

Newsletter

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From The Heart

A Dream Achieved !

Editor's Note

Dear Readers,

With this edition Connect Special takes one more step ahead in bringing you news on path breaking innovations leading to inclusion .

My sincere appreciations to David Banes, Director, Access and Inclusion through Technology for agreeing to share articles.

So more exciting news to all of us every month!!

Happy Reading!!

Regards

Bhavna Botta



I grew up in remote villages of coastal Andhra Pradesh. I hail from Gajapathinagaram which is a hub of nearly 200 small villages and hamlets surrounding it. Both my parents were medical professionals. So when I was diagnosed with polio since birth, one thing was for sure, that of timely medical care. Naturally, as I was lucky to have resident in-house doctors.

Disability is not a guest to me; it is an integral part of my life. My father is a service oriented man. So were my mother and grandmother. The trio used to be a combination of compassionate service to humanity in whatever form they could. Under the aegis of Lions Club my parents used to conduct eye and polio surgical camps quite often. Success of one camp led to another and after a point it became a family ritual and a yearly mega event. Every summer my cousins and I spent a considerable time in serving post operative eye patients. From that age we were taught by my father that 10% to 20% of our earnings are resources that belong to the community. He frequently says, "If one cannot donate a part of his earnings, at least one should donate a bit of his time and skill." We grew up listening to his sound advice. I was unaware of my disability and its limitations.

But the memory that was freshly etched in my mind was that of me trying to kneel down holding a cup of soup to feed the patients who underwent eye surgery. The patients, post their eye surgeries, were totally dependent on others. Serving them with food and medicine was the prime job for us as volunteers. When I used to enter their camp with food or medicines I used to get agonized seeing the ill-treatment and negligence of the patient by their own family members. Sometimes the patients had to wait for hours just to relieve themselves in the urine pan without any reason for the delay. The contempt and lack of respect that I had seen in many caregivers' faces made me flinch. I used to dream a lot about changing this world where every disabled person would be treated with respect and dignity. I dreamt about many institutions where all the disabled were happy due to the treatment meted out to them.

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I was fourteen then. The next ten years I got busy with my education and several rehabilitative surgeries that I forgot about my dream.

The dream re-surfaced again with a painful harsh reality. I was bed-ridden at the age of 24 with lung infection and severe spinal column pain. My life got stopped in its tracks. I could not move an inch. We were searching for solutions for my pain and the revival of my almost collapsed lungs. Finally, at the age of 26 I had to undergo total spine reconstruction surgery. Everyone including our family astrologers predicted and feared my death. Whereas, my problem was not of death but the quality of life, if at all I managed to survive.

The first stage of recovery was to sit and transfer myself into a wheel chair and it took me two years to manage it. That was when I started thinking of my once forgotten dream. I think during that extreme helplessness times I conceived the idea of an institution but the idea did not have a name then.

The naming was done after Anand came into my life. Anand, me and some of my friends in India and US used to have endless discussions about a permanent project supporting persons with disabilities in India. There were constant E-mails and collaborative phone calls from both sides. But nothing was taking shape or moving ahead as all of us had ideas only. None of us had money to pursue our dreams.

Then suddenly, out of blue moon, Anand remembered my article 'Ability in Disability' {AID}. Those articles which touched every aspect of disabled person's life became very popular after they were

published and republished in several online magazines.

Anand suggested the name "AID International" based on the series of articles. Then my friend, Mr. Ram Sunder suggested the name 'Global AID Ability in Disability' with a vision to nurture abilities beyond disabilities.

The rest is history. I got married to Anand in March 2008. We both along with a few of our friends started Global AID as officially registered society in the year 2008 December. I consider Global AID as our baby very beautifully conceived and delivered exactly ten months after our marriage.

Global AID will be completing ten years of service by 2018. It's the most satisfying journey of my life. Everyone cautioned me saying that it would not be an easy job to run an organization as such and sustaining it with the same core values. But a mother never gives up. We all worked hard and gave our best. We never had to resort to any shortcut methods or bribery to accomplish our work.



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I still remember the words of income tax commissioner while he was signing our tax exemption certificate. He said that, "Madam I had a brother with polio and I know how depressing it is to be kept aside like an unwanted object. You are using your disability as a powerful message of possibility and hope. Let me do what I can." I think that was the best certificate our team received for its sincerity and transparency.

Author Paulo Coelho once said, "If you really wish for something to happen with all your dedication, the Universe conspires to deliver that wish to you."

It sounds strange but I was a witness to such a miracle. Today Global AID is currently serving 300 under privileged children, 140 disabled children and adults. It has a staff of 15 members and is also supporting 5 basket ball players with disabilities. Isn't it a miracle for a person, who is confined to a wheelchair since 30 years to achieve this fete?

Global AID taught me a profound fact that humanity and compassion has immense ability to transform lives beyond all real and perceived disabilities.



Mrs.Sai Padma, Founder-President of Global AID , a registered organization that aims to bring change in the lives of persons with disabilities facilitating Mobility, Accessibility, Employability and Sustainability. She is a writer, singer, fund-raiser for causes. Her articles on areas of disability in India were published in ILO journal, India Disability journal, Indian Women Online etc.. Short collection of her poetry titled "LIFE" was also published.

www.globalaid.in

<http://lotusbeats.wordpress.com>

<http://saipadma.wordpress.com>

<http://thammimoggalu.wordpress.com>

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Straight Talk

Meet Kumaran Kumanan author of *Aanantha thaandavam*, an autobiography in Tamil. The English version of the autobiography aptly titled "CP to CP, Cerebral Palsy to counseling Psychologist" was released on September 11 2014.

Tell us about you, Kumaran.

I am from Chennai! I have cerebral palsy -diplegia. This makes me a wheelchair user when outdoors and supported walker indoors.

I'm a counseling psychologist by profession and have my own clinic called "K Point" which is located in the same building of my home. Now I'm doing my PhD in psychology from Bharathiar University, Coimbatore!

I was part of a normal schooling environment till my 5th grade. Due to unfortunate situation of lack of accessible classrooms, which was denied even after very clear request, I had to move out of that environment.

After searching for alternatives, in the same year, I got enrolled in NIOS and started studying from home

This meant I had to do 10th grade directly, followed by 12th grade. Psychology was one of the subjects in both the grades. This was a firm suggestion of my father Mr. Elango Kumanan as he was absolutely sure about making my education a continuous process, *No matter what*.

Simultaneously, I learnt French from Alliance Francaise of Madras and Hindi through home tuitions. I finished my post graduation in "Counseling Psychology" in 2011 and pursuing PhD from a university outside Chennai, as I was denied the opportunity in my city. All the academic achievements are due to my prime tutor, my mother, Mrs. Karpagam Kumanan!

How can inclusion be made possible for all

First the basic thought process has to change! Places have to be built by incorporating inclusive structure right from the beginning. Even if it is difficult to do so! Lack of accessibility would somehow have a role in lack of sociability. I had to depend on Facebook actually to get a proper friends circle and it took me 5 years to achieve what I desired. An inclusive circle, despite being away from an academic

atmosphere. People must not hesitate to make friends with fellow citizens with disabilities. It may be a teacher-student relationship, a friendship or even romantic relationship. Needs just keep varying with age and have to be given due respect.



Is inclusion just being there in schools and colleges or getting equal opportunities

Unfortunately inclusion is nowhere near giving equal opportunities. The lack of accessibility factor keeps us away from being included directly in any academic atmosphere. Sometimes, an inaccessible stairway would make a set of people stay down and away forever like me!

How inclusive is the job sector

Since I am self employed, I cannot say directly about the accessibility factor or

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inclusive factor of the job market! Yet, I've been seeing people with disabilities taking up jobs which are extremely irrelevant to their actual academic qualifications and they do hold on to the same job even when they aren't having that self satisfaction, just because of the fact that they have to have a financial security .

How inclusive is this community -what is it that you feel has to be changed immediately

Personally I think it is completely up to person with disability to reach out to the rest of the world and mingle with others by choosing a correct circle of friends.

In a country like India which is highly inaccessible, it is not wise to have only people with disability as friends, or to plan a married life if both the partners are disabled and lack physical movement and are in need of assistance of others.

At the same time the society at large should get over their hesitation to begin even a general conversation with a person with disability. The happiest day of my life would be when I see an inclusive society with loads of friends for every person with disability, just like what I have! I thank God, my parents, family and friends for this.

What about your profession Kumaran.

My experience as a counselor has been really productive and is firm to the extent that i maintain a trustworthy and firm connect with my clients and some of them

have become close to me in my personal life too .

In case if I can't handle any specific case due to my physical limitations, I either take assistance of others around or refer the client to others. I have been working since 2012. Yet I have made my working procedure limited to "On calls " as of now till I complete my PH.D and make another place ready for work .



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AAC IN MY LIFE

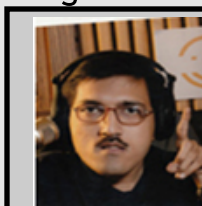
Augmentative and Alternative Communication, actually has made a huge difference in my life. For twenty-five years my life, I was a non-speaking person. I have a rare genetic disorder which has caused in limited Dopamine secretion, owing to this reason I could not speak, move or you can say, couldn't do anything. During that time I had to communicate to live my life with dignity. AAC was introduced to me when I was around 11 years old.

Thankfully my cognitive ability was like anyone else. During the early part of 1990s there were no other options rather than a 'system' which would be in English. Thus my English language development began. It is quite funny when I look back in time. My mother tongue is Bengali and when I was 11 I knew nothing other than it. Communicating in English was a far fetched idea. On top of that I was out of IICP for 5 to 6 years as my father as transferred out of Kolkata. Being a government servant he was in a place where hardly a few could speak English. (If this was Europe no one would have bothered on not knowing English). But here in India especially the cosmopolitan society, the colonial language is really a criterion for social status. Coming back to my life it was really difficult to learn a language only because I was losing my ability to speak. Gradually, with the help of a fantastic English teacher, who was actually a volunteer I could overcome the need.

Mrs. Maya Ghosh was the person who made it sure that I learnt the needful so that the communication system was introduced. Getting the aid, which was a simple communication board, I was not at all happy. I

thought it would stop my speech totally. It took lots of persuasion and counseling to convince me about the communication system enhancing my abilities. It took 6 or 7 years before I got convinced about AAC helping my life. There was a time in 1995 when I realized that the language I started to learn (English) and AAC have opened a new horizon in my life. I was introduced to computer as AAC for the first time. Even though, I could not use my fingers due to the disabilities but I was made to understand the 'there are always alternative, if you are flexible'. I started to use my tongue with a micro-light, along with a special word predicting software which made commutation easy.

To my readers I would like to tell that there is no harm in communicating more rather than doing it less. This experience comes with lots of harsh realities. When communicating your daily needs becomes a challenge for you, you want to find a way out so that you can at least eat, drink and sit comfortably in your wheelchair. As a person with disabilities, at times life becomes difficult more than people realize but they say life is not a bed of roses. During those days when surviving was a challenge for me, AAC came as heavenly blessing to pass me through the stormy part of my life. I do have many other incidents. Some of them funny, some of them ironic, some of them painful which I shall reveal with the upcoming articles in this magazine.



Sayomdeb Mukherjee is an actor, known for One Little Finger.

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Inclusive Work Force

Mrs Neera Chawla,
Director of Muskaan, an
NGO which strives to
empower adults with
disabilities, talks about their
employment programmes
and how they try to make
inclusion a reality.

What categories of disabilities does Muskaan work with? What are the programmes you offer?

We primarily work with adults who have intellectual disabilities and multiple disabilities. We have a few cases of Autism also.

We mostly have adult training programmes, which are ascertained according to the different degrees of support required by them. For individuals with high support needs, we have an Art and Activity centre. This programme gives them exposure to various art and craft activities, which act as therapy for them and through which they can express and empower themselves at various levels. If a person manages to gradually get over this high support need with adequate training, then she/he can go for vocational training.

For others, we have a vocational training programme which prepares one for employment inside Muskaan or even outside. There are usually 4 levels of vocational training. The 4th level, called employability training, prepares one for employment. We also have a computer training programme. We have a batch completing the course in Data Entry, which has also been made an integral part of our vocational training.

We conduct training programmes for life skills, sports and physical fitness, as well as therapy programmes for physiotherapy and occupational therapy. Our recreational activities include in-house activities like festival celebrations, fun games and visits to different places.

We have a residential facility at a different location, near Chattarpur. Eighteen young adults live there and are trained to do things on their own, which we consider a definite achievement in terms of the success of the programme.

Please tell us about your employment centre and the vocational training imparted.

We started the vocational training centre way back in 1989. At that time, we had no model to follow, in terms of training etc. We created our own training and supported work centre models.

The main idea behind the supported work centre was that they would work and earn also. We have realised that the importance of a work centre is two-fold: first, that the majority needs a supportive work centre. Secondly, the outside world is very challenging, and not everybody can meet those challenges, specially as the challenges also keep changing everyday. 15 - 20 percent can go out and work. The rest depend heavily on an internal employment centre, where they can work comfortably and get paid also.

The last four years have, of course, seen major breakthroughs in this sphere. Hospitality is the major sector which have employed the maximum persons with disabilities. From Muskaan, 28 placements have taken place, 4 in petrol pumps and the rest in hotels.

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Why do you think employment is important for people with disabilities? Can you give examples?

Any kind of work or service is important for any human being. Adulthood is the longest period of our life. If we do not have a meaningful engagement, if we cannot contribute to society, we tend to feel frustrated. It is exactly the same with people with disabilities. And more so, because they are capable of becoming contributing members of the society. They are usually very sincere workers who take a lot of pride in their work. Outside placements have proved that. One reason why companies are showing keenness to hire them is they are very focussed in whatever they do. The other reason is the low attrition rate. So the company feels it can retain them. When they were hired from Muskaan, companies came and observed how they worked in our supported work centre. And they found quality, sincerity and an overall happiness in the work. Which is why the companies decided to give them opportunities. This is wherein lies the importance of the supportive

work centres. Over time, we have seen how persons with disabilities have matured in their work places to become responsible employees. They value their work like anything. Some have even picked up sign language for the benefits of some of their colleagues, who are hearing impaired.

Do you have programmes tailored for each age group? Is there a particular age group that you specifically train for the employment sector?

We usually start at age 16, and for younger age groups, families are also provided counselling and guidance. For the employment sector, the ideal age group that we train is between 20 to 35 years. Below 20, we feel, they would be too young to handle the pressure.

And for the above 35 age group, a challenging environment often becomes difficult to tackle, which is why we do not like to stress this age group much. We also have designed some senior age programmes for those above 45 years.

How did you start with your employment programme?

In 1995, when our first batch

got ready for work, we started looking for employment opportunities but in vain. We had clarity that without providing meaningful work to our trained graduates, there is no meaning in continuing to churn out batches after batches. We decided to start our own work centre as we had confidence that they can work and contribute to the society. We chose consumable products which they could make and there was also market demand for these products. We continued searching and placing few students in outside world also but we realised that lack of awareness creates many challenges for them.



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Please share with us about the Lemon tree initiative? What adaptations did you need to do to equip people to be employable?

Lemon Tree put in intensive efforts to employ persons with disabilities. In fact, it is a part of their HR initiative. We start with sensitisation of their HODs, Managers, & Employees. Job mapping has to be done for each role and few adaptations within the role are to be made. We develop some adaptations/solutions so that our students can work there with minimum supervision. We provide the initial training to all those who are selected. We are also the partners for training them on the job. We are there on the premises to support them always. Plus, we have continuous reviews of how they cope with the situations. The sensitisation and re-sensitisation is a continuous process as employees keep on changing.

Are there other organisations that you work with? How has the experience been?

Yes, now we are working with Four Points, and also with the Carlson group. These

companies are also encouraging placements with us. We have, till date, worked with 5 Lemon Tree hotels, so naturally the experience with them has been more extensive. The others did not have so much clarity in their vision of employing persons with disabilities which had initially started off as a CSR activity. But we have seen that we need to have a continuous dialogue with the employers on equal rights etc., before the employer picks up the cues.

What reasonable accommodations do organisations need to make to employ people with intellectual disabilities?

The hospitality industry works in shifts and even petrol pumps have shifts. There are certain accommodations which these companies make for employing persons with disabilities. They are exempted from working on night shifts. All companies have agreed to that. But the number of working hours remains the same and the travel arrangements are usually made by the family. But we always tell the company that each job involves various tasks and t

that these employees should not be expected to perform every little chore. There will always be a few jobs which will remain outside their purview. For instance, they are likely to perform all the duties at a hotel coffee shop, except for taking orders, as communication with the guest might be a problem. The second thing they will, in all likelihood, have a problem with, is preparing the bill. Yet another problem they usually face at work places is scheduling or a long sequencing of tasks. To counter this, they have started a ME book, a pictorial sequencing of all the chores they are supposed to perform.



They usually follow that, so no one has to remind them of their duties. It is a spiral bound book, leading them towards independence.

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We do the pictorial sequencing for them, which they actually only need in the initial stages. The rest they pick up from visual cues in the environment.

What do you really understand by inclusiveness? How does Muskaan aim to continue with its programme? When we say inclusion, we mean inclusion in every situation in life. Inclusion as in also being the equal family member. *We need to have continuous dialogue with the company to treat the persons with disabilities as a regular employee.* We also try to ensure that they should be given work to do, and be considered employees in proper sense of the term. We urge the employers to employ them as equal members of their workforce, with equal salary and benefits.

This article was originally published at

www.patientsengage.com/

Tech Corner

Tactile screens for touch devices - RAY

Shared by

David Banes ,Access and Inclusion through Technology

I first met TACTUS in CES 2013 promising to provide "Application controlled, completely transparent physical buttons that rise up from the touch-screen surface on demand". The excitement in having such product available for blind and visually impaired people is obvious. It enables seamless integration of touch gestures available in smartphones and tablets with the ease of use of physical keys and tactile feedback. Working with blind users, we at Project Ray understand the value of it first-hand. Such technologies promise to eliminate a major barrier in blind users' adoption of touch-based devices and make digital accessibility possible.

Three years later and TACTUS is closer to ship its first commercial product, "Phorm" – a glass cover for the iPad mini that upon activation raises physical 'dots' in the shape of a keyboard – "World first morphing touchscreen".

True, this first product is a bit different from the initial promises. It requires physical activation when one knows that there is a keyboard on the screen, the dots are there for marking the different keys but not for actual pressing, the experience is limited for keyboard morphing, and availability is still a few months away. However, it is certainly a huge step in the right direction and a technology we are eager to have and use.

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