**Success & ABILITY**

India’s Cross-disability Magazine

July 2016

**Cover Feature**

**To Sign or Not to Sign**

The debate continues

**It MATTERS!**

**Let’s define INCLUSION**

**Rahul Bajaj**

The first Indian with visual

impairment to bag the

coveted Rhodes Scholarship

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WE’D REALLY LIKE TO HEAR FROM YOU

Whether you are a person with disability, or a parent or a friend or just someone who cares, we look forward to getting to know you and your concerns. You are just a [click](mailto:magazine@abilityfoundation.org) away! Do write to us at [magazine@abilityfoundation.org](mailto:magazine@abilityfoundation.org)

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**From the Editor’s Desk**

*Friends,*

*The cover of this issue may be a little perplexing to you. To sign or not to sign?! What kind of thinking is that? We ask you an open ended question here. We have two articles – both by authors who are deaf. And yet, with two totally different points of view. To use sign language or to mingle with the hearing world, trying to blend in and lip read and speak – however hard?*

*Personally, I have always wondered why we should talk in absolutes. Why do “experts” of “deaf education” look down on signing and insist on the oral mode of education? Why this false dichotomy between deaf people who use sign language and those who lip read and speak? Why are there two camps: the oral (the lip reading speakers) and the culturally Deaf (who only sign)? The oral ones might prefer to take on board the mainstream hearing society and augment their speech and listening skills, while the culturally Deaf choose to sign fluently and are damn proud of their vibrant language and culture (and rightly so). No matter what one’s mode of communication, the best form of education and life skills should be made available to all. One should not have to stand to lose out for any reason whatsoever.*

*And wait… there is also a lesser known third camp amongst deaf persons: the bread-is-butteredon-both-sides guys, the in-betweeners, the flip-floppers. They are the ones who use both speech and sign. They are equally at ease (or inept) in both the hearing and Deaf worlds. I think I’m one such person. And I know others like me too.*

*I honestly do not see the hearing and the deaf worlds, with their respective languages, as mutually exclusive. If someone speaks and cannot sign, I will speak with them because I’m interested in what they have to say. If someone signs, I will happily sign with them because I’m interested in what they have to say too. To communicate is paramount. The mode of communication is irrelevant. But… do read what Dr. Madan Vasishta and Angshu Jajodia have to say about this. Deaf people, like everyone else, live the same lives as anyone else, hold the same values, and lead the same lifestyles; their choices vary according to their needs. It is not a one size fits all aspect.*

*Freedom and choice are wonderful things, aren’t they?*

*You tell me.*

Jayshree Raveendran

NEWS & NOTES

**Researchers develop artificial nerve system**

This research work, reported in Science, is a step towards creating artificial skin for prosthetic limbs, to restore sensation to amputees and, perhaps, one day give robots some type of reflex capability. Stanford and Seoul National University researchers have developed an artificial sensory nerve system that can activate the twitch reflex in a cockroach and identify letters in the Braille alphabet. According to Zhenan Bao, a professor of chemical engineering and one of the senior authors, this artificial sensory nerve system is a step towards making skin-like sensory neural networks for all sorts of applications.

The paper describes how the researchers constructed an artificial sensory nerve circuit that could be embedded in a future skin-like covering for neuro-prosthetic devices and soft robotics. This rudimentary artificial nerve circuit integrates three previously described components. The first is a touch sensor that can detect even minuscule forces. This sensor sends signals through the second component – a flexible electronic neuron. Sensory signals from these components stimulate the third component, an artificial synaptic transistor modelled after human synapses. The synaptic transistor is the brainchild of Tae-Woo Lee of Seoul National University, who spent his sabbatical year in Bao’s Stanford lab to initiate the collaborative work. According to Lee, a second senior author on the paper, biological synapses can relay signals, and also store information to make simple decisions, and the synaptic transistor performs these functions in the artificial nerve circuit.

Source: news.stanford.edu

NEWS & NOTES

**“E-Dermis” to sense touch & pain**

A team of engineers at the Johns Hopkins University has created an electronic skin. When layered on top of prosthetic hands, this e-dermis brings back a real sense of touch through the fingertips. Made of fabric and rubber laced with sensors to mimic nerve endings, e-dermis recreates a sense of touch as well as pain by sensing stimuli and relaying the impulses back to the peripheral nerves.

The work – published in ‘Science Robotics’ – shows it is possible to restore a range of natural, touch-based feelings to amputees who use prosthetic limbs. The ability to detect pain could be useful, for instance, not only in prosthetic hands but also in lower limb prostheses, alerting the user to potential damage to the device. The research team includes members from Johns Hopkins’ departments of Biomedical Engineering, Electrical and Computer Engineering, and Neurology, and from the Singapore Institute of Neurotechnology.

The e-dermis conveys information to the amputee by stimulating peripheral nerves in the arm, making the so-called phantom limb come to life. The e-dermis device does this by electrically stimulating the amputee’s nerves in a non-invasive way, through the skin, according to the paper’s senior author, Nitish Thakor, a professor of biomedical engineering and director of the Neuroengineering and Biomedical Instrumentation Laboratory at Johns Hopkins.

Source: Johns Hopkins University

**ACCESSIBLE ELECTIONS: ECI SHOWS THE WAY**

The Election Commission of India (ECI) has launched a slew of measures for the maximum participation of persons with disabilities in the electoral process. At the conclusion of the two-day National Level Consultations on Accessible Elections organised by the ECI, the Chief Election Commissioner Om Prakash Rawat launched the distribution of Electoral Photo Identity Cards (EPIC) with Braille features for visually challenged voters.

The ECI has also decided to establish auxiliary polling stations for persons with disabilities during elections. Disability Coordinators would be appointed at the levels of Assembly Constituencies, Districts and States. A mobile app would be developed for persons with disabilities to facilitate their full participation in the electoral processes. The ECI would make available all its election related

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awareness materials in accessible formats. Photo voter slips would also be made in accessible formats for persons with disabilities. For the use of hearing impaired voters, sign language windows will be incorporated in all audio-visual training and awareness contents of ECI. A new unit called Accessible Division would be established in the ECI-run International Institute of Democracy and Electoral Management (IIDEM) in New Delhi. Accessibility Master Trainers would be employed to provide cascaded trainings for the welfare of persons with disabilities.

A follow up of the actions taken based on the recommendations made during the National Consultations on Accessible Elections is to take place in the next three months.

The deliberations held during the two-day consultation resulted in a comprehensive “Strategic Framework on Accessible Elections” to help make the electoral processes more accessible in the forthcoming State and Lok Sabha Elections. The Framework includes 14 important parameters like identification of barriers and respective solutions, voter registration and polling, inclusive voter education, leveraging technology for accessible elections, research and knowledge sharing, role of partner departments, educational institutions, CSOs, volunteers and media, training and sensitisation of staff, alternative voting methods, legislative initiatives and special four tiered committees on accessible elections.

ECI’s theme for the year 2018 is Accessible Elections.

Source: Press Information Bureau, Government of India

**STUDENTS DEVELOP REVOLUTIONARY WHEELCHAIR**

Led by their professor, Dr. Rajesh Kannan, three final-year B.Tech students of Coimbatore’s Amrita Vishwa Vidyapeetham – Chinta Ravi Teja, Sarath Sreekanth and Akhil Raj – have developed an inexpensive self-driving wheelchair that can safely take a user from one point to another by navigating its own path, avoiding obstacles on the way. Called Self-E, the revolutionary wheelchair uses a Robotic Operating System (ROS) for autonomous navigation. It creates a map of the surrounding space, along with static and dynamic obstacles, using a laser sensor and displays it through a smartphone app. The user can then touch any point on the generated map, and the wheelchair will drive to that place automatically without user intervention.

In contrast to imported self-driving wheelchairs which are quite expensive, cost of the Self-E prototype is below one lakh rupees. According to Dr. Rajesh Kannan Megalingam, Asst. Professor of Electronics and Communications and Director of Humanitarian Technology Lab at Amrita Vishwa Vidyapeetham, the Self-E self-driving wheelchair is the first self-driving wheelchair in India built by a research lab of a university without any collaboration with foreign universities or companies. The wheelchair is to be tested in different environments like hospitals and airports with patients and wheelchair users. The current version is a successful prototype and, with the help of Technology Business Incubator of Amrita Vishwa Vidyapeetham, the wheelchair would be commercialised.

Source: India Education Diary

COVER FEATURE

**To sign or not to sign**

**That's the**

**Question**

*The oral vs. sign debate has persisted for decades. SUCHITRA IYAPPA brings forth her thoughtful reflections on these two divergent and equally valuable perspectives – of DR. MADAN VASISHTA, researcher, writer and former teacher and administrator at various schools for the deaf in the U.S.A., and ANGSHU JAJODIA, researcher and teacher at Visva-Bharati University, Santiniketan – two dynamic deaf people and achievers in their own right – presenting their differing views on this.*

Over the years, there have been several opinions and studies on how to educate and communicate with the deaf and hard of hearing child. In fact, the oral vs. sign debate, or oralism vs. manualism, has persisted for decades, dating back to the 1880s during the 2nd International Congress on Education for the Deaf in Milan, Italy.

The oral method refers to the sole use of the spoken language, lip reading and voice training in communication. This method makes an attempt to enable the deaf child to overcome his deafness by learning to speak and to comprehend (whether from a hearing aid or lip reading, or both). Training begins at a young age. The children learn to hear with a hearing aid and to apply their voice to speech.

The oral method is recommended by hearing people who want children to abstain from sign language and interpreters. According to them, a child habituated to sign language will stop trying to lip read and speak. Therefore, hearing parents of deaf children prefer the oral method for communicating and teaching their child. But there is a downside to this method of communicating and educating.

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Oralism attempts to enable the hearing impaired to function normally in society, but unfortunately, it has resulted in making deaf people feel isolated as they struggle to communicate with their families and friends and a totally hearing society. Also, it takes tremendous patience, commitment, training and time before a child is able to lip read enough to understand conversations, and even tougher yet, to be understood when they speak.

The other approach, the manual method or manualism, is based totally on sign language and using the hands or physical ways to communicate. This method seeks to provide a way for the deaf to interact with others without the use of spoken language. Children taught using this method need not worry about learning to speak or develop lip reading skills. This method is considered the natural way that deaf children learn to communicate, instilling a feeling of fellowship amongst each other.

Sign language puts no pressure on a child to struggle to understand sounds and form words. However, this very reason can also act as a huge limitation. A child taught with this method will never be able to participate in a conversation with a hearing person without the assistance of an interpreter. The manual method tends to exclude hearing people from the deaf world and vice versa, and the only way to communicate is either by writing things down on paper or by learning to communicate through sign language. It is thus that hearing parents of deaf children may find this method of communication rather frustrating, as it demands that they learn sign language too to communicate with their child.

What then is the most effective approach to empower and educate a deaf child to face the world? With the changing face of technology, there are new methods on the anvil, a combination of them both. What is imperative is to ensure that the deaf are able to engage in a two way communication with the hearing world and face life with confidence. Yes, we in India have many more challenges to contend with – a paucity of interpreters and skilled sign teachers, multiple languages that pose a barrier to the lip reader and a nascent supporting infrastructure.

It is heartening to feature two very successful products of the oral and manual systems of deaf education, who share their thoughts and stories. Dr. Madan Vasishta communicates mainly through sign language while Angshu Jajodia lip reads and speaks. Their lives testify to the inherent merits of both approaches as they present their case in their distinctive, articulate styles.

Read on…

**What is full inclusion for deaf children? DR. MADAN VASISHTA**

The term ‘full inclusion’ was coined in the United States of America in the late 1980s. It was introduced by parents who were unhappy with the implementation of the Least Restricted Environment (LRE) mandate of the law (Individuals with Disabilities Act). They felt that LRE was not implemented completely and their children were only partially mainstreamed or included in general education classes. They wanted their children to be ‘fully included’ and the term was thus coined.

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‘Full inclusion’ is not a law; it is a philosophy. Another term for it is ‘inclusive education’. A disabled child, according to this philosophy, should be involved in all educational and affective domain activities equally with his non-disabled peers. Under this philosophy, there is no room for “Oh, he cannot do this, therefore, he can sit this activity out”. Thus, this term is great and attractive.

Politicians and educators who live in ivory towers picked it up fast and began to push for it without understanding what it really means. After an initial euphoria in the United States, it was used sparingly. However, in India it became a mantra for politicians and ivory-towered advocates. “I hate special education” and “segregated schools should be burned” became the slogans. “We must have inclusive education for all children” was pushed as an agenda without defining the term.

Before we go further, we need to remember that no two disabilities are alike. Children with mental, visual, hearing and physical disabilities have different needs. A child with a physical disability can be fully included in a regular classroom because he can see, hear and think like other children. He cannot join regular football, but can have physical activities according to his ability. He can be included if there are ramps and if he has technological support for writing, if needed.

A blind child can also be included in a regular classroom; however, we have to make sure that everything the teacher writes on the blackboard is simultaneously transcribed into Braille text – not after the class. We have to make sure that the blind child has access to a Braille machine to “write” when other students are given written assignments.

Children with mental and emotional problems can be included with support from counsellors and psychologists. The teachers must be given training in teaching children with those disabilities, so that she can provide the support that these children need.

The situation for deaf children is VERY different. Deafness causes communication problems. A deaf child’s inclusion in a classroom depends on his expressive and receptive communication skills. If a deaf child can speak perfectly and hear well enough to understand his teacher and classmates without any help – both in small and large groups – then, that deaf child can be fully included in that classroom. Many children with cochlear implants and extensive speech and audiological therapy can, and are included in regular classrooms.

A deaf child who has good speech and can communicate effectively individually can participate in a classroom when he is in a one-on-one situation. However, if he

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cannot follow group discussions and understand the teacher, then he is, at best, partially included. Do we want our children to be partially included?

For the majority of deaf children who cannot speak clearly and cannot lip-read or hear even with the help of hearing aids, being in a general education classroom is only physical inclusion. They may be physically included in that classroom. Educationally, they are not fully or even partially included.

Having an interpreter in the classroom will alleviate the situation a little bit. The child will understand what the teacher is saying and express himself through the interpreter. However, it will depend on how skilled the interpreter is. In India, based on my observations, we may have at most 50 interpreters who can do the job satisfactorily. We need a million trained interpreters to meet the needs of deaf children in mainstream settings. Even with a skilled interpreter, a deaf child is only partially included. Children learn from each other. A lot happens between classes. The interpreter will not be there all the time with the child.

A deaf child will be fully included only if the teacher is a fluent signer and the students with hearing too can sign fluently. Deafness is a communicational disability and as long as the barrier of communication is not removed, a deaf child cannot be included – partially or fully.

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As a parent, it is imperative that you make sure your child gets the best education that is possible. You need to look at your child’s strengths as well as weaknesses. You need to realise that your deaf child is different from other deaf children. In order to make sure that your child is included in a real sense, you have to ensure he can understand what his teachers and classmates are saying, and that his teachers and classmates understand him.

Full inclusion is not just being physically placed in a general classroom; it is much more than that. If your child does not have a full two-way communication, then he is actually ‘fully excluded’.

**What exactly is “Deaf Identity”? Angshu Jajodia**

“We are born naked, wet and hungry. Then things get worse.” – Anonymous

I read this quote a few years ago, and it made a very powerful impression on me because it embodies the sacrosanct role of a mother in any child’s life. When a baby is born, it is the most vulnerable creature on the planet. In this extremely vulnerable state, the mother emerges as the protector, provider and primary figure in the child’s life. For the child with hearing impairment, the role of the mother becomes even more pronounced because she is probably the only person who will be able to instinctively understand and communicate with her child. Instinctive communication does not require any language.

When I was very small and the world was a threatening melee of unknown dangers and people around, my mother was the only person with whom I could communicate seamlessly about my needs and she would instinctively understand what I wanted to say, even though I didn’t hear and speak.

It would not be an exaggeration for me to say that my mother was the window through which I saw the world during my early childhood.

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If someone were to ask me what the turning point in my life was, I would attest to just one incident that changed the course of my life completely. It occurred 25 years ago, in the spring of 1992, when my mother walked into the chambers of a highly acclaimed audiologist at one of the top medical institutes in India. She had just one question for the audiologist: “Will my child be able to talk?” The audiologist asked her, “What do you want from your child?” “I want him to talk to me, play with me, fight with me and do everything that any other child does!” my mother said. The audiologist decided to give my mother a reality check. In his opinion, these were out-of-the-world fantasies for a parent of a deaf child. He said, “Remember, your child is deaf. If he can say *Ma Baba* at the age of 15, consider yourself a lucky mother”.

Well, it has been a long two decades since that ‘reality check’. I learnt to talk, I went through college, then university, and I’ve had a truly fulfilling life in general. And in 2014 came the watershed moment in my life and the lives of my parents. Having enrolled at Visva-Bharati University for a Ph.D. as a Junior Research Fellow, I started teaching Masters level students at the university. I was not supposed to speak, and here I was, poised to make a living from speaking and teaching. Irony strikes with the force of a cartoon anvil, indeed.

We all have heard the famous quote: “The hand that rocks the cradle rules the world.” My mother was truly my guiding light and I am thankful to her for giving me the present that I have now. I believe that if my parents hadn’t taught me to speak, I wouldn’t have been able to reach where I am today. I doubt if I would have had the same opportunities that I have now if I used sign language as a major means of communication. By no means am I denigrating sign language communication, but the fact remains that in a country like India, it is difficult for sign language communicators to integrate fully in the mainstream where the resources required for complete inclusion of the deaf are scant. For instance, I wouldn’t have been able to go to university in India, because as far as my knowledge goes, there is no university in our country as yet that uses sign language as a medium of instruction.

Sign language and oral communication for deaf people are two different choices. The decision to choose which to go for will depend on the circumstances and environment of the person in question.

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My mother, who is a professor of economics and currently the principal of a girls’ college in West Bengal, wrote this small piece to share her thoughts on why she chose to teach me to talk rather than use sign language as a major means of communication.

“The other day I was being quizzed by a knowledgeable person in the field as to why I opted for the oral rehabilitation route for my deaf child. Why did I invest such effort to ‘mainstream’ my deaf child? The quizzing bordered on heckling, with this person insisting that I had done a great disservice to the world of the DEAF, that I had taken away my deaf child’s IDENTITY.

My first rejoinder: who defines an IDENTITY? Is it beyond an individual’s right to carve his/her own identity or must all conform to a clichéd, stereotyped identity? Is such conformation really necessary for any person? Perhaps it is more required so that those who make a living from this maintenance of ‘identity’ can continue to thrive.

My second rejoinder: in a civilised, progressive, open-minded society, each individual should be really and truly free to make choices. Then who am I, as a parent to determine the choices my child will make in future? The problem with oral language learning is that the foundation for it must be laid within the first half-decade of a human’s life. The choice to use it or not can be made much later in life. My father, who remained a perfectly ‘hearing’ person till his end, was generally a silent man. For us, his silence spoke volumes, and his few words carried so much weight with us. Without any overt imposition of his likes or dislikes, we just adhered to his preferences. Such was his genial personality!

If, as an adult, my son wants to toe the line of the “deaf identity” as defined, he can do so on the basis of informed choices; choices he has been given the opportunity to evaluate over his growing years.

The option remains with him to throw away his hearing aids and keep his mouth shut, and *voila*! He enters his DEAF identity. But if he had not been given the opportunity to learn the oral language, try as he might, he wouldn’t be a speaking adult”.

This goes on to show that the choices we make must be made in the context of an environment, and not just to suit the rhythms of disability politics or ideals we may hold dear.

**End of Article**

TRAILBLAZER

**MATTER OF HONOUR**

**“Friendly, sometimes funny, would-be lawyer, introspective, a bit**

**Silly, visually impaired, bibliophile, procrastinator and believed to**

**Be human.”**

**Yashasvini Rajeshwar**

Thus reads Rahul Bajaj’s Twitter profile, an appropriate list of qualifiers for this multi-faceted and incredibly articulate twenty-four-year-old. What it does not say, however, is that he is a practiced public speaker, a citizen of the world who thinks deeply and feels strongly for the state of affairs around him, and does not shy away from a good conversation. Rahul Bajaj is a man of many

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hats, and every conversation with him leaves one with the satisfaction of a well-brewed, deeply steeped thought.

Born and raised in Nagpur at a time when accessibility and the dialogue around disability were not yet as mainstreamed, the resilience and grit that would come to define his trajectory over the next many years became the garb of everyday life. Trial and error became a lifestyle that got adopted naturally in small-town India in the 1990s. Every day was an effort to “play catch-up even if I never quite got there”. Bajaj had no choice but to pave his own path.

It is this matter-of-fact attitude that comes forth when you ask Bajaj for stories from his childhood. He speaks of the difficulties of schooling, of not being meaningfully socialised and losing out on the opportunity to participate in recreational activities. He talks about the limitations of his teachers, their inability to integrate him into the classroom, and their difficulty in adapting visual cues. He talks of a time when disability was not as mainstreamed, when the worth of persons with disability was still questioned. “I had more time on my hands because I did not have a social life. Between that and the fact that the scope to succeed is limited, you do the best you can. You must learn to compensate for the disability, and this feeds a zeal for independence.” It was this zeal that pushed Bajaj to dream of being a lawyer. Recognising that the biggest names in the country did not have the facilities to accommodate his needs, he chose to study from home in Nagpur. In the next few years, he graduated from Nagpur University as the topper of his batch, and bagged twenty awards while he was at it. He interned at the Delhi High Court as well as with a judge in the Supreme Court, worked as a litigator for one of the biggest law firms in the country, and blogged extensively about lawyers with disability. He sought out knowledge with a vengeance, recognised his passion for intellectual property and constitutional law, and made sure he chased down every opportunity that came his way.

When someone suggested he apply to the famed Rhodes scholarship (to study at Oxford, given only to five Indians a year), he decided to give it a shot even though applications in the field were traditionally the strongholds of the premier law schools in the country. In 2018, Rahul Bajaj became the first visually impaired person to be awarded the Rhodes Scholarship.

“The Rhodes came as a powerful reaffirmation of my capability for intellectual rigour and an acknowledgement of a well-rounded personality”,

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says Bajaj. “Their selection criteria involves things like ‘the ability to use energy to the fullest’, ‘courage and devotion to duty’ and ‘moral force of character’, apart from leadership skill and scholastic achievements. When I applied, I just tried to show them the odds I was facing and that I did the best I could in the circumstances.”

It was a story that caught Oxford’s eye and kicked up a media storm back home. Reactions have been many and support has poured in, but Bajaj has two bones to pick. “There are some who say disability is just like someone’s hair colour or height or such, that my achievement has nothing to do with my disability. I don’t agree. I have less than 5% vision. It puts me behind someone who has all five senses. It did mean I had to put in more effort to do some things. But there is also the second reaction, with some headlines talking only about my blindness to the exclusion of all my other identities. My competence should not play second fiddle to my disability. That is not fair either.”

As he gets ready to set off for Oxford, Bajaj’s wish list is clear. Lawyers with disability should have accessible legal material and physical spaces, an accepting professional environment, and the same opportunities to represent clients and get the job done. Change must be two-fold, attitudinal and infrastructural.

Ask him what he thinks his scholarship is doing for the community, and Bajaj’s response is the characteristic balance of worldliness and self awareness. “For a scholarship famous for its assumed focus on physical vigour and sports, hopefully it shows that persons with disability are on an equal footing. It would be presumptuous of me to assume that it will cause a paradigm shift, but it is yet another glass ceiling broken.”

When author and psychiatrist Victor Frankl said the last freedom of a man is only his ability to respond to a given set of circumstances, little did he know that many years later, a young man in India would take his words and redefine them, following them in spirit to the last letter.

Rahul Bajaj is a visually impaired bibliophile lawyer with a determination and clarity of thought far beyond his years. If his response to circumstances so far is anything to go by, the folks at Oxford are not going to know what hit them.

**End of Article**

POLICY

**GETTING EXPLICIT**

**LET’S DEFINE INCLUSION**

*Individuals and programmes define inclusion very differently, which leaves much room for interpretation and its subsequent implementation. So there is a need to arrive at a nationally validated position on inclusion, writes Camille Catlett, Scientist Emerita, University of North Carolina. As a member of United States’ National Professional Development Center on Inclusion’s work group, she played a key role in developing the U.S. definition of inclusion.*

Several years ago, I visited a programme for young children and asked the director what I thought was a simple question: Is this an inclusive programme? “Why yes,” she said. She then took me to a classroom at the end of the building where all the children with disabilities in the programme were made to spend the day. “Here is our inclusion classroom”, she said.

Not for the first time, I realised that individuals and programmes define inclusion very differently, which leaves much room for interpretation. Is inclusion a place? Or is it a construct that is applied in home, programme and community settings? In inclusive programmes serving young children with disabilities, does inclusion mean learning and developing with peers throughout the day? Or might it be enough for the children with disabilities to drop in for art, music, or meals? And whose job is it to orchestrate quality inclusive experiences – Classroom teachers? Special educators? Administrators? Families? All of the above?

These and other questions drove an effort in the U.S. to craft a nationally validated position statement on inclusion that provides a specific definition. The effort was coordinated by a federally funded project with a mission to build systemic opportunities for inclusion, the National Professional Development Center on Inclusion (NPDCI). By design, the consistent partners in every step of the process were the National Association for the Education of Young Children (NAEYC), the largest U.S. member organisation in the early childhood field, and the Division for

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Early Childhood of the Council for Exceptional Children (DEC), the largest U.S. member organisation in the early childhood special education field. NPDCI’s decision to work with both organisations was cunning and strategic. By getting both organisations to craft the document, they anchored the responsibility for the inclusion of children with disabilities on both early childhood teachers and early childhood specialists.

The process of creating the definition took over a year and unfolded through a series of carefully choreographed steps that sought and obtained input from a wide array of consumers within the early childhood and early childhood special education fields (e.g., teachers, practitioners, families, faculty and professional development providers, administrators, specialists, researchers, policy makers). Table 1 summarises the steps that were taken in the development and validation of a joint position statement.

The definition of inclusion, which appears on page 3 of the joint position statement, addresses the questions raised in the opening paragraph of this article.

Early childhood inclusion embodies the values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society. The desired results of inclusive experiences for children with and without disabilities and their families include a sense of belonging and membership, positive social relationships and friendships, and development and learning to reach their full potential. The defining features of inclusion that can be used to identify high quality early childhood programmes and services are access, participation, and supports.

This definition reminds us that access is essential – access to the physical space, to the learning, and to the other children who can be both role models and friends. The definition underscores the importance of the full participation of children with disabilities, in learning, work, and play. As Vernã Myers said in her TED talk, “Diversity is being asked to the party; inclusion is being asked to dance”. The definition also acknowledges the systemic supports that are essential for quality inclusion. Among others, these include professional development for teachers, specialists, and families, as well as time to collaborate in the development, implementation, evaluation, and monitoring of individualised plans.

POLICY

**Table 1: Steps in the Development and Validation of a Joint Position Statement**

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| --- | --- |
| 1 | Input from the field was obtained through “listening sessions” at national conferences. |
| 2 | A Joint DEC-NAEYC work group was established with four of the eight members nominated by each organisation. |
| 3 | An NPDCI work group drafted a joint position statement, based on a review of the literature, including existing definitions and position statements. |
| 4 | The joint DEC-NAEYC work group reviewed the draft joint position statement and provided written feedback. |
| 5 | The NPDCI work group revised the draft position statement, then sent it to the DEC and NAEYC governance boards for input. |
| 6 | The NPDCI work group revised the draft for national validation. The draft was posted on a public website and broad, diverse, early childhood and early childhood special education audiences, including family members, were invited to review the draft joint position statement, rate its quality and acceptability, vote on whether to endorse it, and provide written comments. This yielded 753 responses. |
| 7 | Responses were analysed by the NPDCI work group and a final draft created. The final draft was submitted to the DEC and NAEYC governance boards for approval. |
| 8 | Both governance boards approved the final draft in April 2009 |

As someone who served as a member of the NPDCI work group, I am privy to some of the “behind the scenes” stories that were part of the national validation effort. Here’s my favorite. When the definition of inclusion went out for national validation, the second sentence read as follows: The desired results of inclusive experiences for children with disabilities and their families include a sense of belonging and membership, positive social relationships and friendships, and development and learning to reach their full potential. In the feedback, many comments underscored that these opportunities – a sense of belonging and membership, positive social relationships and friendships, and development – should be an essential part of what children with and without disabilities experience. And so, the language was changed to reflect that feedback.

After the joint position statement was completed, the next priority was making it widely available, by sharing the document in multiple languages and formats (large print, audio), sharing the story of its development and validation, and providing a set of PowerPoint slides that leaders and instructors could use to share information about the document. And so a “landing pad” was created to allow everyone, from families and teachers to therapists and policymakers, with a single location over which they could hover and select resources of interest. The “landing pad” features the full position statement and a two-page summary of the document, as well as a video, ‘Foundations of Inclusion Birth to Five’, which was created to share key concepts of the document (<http://npdci.fpg.unc.edu/resources/articles/Early_Childhood_Inclusion>).

POLICY

In the time since the position statement first appeared, it has become apparent that there are tremendous benefits to having a document that underscores the shared responsibilities of teachers, therapists, families, and administrators to support the full participation of each and every child. With each reading, it reminds us that all children are our children, and that colleagues across early childhood, child development, early childhood special education, and early intervention, in concert with families, are responsible for supporting any child in achieving his or her full potential.

And the definition of inclusion has helped all early childhood colleagues in the U.S. to understand that in the classroom, in the lunch room, on the playground, at home, and in communities, inclusion is not a place but is rather a shared understanding of our commitments to provide access to learning, opportunities for full participation, and systemic supports that will help each and every child to join in the learning and the play.

Shortly after the publication of the U.S. definition of inclusion, Early Childhood Australia (ECA) collaborated with Early Childhood Intervention Australia (ECIA) to produce a joint statement on the inclusion of children with disability in early childhood education and care (http://www.earlychildhoodaustralia.org.au/wp-content/uploads/2014/06/ECA\_Position\_statement\_Disability\_Inclusion\_web.pdf), following the model created by the U.S.

Perhaps, sharing this story will pave the way for other regions and countries to take action towards defining inclusion and taking the first bold step toward making quality inclusion a reality for each and every child.

**End of Article**

BOOK REVIEW

**BOOK REVIEW**

**Author: Utpal kant Mishra**

**No. of Pages: 257**

**Price: Rs. 349**

**Publishers: The Write Place**

With characters and settings that every reader can relate to, conversations worth having, and encompassing both hits and misses, ‘T21 in Downs Lane’ is best looked at as a resource guide to understanding Down’s syndrome, surmises YASHASVINI RAJESHWAR.

Utpal Kant Mishra’s ‘T21 in Downs Lane’ is a story of friendship and discovery of new worlds. It narrates the journey of Aashima, a journalist, who befriends Jay after he becomes a social media star. Jay has Down’s syndrome and recently completed his graduation, an achievement that not only catches the eye of the local press, but also brings into his life his first friend, Aashima. Through the 200 odd pages of the book, the story not only reveals how their friendship blossoms but also the background behind Jay’s birth – when his parents come to know of the diagnosis and their turmoil in coming to terms with it.

One of the most endearing aspects of Mishra’s story is how realistic it is. The characters, the setting, the smaller details that make up everyday life are all those that every reader can relate to. Jay lives in a house that always has crunchies and munchies ready for an unexpected visitor, and his solution to any difficult moment lies in the kitchen. His single mother Ayesha is painted in alternative colours of resilience and fatigue, and her character gradually ages through the narration of Jay’s story. Social media likes and comments initiate many conversations, and one can almost

BOOK REVIEW

visualise Jay compulsively refreshing his page after uploading a new video. All in all, the environment and the pictures it evokes are comforting in how relatable they are.

Throughout the course of the plot, Mishra has touched upon many conversations that are worth having. Early on in the narrative, Ayesha talks of how persons with disability are either put on a pedestal or seen as a burden to the family, hinting at the importance of mainstreaming disability. In a conversation with Aashima, the two discuss the debate on the right to life for foetuses with a disability, and the back story shows Ayesha taking a forceful stand to save her baby’s life even as others seem unsure. Later on in the story, there is a commentary on how many organisations catering to disability see the category as homogenous, a characterisation that is not just false but also does no favours to those it seeks to cater to. Time and again, Mishra finds the space to sneak in important questions surrounding disability into the narrative.

There are, however, some aspects of writing that seem to take away from Mishra’s goal of building awareness. In the book, Mishra’s doctors often use terms like “that kind of child” to refer to the unborn Jay. Jay himself repeatedly identifies with his disability, and there is regular mention of the word ‘retard’. In a world where there is shared consensus on the role of language to mainstream ideologies, this choice of words does not do justice to Mishra’s otherwise sensitive intent. It does not seem congruous to repeatedly reinforce language that has been universally agreed upon as insensitive, demeaning and plain incorrect. The repeated equation of Jay with his disability seems contradictory to Mishra’s aim of painting those with Down’s syndrome as complete personalities. When there is so much more to him (he cooks, he plays the piano, he is generous with his hugs), why would Jay introduce himself time and again with “I am a Trisomy 21”? As a writer, one would expect Mishra to be more responsible with his characterisation.

At its core, Mishra’s book is best looked at as a resource guide to understand Down’s syndrome. Well researched and documented, the book also includes a comprehensive FAQ section and a health checklist. Within the plot as well, there are regular references to the science behind Down’s syndrome, showing how thoroughly Mishra has done his homework. Though the literary aspects of the story are marred by poor editing and numerous errors of language, one ends ‘T21 in Downs Lane’ with a feeling of having peeked through the window of someone’s life and come away with an understanding of the medical condition and its associated social implications. Jay’s life can be a guidebook to Down’s syndrome, if ever such generalisation was possible. With better editing, it could make for a powerful story.

**End of Article**

POETRY

**In the Sanctuary of a Poem**

**Salil Chaturvedi**

|  |  |
| --- | --- |
| **the ants on my floor**  If only we could live  like the ants on my floor  toiling as they do  without an audible cry  kissing each other  as we pass by.  **the grave of two friends**  It’s an awfully  large tombstone  for a tree so small  and the little bird’s call  so big  this mall. | **In a dream I had about half**  a year ago  I was licking myself  all over like a cat. There were  crocodiles sunning themselves  on the banks of a river. It was clear  that they were all poets  out hunting for images  to drag them into the deep  of language. I told them all to  bugger off. I told them to stop  writing poems  and to start growing flowers  and while I had their ear  I quickly slipped in that  we are all equal  in our sleep and that all  the joy in the world  pours forth from forests  in the cool of the night. |

‘In the Sanctuary of a Poem’, is a compilation of poems published in 2017 by Salil Chaturvedi, award winning writer and multi-faceted personality.

**End of Article**

LAST PAGE

**Quote – Unquote**

If you want to shine like a sun, first burn like a sun.

Dr. A. P. J. Abdul Kalam

I am just a child who has never grown up. I still keep asking these ‘how’ and ‘why’ questions. Occasionally, I find an answer.

Stephen Hawking

I would rather have questions that can’t be answered than answers that can't be questioned.

Richard Feynman

Life is far beyond meaning, and that’s why it is so beautiful.

Jaggi Vasudev

It’s one thing to learn about the past; it’s another to wallow in it.

Kenneth Auchincloss

Often the best way to win is to forget to keep score.

Marianne Espinosa Murphy

I believe in giving more than 100% on the field, and I don't really worry about the result if there's great commitment on the field. That's victory for me.

Mahendra Singh Dhoni

While an original is always hard to find, he is easy to recognise.

John Mason

The Olympics is where heroes are made. The Paralympics is where heroes come.

Joey Reiman

Disability is a matter of perception. If you can do just one thing well, you’re needed by someone.

Martina Navratilova

-End of Article-

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