being subjugated to, he slowly stepped out of his shell.

Historically, Nepal's rulers have never invested much in healthcare, sanitation or education. This lack of infrastructure and services has been a major drawback for people with disabilities, who often have no access to health care services. Based on WHO estimates, between 5 to 10% of Nepal's 29 millions are with disabilities. However, the 2001 national census placed the disabled population at a mere 0.45%, while the National Planning Commission placed it at 1.63% for the same year. Shudarson believes that the difference in numbers between the two government agencies and WHO shows complete negligence in accurately measuring the disabled population. Shudarson explains that accurately assessing the number of people with disabilities is made difficult by family members who see disability as a shame. Shudarson's own research leads

him to estimate that there are more than three million people with disabilities in Nepal. Only 5% of them are employed, claims Shudarson, who sees this as a testament of the attitude of dependence that people with disabilities portray and embody in society.

Disability in Nepali society is viewed through the eyes of destiny. It is seen as the result of a Karmic cycle. At best, the disabled are seen as a means through which one can establish good Karma. But usually people with disabilities are treated as little more than burdens to society. The belief in disability as Karmic punishment also makes disability a personal problem, one that is to be handled by the disabled and his/her immediate family, rather than something that the state is responsible and accountable for. When raised in an environment that treats them as justly punished and/or as burdens, it is no surprise that most people with disabilities in Nepal lack self-confidence and do not believe in their own abilities.

Throughout the 1990s, Shudarson worked in a variety of Human Rights and disability-focused organizations only to grow disillusioned with them. Most Human Rights organizations marginalized disability rights, while the disability organizations in Nepal were focused exclusively on treating particular cases of disability. As he traveled and met people with disabilities, he quickly realized that throughout Nepal they were at a great disadvantage. They

suffered discrimination from both Nepali society's attitude and a limited state apparatus for securing their rights. Even if they had the courage and nerve to stand up for themselves, they still faced constant discrimination from a population that regarded them as worthless. Shudarson was profoundly influenced by this injustice.

Shudarson believed that people with disabilities needed to stand up for their rights as equal members of society. He firmly believed that only when people with disabilities stood up for themselves, would the social attitude towards them change. People with disabilities needed to change their mindset from that of a dependent receiver to that of an independent deserver of rights and rewards. He also realized that the state structures needed to secure the fundamental rights of people with disabilities. Once acknowledged by the state, he foresaw that these guaranteed rights would act as beacons of hope for people with disabilities to advocate, lobby, and demand their rights throughout the nation. It is this insight that makes Shudarson a true visionary.

In response to his vision, in March 2000, Shudarson established the Nepal Disabled Human Rights Centre (DHRC-Nepal). This was the first organization in Nepal to address the human and legal rights of people with disabilities through advocacy, media relations, and the legal system. Shudarson saw the organization as a means to lobby for



disability rights with the government, and to sensitize other organizations, institutions, and companies on disability issues. Most importantly, it was a means to empower people with disability to seize their rights and take control of their lives.

For the first five years of its operation, DHRC functioned on a miniscule budget and made ends meet through its first income generating venture, Disability Voice magazine. Started in May 2000, Disability Voice disseminated information on disability issues, rights, and policies. The magazine was quickly recognized as a national journal, gaining acceptance from the Information and Communication Ministry and the Nepal Press Council as a legitimate source of information. At present, it has a circulation of around 3000 copies, is read throughout the nation, and subscribed to by over 75 different organizations directly or indirectly working on disability. Shudarson realized that people with disabilities needed hope and inspiration and that the magazine could not reach a mass audience. So in April 2002, DHRC started a popular radio show named after their magazine, Disability Voice. Broadcast initially through Radio Nepal, it covered all of Nepal and was able to reach an audience base that DHRC had been unable to reach through its magazine. Since its launch, DHRC has successfully established over 245 radio listener clubs with over 5,000 members throughout Nepal. It estimates a total audience of around 2-3 million listeners for each of its Disability Voice radio shows.

Disability Voice, the magazine and radio show, were the first of their kind in Nepal. They were both focused on disability issues and, more importantly, were the first media outlets fully owned and operated by people with disabilities. The realization that people with disabilities were running and operating these media outlet was a source of considerable inspiration for people from the disabled community, and this led them to believe that they too could do something. With the intention of expanding the program and its reach, DHRC conducted a series of journalism training workshops throughout Nepal. As a result, Disability Voice has a group of well trained journalists working for it. Since Disability Voice magazine was launched, three new magazines focusing on disability issues have started being published. There are 10 journalists with disabilities running 10 different local radio shows throughout Nepal


and another 20 of them working in mainstream media outlets.

In 2001, while working for DHRC, Shudarson enrolled in a Bachelors course in law at Nepal Law Campus. During his thesis research, he came across the Disable Welfare and Protection Act of 1982, which guaranteed all people with disabilities the right to a free education. "I had no idea that I was paying for an education that I was freely entitled to. You can imagine my surprise!", explains Shudarson. He continues, "I first went to the campus administration and told them about the provision. They were unaware and unwilling to implement the provision." Shudarson next went to the education ministry and demanded immediate implementation of the provision for free education for all people with disabilities. The ministry registered Shudarson's complaint, but did nothing.

In 2003, Shudarson filed a court case on behalf of DHRC against the universities, the Ministry of Education, and the Government of Nepal. As a public interest litigation, it came under the jurisdiction of the Supreme Court and was the first and most publicized case on disability rights in Nepali history. The Court ruled in favor of Shudarson, DHRC, and the rights of people with disabilities. It marked a momentous victory for disability human rights activists and brought disability issues into the forefront of the national conscience. Shudarson successfully publicized the event through Disability Voice's radio program and magazine along with mainstream media outlets. Since then, over 3,000 people with disabilities have received the free education guaranteed to them by the government. The Supreme Court decision also sparked the government into action, leading to a revision of the educational law. The law now ensures a better educational standard for people with disabilities, along with a special provision for an hour's extension of normal examination times for specific cases of disability.

In 2005, Shudarson was recommended to Ashoka as a potential social entrepreneur. When Ashoka first got in touch with him, he had neither heard of Ashoka nor known of social entrepreneurship. After a rigorous selection process, he was inducted into the Ashoka Fellowship that very year. This opened quite a few doors for Shudarson and suddenly he found himself at the centre of attention





on all things related to disability rights. “A long-standing dream of mine had always been to establish a resource centre on disability issues,” says Shudarson. With that in mind, DHRC established a resource centre on disability issues and rights containing over 300 books on disability laws and legislation from around the world. Through DHRC and the resource centre, Shudarson then conducted capacity development training for people with disabilities so that they too could seize upon opportunities to develop and express themselves. Through these intensive training programs and workshops DHRC has been able to produce over 30 journalists with disability, over 200 leaders of disability organizations, and over 100 disability and human rights defenders.

“Even with the proper sets of skills and training, people with disability are often barred from gaining employment because of accessibility and mobility problems,” laments Shudarson. He believes it is the responsibility of the government to ensure that buildings are built to be disability-friendly. Working with the National Disabled Service Coordination Committee Shudarson now plays an important role as an advisor to the government on disability related policy making. Through this committee, he is working closely with government officials in drafting a five-year disability plan for Nepal and has already helped the Government of Nepal draft its first disability-friendly building code. The first government building planned since then, the Ministry of Women, Children, and Social Welfare, is designed on a fully accessible concept.

In an attempt to rouse the private sector, Shudarson gathered the support of all disabled account holders in Macchapuchare bank. “We told the bank that we would take all our money out and put it somewhere else if they did not make the bank disability-friendly,” tells Shudarson. In response, the bank’s management made all its ATM machines disability-friendly. This challenge to the bank attracted a lot of publicity and further assisted in bringing disability issues to the attention of the general public. Nor was the lesson of the power in uniting lost on Shudarson. Quite the contrary – it led him to establish a network of over 60 disability organizations, the Forum for Rights of People with Disability (FRPD), which provides a collective front for advocating the rights of people with disabilities.

“There is still plenty to do,” states Shudarson, who was awarded the Champions of Change award by the Non-Resident Nepali Organization and Federation of Nepali Chambers of Commerce and Industry (FNCCI) in 2005. He humbly continues, “The awards are a good means to increase attention on the issue. But we have barely scratched the surface. The real sufferers from discrimination are yet to be reached.” Shudarson is now looking at previously marginalized areas within disability like HIV/AIDS and is seeking means to secure their rights as well. In March 2008, DHRC successfully held a nation-wide disability conference involving all the major disability organizations. That conference produced the Kathmandu Declaration, 2008, which demands the immediate ratification and implementation of the United Nation’s Convention on the Rights of People with Disabilities by the Constituent Assembly in the new constitution. It also advocates for the integration of disability issues into mainstream development projects conducted by donor agencies, INGOs, and NGOs.

There is reason for Shudarson to be happy, as his work is garnering more and more public interest and support, people with disabilities are increasingly stepping forward into society with a new found confidence, and there is an increase of participation on the part of people with disabilities at all levels of society, including the government’s policy making level. His work has not only been a beacon of hope for people with disabilities in Nepal, but has also inspired them internationally. The Disability and Development Partners (DPP), an NGO from the United Kingdom, has established a working partnership with DHRC to replicate its work in the UK. Having worked on disability rights for over a decade now, Shudarson sees disability rights as a part of the social structure itself and a means to ensure a more inclusive and equitable society.

“Shudarson Subedi and his organization DHRC are the first people to approach disability through a rights-based approach. The historical Supreme Court ruling of 2003 has further enhanced his reputation and has become an important step in securing the rights of people with disabilities. Shudarson himself is undoubtedly a leader. Without his leadership, motivation, and dedication, the Supreme Court case might never have happened. However, his work since then has been even more impressive. He has successfully brought together all the disability organizations,



in spite of the factionalism and political squabbling that goes on between them, and has convinced them to sign the Kathmandu Declaration, 2008 demanding the immediate ratification and implementation of the United Nation's Convention on the Rights of People with Disabilities in the new constitution. Without Shudarson it is unlikely

that these events would have transpired now or in the near future".

Niraj Dwadi – Human Rights Officer, United Nations
Office of the High Commissioner for Human Rights
(UNOCHR)

◀ ▲ Photos:
Shudarson
Subedi's archive

Shudarson Subedi, 37, married, with a daughter and son, is the founder and the president of Nepal Disabled Human Rights Center (DHRC-Nepal). He has mobilized the disability and human rights movement and established public interest litigation on behalf of people with disabilities in Nepal. He has trained 1000 activists and set up 250 local radio listener clubs to promote the rights of people with disabilities. He has also worked to empower the disability rights movement through national and international human rights network. A member of the National Disabled Service Coordination Committee. He published a book on the legal situation of people with disabilities in Nepal and more than 100 articles in national and international media. Ashoka Fellow since 2005, elected to the Fellow of Asia Society in 2007. He received the Champions of Change Award from the Nepal Government, Non Resident Nepali Association, and the Federation of Nepalese Chambers of Commerce.

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Kamile HandiFestival



septembre 2006
Dakar - Sénégal

Ame Thiam

Association Handicap.sn, Senegal

Ashoka Fellow since 2008

The Handicap.sn portal: accessible IT services for people with disabilities

by Wilma J.E. Randle

In the crowded urban community center room, all eyes are on Ame Thiam. He is standing in the center of the floor, conducting a computer training workshop and very enthusiastically talking about how to use computer graphics to create high impact communication media.

To the casual observer this appears to be a very homogenous group. The participants are all black, young, mostly in their teens to early 20s. There's a fairly even mix of males and females. But take a closer look around the room and a few things stand out. First of all, there are not enough computers to go around, so people are sharing, sitting two to three at a machine. At several of the machines, pairs of crutches are leaned against the tables.

When Ame Thiam looks around this room what he sees is potential – potential in the abilities of the young people gathered here and in the computer skills and access to information to help improve and empower their lives. Particularly of those with disabilities.

Thiam's passion is computers and information technology. He loves learning and sharing his knowledge with others, most particularly with those who, like himself, are physically disabled. Thiam, now 30 years old, was crippled at age three after contracting poliomyelitis. Over a period of many years and several operations he now has rather good mobility, although at times he has to use a cane for walking.

In 2007, Thiam channeled his passions into the creation of **Handicap.sn**. **Handicap.sn** is the first-ever association created in his home country Senegal to focus on offering access and training in information and communication technology (ICT) to people with disabilities. **Handicap.sn** relies on innovative projects aimed at using computer science to help bring about social change.

In 2008, Thiam was selected as an Ashoka Fellow for this innovative effort. For it includes the creation of the first-ever disability-targeted web portal in Senegal, and probably in all of Africa, www.handicap.sn. The website is designed to serve as a bridge linking people with disabilities in Senegal to the information Super Highway and to serve as a connecting point and one-stop resource site for people with disabilities within Senegal, throughout Africa, and beyond.

"For the longest time people with disabilities in Senegal have been marginalized," he says. "They have suffered from a lack of access physically to infrastructure as well as a lack of access to basic social services in areas such as health, employment, and education. Politically they have been ignored generally in all areas."

Thiam was born in 1978 in Morocco, as the eldest of four children (three boys, one girl) to a Moroccan mother and a Senegalese father. Thiam spent a good part of his childhood living outside his native Senegal. This was primarily

because of his father's career in the Senegalese diplomatic corps, but also for personal medical-related reasons.

Thiam came of age in a generation for whom computers were considered "expensive toys" as well as learning tools. "Other boys my age were out competing in physical games, running, playing soccer... I couldn't do that," he recalls.

"I got my first computer very early," he recalls. "My father gave it to me on my 10th birthday. It was the best gift he could have given me... I used to play with that basic programming language to write songs, to draw, to rewrite programs just to see the magic of programming".

At age 14 Thiam's family was living in Senegal when an acquaintance of an uncle who lived in France came to Senegal for vacation and called on his family. During her visits with Ame's family conversations with his parents led to his health and to discussions of medical treatments for polio.

"At the time, in France, doctors were performing a new type of surgery that was said to help people with polio regain use of their muscles," Thiam explains. The adults continued their discussions, and by the end of her vacation, this woman, Josianne Sutter, had offered to take Ame home with her to France.

Thiam describes her as being a "very human, very compassionate woman" with whom he lived for a year and

attended high school in her small town, while awaiting medical evaluation and surgery.

His French guardian made him promise that when he was grown, he would not only make something good out of his life but "share the gift I'd received, to help others," he recalls, adding, "I promised I would. So it's like repaying a debt."

Living in different cultures, Thiam states he was very early on aware of and sensitive to the economic and social disparities that existed in the world. And, he explains, even though he was interested in business and computers, it was always the people-connected parts of these sectors that interested him. "I was always interested in working with people and work that helped people."

Returning home to Senegal, Thiam experienced a bit of re-entry culture shock. He became aware of just how much he'd taken for granted living in countries, like Germany, that were far more advanced when it came to addressing the needs and rights of its citizens with disabilities in terms of providing equal access to transportation, social services, financial aid, etc.

Senegal is a relatively small country located on the far western tip of the African continent, on the Atlantic ocean. In development statistical terms, it is "typical" in that



poverty is widespread, the majority of the population lives on less than \$2 a day, and there exists all the related developing-world concerns: from education and literacy, to access to basic health care and services. Moreover, the government-provided social safety nets basically do not exist. In this environment it is women and children who often suffer the most and where people with disabilities are often among the most marginalized of the marginalized. It is a country where, as is true in many African societies, old traditional fears and beliefs about people with disabilities, particularly those born with birth defects, persist and serve to keep old prejudices and stigmas alive.

No one knows for certain the exact number of people with disabilities among Senegal's estimated population of nearly 11 million. There are just guesstimates. But take a walk along any major thoroughfare in the bustling, densely populated capital city of Dakar and the number would seem to be "A Lot".

There seems to be ever-growing numbers of young people, children, mostly boys, sent out to beg for alms. Others just wander randomly. There is also a visible and increasing population of young women, most of them in wheelchairs, occasionally a blind woman among them, often with a baby or a child in tow. They seem to be, save for their obvious physical infirmity, fit. Yet they are required to beg for their daily keep in a world where work for those who are not physically disabled is scarce.

For others with disabilities, but not faced with such dire economic straits, Senegal, like so many other developing countries in Africa and elsewhere, offers a basically inaccessible environment in terms of access to transportation, public facilities, and access to social services. Education is mandatory and public school free, but schools are not disable-accessible and laws to require such also are non-existent.

Ironically, and despite the economic challenges it faces, Senegal has one of the continent's most advanced telecommunications infrastructures. Mobile telephone use is wide spread and over the past decade there has been a steady increase in the number of small cyber cafes where for a fee (less than a \$1 an hour) people can have access to the Internet.

In 2005, in an effort to better understand his country's realities, and also how he might contribute to positive change, Thiam got involved with a group called SOS Handicap. This is a local association for people with disabilities, one of several such groups in the country. Thiam created its first-ever website and oversaw production of the association's magazine, *Disabilities Sketches*, which was the country's first-ever disability-themed magazine.

Inspired by Thiam's efforts a colleague from the Ministry of Culture launched the HandiFestival, the country's first-ever disability-themed information and cultural arts festival. It has now become an annual event celebrated in connection with the U.N.'s International Disabled Persons Day, which is held each December. Thiam continues to collaborate on this project, assisting with marketing aspects of the program. Most notably, he creates and updates the event's website (www.handifestival.com) in order to give the event greater visibility.


Thiam explains that **Handicap.sn** is designed to serve as an Internet-information umbrella linking all the disability organizations and related-entities in Senegal – with the region, the continent, and the globe – via the web portal, www.handicap.sn. In this effort Thiam has made connections between different associations and has worked across the spectrum with various groups.

"In fact, the lack of information currently available about disabilities issues on the Internet that are Senegal-specific aggravates the feeling of isolation and disconnect for many people with disabilities," Thiam laments.

"Computers and the Internet are very democratic and very liberating," he says. "The Internet allows you to build community solidarity. But currently", he goes on, "there are less than 5 websites in Senegal that are disability-themed. These are often the websites of international non-governmental organizations or other international groups". In contrast, "more than 95% of the Senegalese associations for the disabled are not yet present on the Internet – they have no website or blogs, no email, etc."

However, the web portal www.handicap.sn does more than just to provide a wide variety of disability-related information, including links to various useful websites.





Soon it will feature employment information and promote income-generating activities by offering online shopping for products made by associations of people with disabilities.

In terms of technological innovations, Thiam's web project hopes to become a model for providing access to people with disabilities and for content related to disability issues. This will be content that is in compliance with international standards for visual and motor skills accessibility, including providing access to visitors to the site who are visually impaired through the use of assistive technology (voice synthesis, Braille screens, screen enlargers, voice recognition, etc.)

Reaction to Thiam's project and efforts has been overwhelmingly positive. "This web portal is an excellent initiative in that it will allow people to become familiar with the different organizations. And those who are not involved in any of these associations will be able to access information about them," says Laba Cissé Diop, who serves as president of the Senegalese Federation of Associations for Persons with Disabilities (FSAPH), sponsor of the draft portal.

Diop is also the Special Advisor to Senegal's President Abdoulaye Wade on Disability Affairs, a post that was created in 2000. The Federation, which has been in existence since 1997, is a coalition of 26 national disability organizations. "The web portal," Diop added, "will also serve to help raise visibility regarding disability issues and related concerns to government leaders."

Thiam says the key to the progress that his association has made so far has been the result of working in partnership with people from all sectors of society. "For example, when I wanted to have access to CRE [a government sponsored community center offering computer and technology training for neighborhood youth] I normally would have had to pay for use of the space," Thiam says. "But," he continues, "Since I didn't have the money, I negotiated with the Center to have access to its computers in exchange for my conducting training workshops for them. I also stipulated that I be allowed to include participants with disabilities in any of the training sessions.

Thiam also joined the Digital Solidarity Club (CSN or Club de Solidarité Numérique), a group that is promoting Internet projects to boost Africa's development. As a result of his involvement with them, CNS decided to focus its 2008 theme on Information Technology Access for People with Disabilities, promoting this message on its website.

Most people who meet Ame Thiam are impressed by the project and the person behind it. "I met Ame after he became a part of the Ashoka program," recalls Abdourahmane Mbengue, manager of CRE (the Centre de Recherche et d'Essais de Plateau) who was elected as an Ashoka Fellow in 2001. "I think he's a very serious young man and someone who could change a lot of things for people with disabilities in Senegal and in Africa," Mbengue says.

At the computer graphics training workshop, Thiam invited seven women with disabilities to participate, all members of the National Association of People with Motor Disabilities (ANHMS). "We targeted them because we know that women are often even more marginalized," he explains.

"I was very happy to be able to participate in this workshop and have the opportunity to increase my knowledge about computers and how to use computer graphics to make business cards, brochures and things like that," offers Seynabou Thiam, who also is ANHMS vice-secretary of the women's section.

Thiam's work in the disability sector is coming at a time when there is a growing consciousness in Africa about the needs of people with disabilities. And this has been a long time coming, despite the UN's declaration of 1983 to 1992 as the "Decade of Disabled Persons." In Africa, so little change was seen following this period that advocates successfully lobbied for governments to do more. And so it was that the African Union declared 1999 to 2009 the "African Decade of the Disabled Person" to raise awareness and hopefully foster the enactment of laws and policies to address issues and needs and help improve the quality of life for citizens with disabilities.

Senegal is one of the first countries to have agreed in principle to the UN's international Convention on Disability Rights, but it has yet to ratify this accord.



Thiam sees the www.handicap.sn web portal as a tool for helping to get this convention ratified. "First we have to raise awareness about it and then we must rally people to advocate for ratification," he stresses. "The web portal is a perfect meeting point for people from all sectors, including politicians, because it can be a one-stop place for them to get the information they need."

◀ ▲ Photos: Pape Seydi

Ame Thiam,

Ashoka Fellow in Senegal since 2008, is the president of the Handicap.sn Association.

He is the initiator of the Senegalese web portal on disability. He participated in launching the first international festival for people with disabilities – the Handi

Festival International. He created websites for organizations and projects on disability. He promotes the inclusion of the disabled community into the Information Society. The portal network has been financed by the ADEN Fund (Fostering digital inclusion), a program of the French Ministry of Foreign Affairs.

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Ashoka Fellow since 2003

Changing Society To Achieve The Inclusion Of People With Disabilities by Carlos David Salinas Olascoaga

Estela couldn't believe her eyes when she realized more than 800 people had signed up to participate in the Summer Camp either as volunteers or beneficiaries. Memories of a time, 21 years before, when only 15 beneficiaries and 30 volunteers had taken part in the first Unidos Summer Camp came to her mind and confirmed that the seed she had planted back then was growing at a truly astonishing rate year by year. What had begun as a dream to include her brother and sister with disability into society in the Mexican city of Monterrey, has developed into a socially inclusive model known as Unidos, now present in more than 10 cities in Mexico. The model has also interested other associations, such as Teletón México. Indeed, over the past years several associations have implemented Unidos' model.

The idea behind the Summer Camp was simple: once a year a group of volunteers led by Estela would organize and carry out several fun activities with people with disabilities in everyday environments. In Estela's words, the objective was to "show the world that people with disability could also enjoy the same activities as they did. Our goal was to take our friends with disability into the real world and give them a good time. By doing this, we wanted to change the way in which society looks at disability. In other words, we decided to get rid of the fear that most people feel when coming into contact with someone who has a disability." This was not an easy task, especially in

Mexico, a country facing several issues regarding disability, the most important one being that telltale fear.

According to the World Health Organization, 10% of the Mexican population (which is about 120 million) suffer from mental or physical disability. 45% of those with disabilities have limitations related to their arms or legs, 29% are blind or perceive only shadows, 17% are deaf or use a hearing aid, and 10% have some other type of disability. While most of the associations attending to this social group focus on one type of disability, either mental or physical, and a certain age range, Unidos, through its Summer Camp and other social recreation activities (such as the Best Buddies Program and field trips) integrates people with all types of disabilities regardless of their age. Whereas other associations mainly focus on the rehabilitation process, Unidos centers its efforts on the socialization and inclusion of people with disabilities by transforming the way in which society sees and treats them. In other words, Unidos seeks the rehabilitation of society, thus constituting a never-before-seen kind of association in Mexico that complements the work of other organizations or serves as their cornerstone.

All of Unidos' activities are designed to create a long-lasting bond between volunteers and beneficiaries in order to change society's attitude towards disability. To do so, Unidos' model has evolved over its 21 years, though it remains

faithful to the concept of *warmth*, which is the essence of the activities throughout the country involving the direct attention of 7,183 people. *Warmth* is understood by Unidos as liveliness of feelings, emotions, sympathy, enthusiasm or zeal. It also represents the quality of being intimate and feeling attached, and ultimately, it brings a resulting brightness, cheerfulness, and coziness to its beneficiaries, who after all are not only the people with disability Unidos reaches out to, but also the volunteers themselves.

Therefore, careful logistics are indispensable to the successful accomplishment of warmth in the activities of Unidos. Thus, twenty different groups have been created and sorted by type of disability and age. These groups are to insure closer contact between volunteers and those with disability, as well as to insure that the recipients will enjoy every activity to the maximum, especially when they take place outside Unidos' one-acre park – for instance, in venues that may not be able to well accommodate attendees. Each group is identified by a distinctive cheer that is usually sung out by both the volunteers and people with disability as a way of reaching out.

Reaching out is the fundamental purpose of the inclusive programs Unidos promotes; for the volunteers it means “to take the opportunity of coming into close contact with a person with disability, in the aim of changing our attitude

towards this social group,” as Estela says. Reaching out changes the volunteers, and they, in turn, change society by becoming ambassadors of Unidos' cause and promoting equality in every activity of their daily lives. Estela identifies several important changes brought about through the Summer Camp and the other activities Unidos promotes, such as trips, going to the movies, or going out at night:

- an increase in the number of volunteers and their leaderships skills, such as self-confidence, sociability, vigor, and original thinking according to the Gordon Personal-Profile Inventory (GPP-I);
- the openness in the volunteers, who encourage others to join Unidos;
- the desire of more venues, of all sizes to host activities related to Unidos;
- people with disability attended by Unidos have decided to venture out into the real world as a result of a positive change in their self-esteem wrought by the close contact with volunteers and the number of activities organized throughout the year in various contexts.

Consequently, Estela is deeply convinced that the idea of reaching out is no less than universal: it may be applied to every association or organization that is truly commit-



ted to changing the world. Indeed, over the past 21 years Estela has noticed that society has been changing little by little in the way it perceives disability. As proof of this, although Unidos began in Monterrey, today the warmth of its model and the urge to reach out is making a difference in 10 Mexican states, either as a social franchise or in alliance with another association that also attends to people with disability. This, in Estela's estimation, has been Unidos' most spectacular achievement. Moreover, it strongly motivates her to continue with the expansion of the model, its replication in and adaptation to other countries, especially those with a context similar to Mexico's, where much still has to be done. As Estela explains, her goal is "to eliminate the fear of coming into close contact with people that suffer some kind of disability and to realize that we share dreams and hopes because of the simple fact that we are all human and find ourselves in the continual pursuit of happiness."

As do all major projects striving to change the world, Unidos has achieved several successes, but not without facing some bumps along the way. At the beginning, Estela remembers, most of the activities were "homemade." During Unidos' first years she was the one responsible for planning, executing, and supervising most activities. As the movement began to grow, more and more families were sending their members with disability to Unidos. Although the activities were growing in number and size, she still wanted to head up the planning and execution of most of the activities. It took her some time to realize that the association needed to include more people in its administrative structure. Finally, she had to make an important decision: to make of Unidos an association with an appointed board. This meant that she would no longer be in charge of making all of the decisions and consensus would have to be reached in order to take any course of action. This decision allowed Unidos to grow at an astonishing rate and still be able to support activities year after year. As a result Unidos has become a truly living organization not dependent on its founder, involving actors such as social leaders, businessmen, and donors.

Another important challenge surfaced when Unidos began franchising its model to other social entrepreneurs. Estela wanted the model to be replicated in the exact same way as it was implemented in Monterrey. This, she


explains, "was a paradox. How could it be that an organization based on a diversity of conditions and ideas had trouble accepting differences in the implementation of its model?" So, Unidos had to learn to respect local social entrepreneurs and even to encourage them to make the necessary modifications to the model in order to assure its success in their own community. Estela feels that the biggest accomplishment Unidos has had is the replication of its model through a network comprised of NGOs that share Unidos' dream of a fairer society. Within this network Unidos acts as a coordinator in both the implementation of its model and its adaptation by providing the know-how and thereby reducing the incidence of false starts.

Even though Unidos has evolved to become a social enterprise, it has never lost track of its original goal. "Our ultimate goal is to achieve a cultural change in Mexican society regarding disability, and we will do whatever it takes to spread our message to as many people as we can. This is a dream I had 21 years ago, and I decided to adopt it as my mission" says Estela, who regards the institutionalization of her dream as a means to an end. She assures that through the safeguarding of warmth Unidos will never lose its human and caring touch while serving people with disability along with the volunteers closely working with them.

Looking back at all she has done in order to achieve her dream of changing the world through Unidos, Estela feels that there is still much to do. Everyday she wonders what is next for Unidos and the evolution of its model. Therefore, the biggest challenge that Estela and Unidos face on a daily basis is to continue with the development and adjustment of the model in order to meet the ever-changing needs of people with disability, as well as that of society. In order to do so, Unidos relies on volunteers.

The volunteers are the heart and soul of Unidos. They are the ones responsible for providing unforgettable experiences to the people with disability who attend the Summer Camp every year and who also look forward to participating in any other activity organized by Unidos. Ultimately the volunteers are the ones in charge of spreading the warmth of Unidos to society and enabling it to reach out to people with disability. Estela is deeply convinced that through the efforts of these young people,





who will become the leaders of tomorrow, a major change in society will occur and people with disability will one day be fully integrated.

It is important to stress that the young people who have served as volunteers in Unidos have developed social leadership skills such as networking, collective action, solidarity, and cooperation. The ultimate goal of Unidos is for these volunteers to foster social cohesion and inclusiveness in their everyday life.

Estela knows that being a social entrepreneur is not an easy task. Although she recognizes that there is no single formula for being a successful social entrepreneur, she nonetheless believes the following guidelines can help anyone willing to deeply commit him or herself to changing the world:

Think outside the box: Don't be afraid of having different ideas and shifting paradigms.

Inspire: Be the first one to be deeply committed to your cause, let those around you to be touched and moved by your enthusiasm.

Persevere: Never give up, always have your ultimate goal in mind. Remember that every experience is something that you can learn from.

Be one step ahead: Once you have achieved a goal, figure out what's next for you and your project.

Since its beginnings 21 years ago, these four guidelines have been present in the development and evolution of Unidos' socially inclusive model. Today, Unidos has reached several turning points in changing society's view of people with disability. Nevertheless, Estela knows that there is much ahead. Therefore she will not give up on her quest for a more just society.



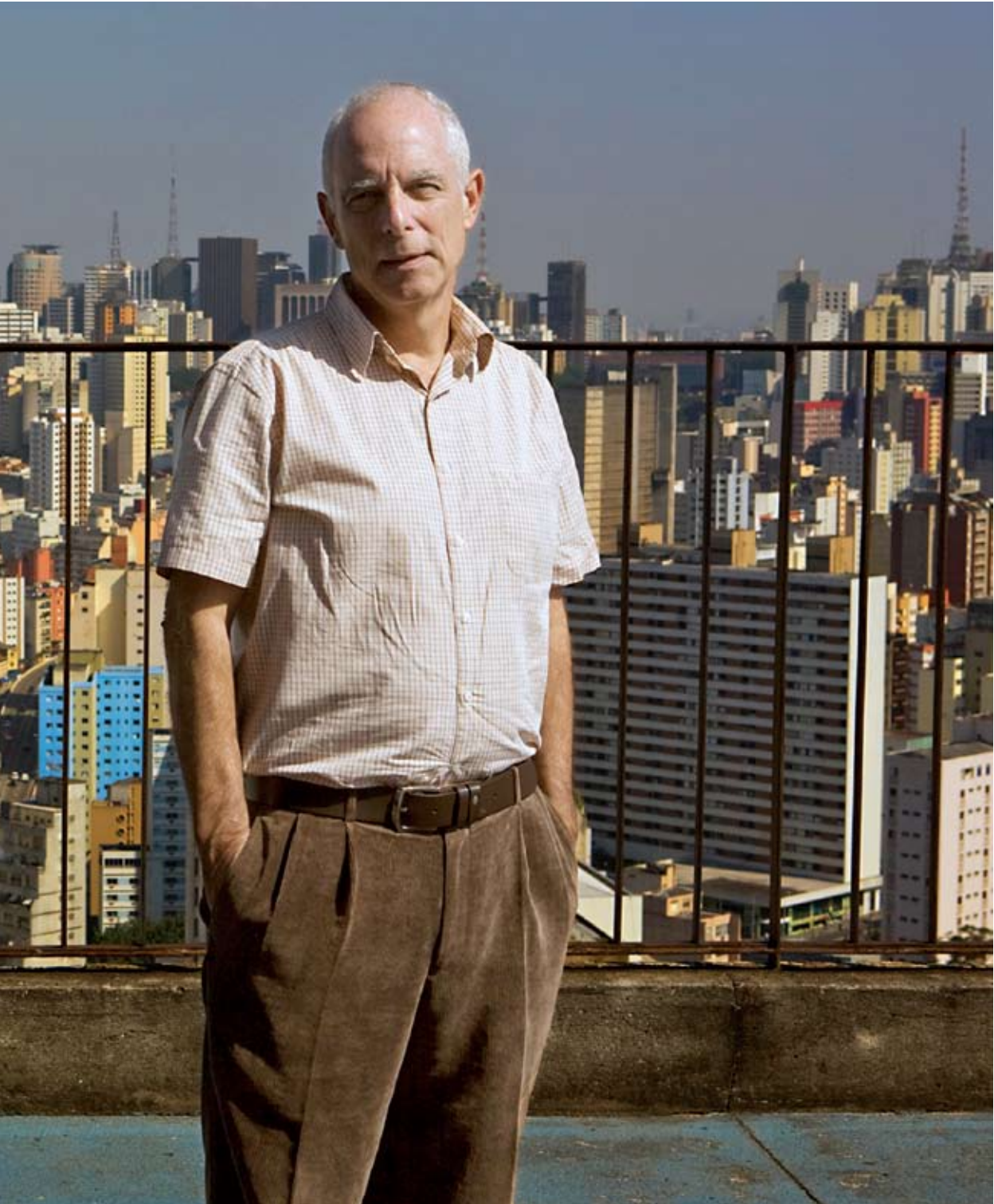
◀ ▲ Photos: Juan Rodrigo Llaguno

Estela Villareal Junco,

Ashoka Fellow in Mexico since 2002, is the Founder and Head of International Affairs of UNIDOS Lo Lograremos, A.C., an NGO dedicated to the social integration of people with disabilities, a passion that arose from her personal experience with two siblings. For more than 20 years, she has been expanding it to many cities in Mexico. For her activity in Unidos she has received many awards, distinctions, and nominations, among them INDESOL's "1 of the 24 best national social practices", Global Leaders for Tomorrow, and on several occasions the Medal for Civic Merit.

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Howard Weinstein

LEGAR Consulting, Brazil

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Silence Breaker

by Rafael Barifouse

In the middle of the morning of January 24, 2002, Howard Weinstein, who had been only 3 days in Otse, a village of 3,500 in the south of Botswana, heard a knock at his door. It was a teacher from the local School for the Deaf with one of her students. She had heard the Canadian entrepreneur was there to make a low-cost hearing aid and wanted one for the girl with her. "Her name is Sarah. She's seventeen", she said. That just happened to be the name of Weinstein's daughter, who would have been that same age if she hadn't passed away because of a brain aneurysm six and a half years earlier. "I have a reason to be here", he thought.

In 1978, Weinstein bought a small plumbing business and sold it 15 years later to a big corporation, while retaining the managing job of the Canadian division. Living in Montreal, he had a life that most people only dream about, with a luxurious home and a country villa overlooking a lake. Then came that night of June 6, 1995. Sarah, a perfectly healthy child, died in her sleep. When Weinstein went back to work after a week, he was fired. "They thought that I couldn't make a profit for them any more", he says. "From a business standpoint, they were right, as I was totally lost, feeling like I was living in a fog."

Weinstein took a year off and did some psychotherapy. After that, he started a new company to make electronic toilet seats for people with disabilities. He went person-

ally bankrupt and lost his home, savings, and all other assets. "My heart wasn't in it", he explains. He decided to go to a developing country to apply his experience as an entrepreneur to social problems. He wanted to be able to provide an income to women so that they could afford medication for their children and not have to suffer like he suffered. "I'm a businessman who knows how to transform ideas in reality", he thought at the time. In 2001 he was invited to go to rural Africa as a volunteer. There he would earn only a small living allowance, live in a one-room mud house, but help start an NGO which would employ rural deaf women to build low-cost solar-powered hearing aids. The Africans have a saying: "the blessing lies close to the wound", he says. "I knew it was for me". This could be his blessing.

It took a year before Weinstein could give a hearing aid to Sarah. When he arrived at Otse, he worked with engineers further developing the new technology: a low-cost hearing aid, rechargeable batteries, and a solar charger called SolarAid. The African NGO, called Godisa Technologies, was the only manufacturer to produce low-cost hearing aids in Africa, and the only one in the world that hires deaf people to make them. Godisa in the local language means "doing something to help others grow". The social business concept was created by Camphill Village, an African NGO whose mission is the empowerment of people with disability. Godisa was started in this special village.

According to the World Health Organization (WHO) there are 278 million people worldwide who need a hearing aid, but only 6 million are produced every year. Of these, only 12% are sold in developing countries, where two-thirds of the people who need them live. Most hearing loss in developing countries is caused by ear infections that can be cured with an inexpensive anti-biotic. But access to medicines and treatments is limited in these countries and almost negligible in rural Africa.

There was another problem. At that time, the price of a hearing aid ranged from \$500 to \$5,000. Most often, two are needed. Most hearing impaired people in the world cannot afford such a price – much less so, then, in Africa. When a person receives a hearing aid, all too often it is not used after the first week, that is, once the battery goes dead. A standard hearing aid battery which lasts on average one week, costs one dollar and generally can only be purchased in the capital cities of developing countries. The solution to both issues would come in the form of a low-cost rechargeable hearing aid with batteries that last two to three years with everything being charged via a solar charger. Solar energy, after all, is abundant in Africa.

Weinstein didn't know a thing about audiology and often jokes that he did not know the difference between a decibel and Tinkerbell. He helped create a sustainable business model, made calls to foundations, consulted

with electronics specialists, and talked to manufacturers. The African Development Foundation (ADF) in Botswana at first rejected his proposal, but Weinstein persisted. His experience in business taught him that a "no" just means "not now" – not "no" forever. He flew to the US to meet the president of ADF, whom he showed the prototype solar charger. It made a deep impression. Weinstein came back with a commitment of \$250,000.

It took Godisa two years to become sustainable. With a selling price starting at under \$100, which included a hearing aid, four batteries, and the solar charger, the revenues would be enough to pay the bills, the salaries of ten employees, and to continue to invest in education and training programs for the employees. Deaf people themselves would manufacture the equipment. Deaf people who speak in sign language have a higher than average hand-eye co-ordination. They are perfect to do the delicate soldering of the electronic components. After six weeks of selection and technical training provided by a British hearing aid company, ten candidates were selected. "They were suspicious at first, but their attitude changed when they understood that it was their project," says Weinstein. Sarah was one of deaf people chosen.

The Canadian entrepreneur almost considered himself an uncle to his new employees. He established a special relationship with the teenage girl he first met at his door-



step. "She called me papa," he says. Sarah became a leader within the team and motivated her colleagues to work harder. He remembers one time when he was going to an audiology conference in Brazil, "Everyone asked me to bring them gifts from Brazil." But Sarah only said, "Go help the deaf there".

This year Howard received the 2008 Humanitarian Award from the American Academy of Audiology. "He isn't a professional in the area, but understood the problem and found a solution", says Sheila Dalzell, chairman of the awards committee. "It's not a sporadic effort. I'm sure the project will impact peoples' lives for a long time."

It's a May afternoon in 2008 when Weinstein in his new house in São Paulo tells me about the five years he spent in Botswana. He remembers the huge parties for weddings and even bigger community gatherings for funerals. But Weinstein was not able to finish his contract. "Too many deaths", he explains. "There's a funeral every week because of AIDS, most of them children". During his time in Botswana, one member of his own community died in his arms. He was heading toward emotional collapse..... again. It was time to go.

When Weinstein arrived his office was a single room with a couple chairs, desks, no products, and no money. He left a successfully operating nonprofit business. In six years, Godisa sold 10,000 hearing aids, 15,000 rechargers, and 20,000 batteries. "This is a truly unique model that can be replicated in other parts of the world", says Michael Langhout, president of AUDIENT, an affiliate program of Northwest Lions Foundation for Sight & Hearing. "We applaud Weinstein's bold creative efforts to meet a very large health care need". By the time he left, Weinstein had taken the steps to ensure the continuity of Godisa. From the first day he arrived in Otse, he trained Modesta Zabula, an administrator 36 years-old, to take over his job and taught her how to be an entrepreneur. She was instrumental in giving the employees the confidence and latitude to try new ideas. Modesta is now in charge of all the aspects of running Godisa. "Howard was very much cherished by our staff because he motivated everyone around him," says Modesta.


In Botswana, the Canadian also helped develop three other new sustainable businesses with Down's Syndrome

villagers at Camphill, including a successful landscaping project. "I wanted to change the mentality in society and demonstrate that a person with a disability could work at world-class levels," he says. "We wanted other companies that had observed the results of these great people and their projects to start hiring them because of their special ability". By the time he left Botswana, 35 people with disabilities were employed.

In 2003, Weinstein was invited to participate at the annual hearing impairment meeting of WHO in Geneva. "They wanted to see the developed product, which the relevant committee had been discussing for past 15 years, and which we had developed in 9 months," he says. During this conference, two Brazilian audiologists asked him to speak at their upcoming annual national conference. There he met Dr. Deborah Ferrari, a noted professor of audiology at the University of Sao Paulo (USP), who invited him to replicate the Godisa project. In Brazil there are five million hearing impaired people, according to the Brazilian Institute of Geography and Statistics (IBGE). In 2006 he left Botswana for a much needed break, traveling overland from Panama to Montreal, Canada. After 2 months in Canada, he decided to go to Brazil to start the next stage in his life. He says, "Brazil is half way between the despair of Africa and the superficial life of North America."

Weinstein has now lived in São Paulo for nearly 3 years. He had to start all over again, developing a new rechargeable digital hearing aid, a second generation solar charger, as well as develop 2 new low-cost rechargeable hearing aid batteries. He also needed to find local partners and all of the required funds. He found a new Brazilian NGO, Instituto CEFAC to be the lead partner. They had his mission and vision, as well as the money to house the project. He raised an additional \$200,000 in foreign grants. All the technology is now developed and production will start in January 2009. The Latin American 3-piece kit will include a new digital rechargeable hearing aid, rechargeable battery and a second generation solar charger. It will be sold throughout Latin America to governments and NGOs for about \$125, which is less than the price of batteries alone over a two-year period. Any company, anywhere in the world will also be able to buy the kit at a slightly higher price, or they can purchase just charger and batteries, as these products can be used with hearing aids





they presently sell or have sold on the market. One of the personally exciting aspects of this project for Weinstein is that the deaf from Botswana will come train the deaf in Brazil. Most technical training today is North-South, rarely South-North or South-South and never internationally deaf to deaf. Sarah is now 24 years-old and will be one of the three employees from Godisa who will go to Brazil to train the new deaf employees.

Weinstein compares the differences between being an entrepreneur in Canada and being a social entrepreneur in developing countries. In Canada, for example, you can easily hire a trained, skilled, educated person. Moreover, in Canada you have an excellent infrastructure in which to work, plus all the social, economic, and political benefits. In Brazil and Botswana it takes a lot of time to raise seed money, find good people, and train them, plus the infrastructure and bureaucracy are serious challenges. Comparing Canada to a developing country is "like being Ginger Rogers", he laughingly says. "You have to dance as smoothly as Fred Astaire, but do it wearing high heels and dancing backwards."

Brazil will provide the low-cost hearing aid and rechargeable batteries for all South America, where 5% to 9% people are hearing impaired, according to WHO. The next two projects will be in Jordan and Mexico. The Mid-East program, called Al-Quads Sound Technology, has a peace component as young deaf adults from Jordan, Palestine, and Israel will work together. Weinstein has already visited or talked to NGOs in Pakistan, Indonesia, Vietnam, the Philippines, China, Russia, and the United States. Each project will have the same mission and vision of empowering their workers who have a disability and of distributing their products in their trading area. The Mexican project, for example, will sell throughout Central America and the Caribbean. Jordan will focus on the Middle East and northern Africa. Botswana will take care of the rest of the continent. Together these independent NGOs will purchase the required components together, in larger volumes, which in turn, will lower the cost for all. "It's a new paradigm for business, as we are creating competitors who will help one another," he says. "But the market is so big that one country couldn't cover the global demand alone."

As in Brazil, the other projects are also developing new technologies. Jordan is adapting one to use Bluetooth

technology for schools, where presently the microphones used in classes interferes with the hearing aid. All of this technology, as along with the empowerment programs, will be shared for free between the projects. Nothing is patented. "It will be great if big companies copy our inventions," he explains. "Their power of distribution is much bigger than ours will ever be, with the end result of more people getting a low-cost hearing aid plus saving hundreds of millions of zinc batteries from being thrown out every year."

Weinstein didn't find only new challenges in Brazil. He also met a new love: Monica, a 41 year-old audiologist. In July of 2008 they married. He lives now with her and is the stepfather of Stella, 11, and Luisa, 15. Stella is the same age Sarah was when she died, so he gets to start his life as a father again. As in Botswana, in Brazil he runs other social projects, now with his wife. "She is very good in looking at the big picture and finding the thread to make the project come together", Weinstein says. In the slums of Cantagalo, in the state of Rio de Janeiro, they work with the local youth association to help them develop sustainable programs that will give them training, experience, and income, but most important a reason to stay healthy and keep their community safe. It was the youths of this community who decided to turn the problems of their community into an opportunity. Howard and Monica were able to raise the money to help them start 3 projects which the youths had chosen – one in photography, one making decorative and household soap from recyclable household oil, and one using the paper garbage from their community to make decorative paper. They hired a professional photographer to teach the youths. Some of the pictures taken are printed on the recycled paper to be used for the decorative boxes for the scented soaps. Monica and Howard's idea is to create future sustainable projects from the revenues generated from the first 3 projects. In all the projects, they address economic, social, environmental, and educational issues. When asked why do all this at once, he says "it's fun, and if it can be done that way, why not?"

In the courtyard of his new home, as he plays with Donna, a Bernice Mountain dog, Weinstein seems happy. "I'm going to live in Brazil for the rest of my life." A former executive turned into a social entrepreneur, Howard likes his new



lifestyle. In his perspective, the challenge is the same as in a traditional business: motivate people and make it work. Looking back at the last thirteen years of his life, he now sees that he started on this path to give meaning to his daughter's death. But in reflection it gave meaning to his own life. He also adds, "Before I was rich, now I am wealthy".

Howard recommends 4 things for success in achieving social change:

- 1) You will learn more from your mistakes and failures than your successes. Please don't be afraid to fail.
- 2) The project you are working on is not about you.
- 3) Being stupidly stubborn is a good character trait and will lead to success.
- 4) It all comes down to love. One word frees us of all the weight and pain of life: that word is love – Sophocles.

◀ ▲ Photos: Howard Weinstein's archive

Howard Weinstein 58, was born in Quebec, Canada. He delivers to any work environment, has a quick mind, an entrepreneurial, creative spirit, and a compassionate heart. Proven international negotiation skills. Maintains a positive attitude and a contagious optimistic esprit in any type of circumstance. Possesses the ability and patience to go from concept to finished product. Has developed and fostered excellent relationships across multi-cultural communities. Tri-lingual, plus sign language.

Honors and Awards: World University International Volunteer of Year 2005
 Ashoka Fellow 2008 <http://pcastilloashoka.webng.com/howardweinstein/>
 American Academy of Audiology 2008 Humanitarian Award
 Lemelson-Ashoka Fellow 2008

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ABOUT ASHOKA

Ashoka – Innovators for the Public is the global association of the world's leading social entrepreneurs – men and women with system-changing solutions that address the world's most urgent social challenges. Since its founding in 1980, Ashoka has launched and provided key long-term support to more than 2000 leading social entrepreneurs in over 70 countries. It provides these "Ashoka Fellows" start-up stipends, professional services and a powerful global network of top social and business entrepreneurs. It also helps them spread their innovations globally.



(Dis)Ability Initiative is a global joint project of Ashoka Fellows, launched and run with the support and engagement of Ashoka Staff and other resources. It has become a model of Ashoka Fellows' collaboration, because of its truly global character and continuity.



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ABOUT THE FRIENDS OF INTEGRATION ASSOCIATION

The Friends of Integration Association is a public benefit non-governmental organization, established in 1995 by Piotr Pawłowski, Ashoka Fellow from 1996. The Association provides professional support to people with disabilities, their families and caretakers focused on information, job activation and education. Being the number one social organization in the field of disability in Poland, the Association influences public opinion, initiates changes in legislation and calls attention to cases of law violations.



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"Fortunately amidst this economic gloom, *Creating Change* is a shining light. *Creating Change* presents a unique and inspiring set of stories of Ashoka Fellows across the world, whose work not only changes the lives of individuals with disabilities and their families, but also how communities, business and governments welcome and include people with disabilities as valued and contributing citizens. The sixteen Ashoka Fellows are all recognized leaders and social innovators in the field of disability. Together these pioneers are creating a new paradigm of disability that has the potential for domestic and global impact."

Eddie Bartnik, Director of Metropolitan Community Support