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# BREAKING COMMUNICATION BARRIERS IN THE CLASSROOM FOR CHILDREN WITH CEREBRAL PALSY

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*"Just because I can't speak, they feel I can't think"*

## *INTRODUCTION*

### *OBJECTIVE*

*The objective of this paper is to discuss issues relating to the augmentative and alternative means of communication for children with cerebral palsy. Application of technology, especially low-cost technology, is the primary focus. Although we have made a beginning, we haven't really gone onto the computer and higher technology yet. The main question is, how do we use available low cost technology in breaking barriers for children to pass public examinations and to mainstream them into universities or open employment?*

## *A PURPOSE*

*What I will attempt to do is to show how 'communication' must have a purpose. It cannot only be used for social interaction per se. I have been working in the area of special education for the last twenty years and at our centres, we have used non-verbal communication not only for social, emotional and psychological reasons, but rather to help children advance in the academic and educational fields with a given officially recognised syllabus..*

***It has been communication with an holistic approach and with definitive goals and objectives. The main purpose has been mainstreaming people with communication disorders into the challenging, demanding, normal world, away from the sheltered environment of a special school.***

## *DEFINITION*

*Cerebral palsy is caused by a brain lesion which is non-progressive, non-curable and leads to impairment of functions in various areas. It presents a series of problems far more complicated than those typical of most other types of physical disabilities.*

*According to Perltein (1949), " Cerebral palsy is a condition characterised by paralysis, weakness, inco-ordination or any other aberration of motor function due to pathology of the motor control centres of the brain".*

*According to Dr. Grace Woods, "The movement handicaps divide themselves fairly distinctly into different types with varying aetiology, movement defects and different degrees of additional handicaps".*

*Cerebral Palsy presents as a multiple disorder, resulting from brain damage causing imbalance and inco-ordination. While the main characteristic is a disorder of movement and posture, there are a variety of associated problems concerned with mobility, manipulation, speech, communication, hearing, sight, intellectual retardation and epilepsy. This paper focuses on breaking barriers created by communication problems.*

## *INTELLIGENCE LEVEL*

*Historically, it was commonly assumed until about the 1930's that cerebral palsy was always associated with severe mental defect -that brain damage was widespread and bound to impair the intellect as well as the motor areas of the brain. We now know that this assumption was incorrect.*

*The earlier assumptions about the low mental levels of cerebral palsied children and adults were based on observations of largely untreated and uneducated cases. Such treatment and education was largely unknown until the 1940's. Now it is considered unwise to infer mental status from the degree of motor disability, as it has been found that some severely motor handicapped children have an extremely high intelligence and some mildly motor*

*handicapped children have very limited intelligence.*

*There have been a number of research surveys done showing the distribution of intelligence levels among children with cerebral palsy. Most surveys report a figure of between forty and fifty percent of cerebral palsied children being of subnormal intelligence, 25% being* ***severe*** *with an IQ of 20-54, 25% being* ***moderate*** *between 55-69. The other 50% are divided thus: 25% are in the* ***dull normal*** *IQ range of 70-99, with 25% having* ***average or above-average*** *intelligence, 100-120. In the last group,* ***6%*** *of children with cerebral palsy come into the* ***above-average*** *grouping.*

***Therefore, we have the oft-quoted phrase, "An intelligent mind trapped in a disobedient body or "a mind that works but a body that doesn't".***

***COMMUNICATION AND WHAT IT MEANS***

*Before we begin to consider the different ways of providing communication for the non-verbal child or the child with severe speech problems, it is important to bear in mind what we mean by "communication".*

*"Communication" is the means we use for social interaction, which is essential for personal development. Communication means the conveying of desires, feelings and ideas from one person to another through the use of symbols. It is upon our ability to communicate with others, that most of our happiness and competence as human*

*beings depends. Language is a structured concept of symbols. Speech or talking is the mechanism we use, but it is only one aspect of the whole complex process by which human beings communicate with each other. These disorders in communication in children have received considerable attention. It is now a well-proven fact that a child who lacks the ability to communicate will suffer from total isolation and rejection. In cerebral palsy, of all the problems of severe handicap those of communication are the most serious. A child with a communication problem is condemned to emotional solitude, an intellectual silence too distressing to imagine and the prospect of remaining crippled in mind and personality.*

## *COMMUNICATION DAMAGE IN CEREBRAL PALSY*

*There are children with cerebral palsy who are extremely intelligent but unable to give a feedback. Both their abilities of speech and hand function are damaged, preventing them from using traditional means of communication with a pen or pencil for writing, or speaking, causing major academic barriers in a classroom. One of the urgent tasks before a teacher and a speech therapist is how to get the outside world to understand the speech disorders of a cerebral palsied child. The traditional means of recording work, getting an output or feedback, or regurgitation of knowledge imparted, becomes impossible.*

*The critical problem in the classroom is how does one develop the intellect of a severely spastic child with little*

*speech and very little hand control amongst other problems? How is he or she to get through to the world around that he or she is capable of thinking. How does one establish a feedback and a system of recording his answers?*

## *EARLY IDENTIFICATION*

*We should begin as early as possible. Visual contact, attending, focusing and visual scanning are all necessary tools for communication. Therefore, we would first of all begin with engaging him or her visually and training visual acuity, so that later, visual problems do not come in the way of reading or 'saccadic' vision.*

## *RECEPTIVE LANGUAGE*

*It is important to remember that even if these children do not speak, they are receiving language and many will be able to comprehend.*

*From the age of two and a half years, symbolic play develops. A great deal of rich linguistic experience for building up receptive language should also be initiated. The variety of handicaps in a school for cerebral palsied children means that several different systems of communication need to be taught and at different levels. These in the early infant years may include gestures, mime, sign language, or perhaps a combination of all.*

*The main objectives of the early years therefore should be:*

- *To build up visual skills;*
- *To increase powers of listening, concentrating and attention span;*
- *To have a systematic build up of vocabulary through pretend or imitative play, rich linguistic experiences, using story telling, dramatics, mime and variety of aids;*
- *To develop speech and/or other levels of communication.*

*A good home management programme with parents' involvement should be simultaneously set up and this, together with a rich primary school experience, can usually help the children enormously at four or five years of age to move onto formal learning.*

## *NON-VERBAL COMMUNICATION RELATED TO ACADEMIC FEEDBACK*

*As mentioned earlier, the main tools of communication (i.e. speech and writing) affecting educational progress may be damaged. Non-verbal communication with a variety of aids will have to be substituted. Fortunately, over the years, a wide range of mechanical and electronic aids have been developed.*

***INEXPENSIVE TECHNOLOGY TO BREAK BARRIERS IN THE CLASSROOM WOULD BE:***

- ***Communication Boards and Picture Boards***
  *Individual and tailor-made communication boards and picture boards for simple recognition of common objects etc. and discrimination exercises in the early years.*

- ***Flash Cards or Magnetised Numbers, Letters, and Words***
  *The simplest and cheapest aids are letter or word boards and flash cards which we use extensively for reading, number, construction of sentences and grammar where a child simply touches, points or looks at the right answer to a question.*

- ***Rubber Stamps***
  *A very cost effective aid used for solving arithmetical problems is the rubber stamp which can be used easily by a student with severe speech problems and unable to write, to answer arithmetical problems in his exercise book.*

- ***Bliss Charts***
  *These charts use a system of symbols for words and all the different parts of speech. Children communicating through Bliss symbols have boards catering to their own needs and level of ability. It is*

*necessary only to point at the appropriate symbol or symbols to communicate through single words or sentences.*

- ***Rotary Pointer***
  *Electronically-operated boards such as the Rotary Pointer are available. With these, the child merely touches a micro switch or panel (with micro-switch beneath) either with his foot, hand or elbow to do simple matching and discriminating tasks.*

- ***Meldreth A4 Touch Tutor***
  *A low cost teaching aid, designed by Malcolm Jones at Meldreth Manor School, Cambridge, using inexpensive home-made programmes for perceptual or visuo-spatial discrimination in matching pictures, numbers, shapes, alphabets to test comprehension.*

- ***Language Master***
  *This is really a tape recorder with a quick feedback used for higher level students with problems of speech and comprehension.*

- ***Typewriters***
  *After the age of seven or eight, we would move children onto more adult forms of communication aids such as typewriters. There are various kinds - manual, electric, and electronic - which can be fitted with key guards if necessary, to prevent the child's*

*finger slipping from one key to another.*

- ***Expanded Keyboard***
  *This is the largest keyboard which can be attached to any electronic typewriter. We have used it for a very severe athetoid who is now in college.*

- ***Canon Communicator***
  *It is the smallest "typewriter" in the world, produced by the Japanese. It is portable and can be fixed onto a wrist or a wheelchair. It provides a print-out on thermo-sensitive paper.*

  *Vipasha Mehta, who is very severely disabled with serious speech/communication problems uses a Canon to communicate her needs. She uses it in lecture halls, in the libraries, in the canteen, whenever someone cannot understand her. Through these means of communication, we would record formal work according to an official syllabus and lead children onto public exams. Vipasha passed her S.S.C. with 74.14 percent.*

***FORMAL COMMUNICATION IN PUBLIC EXAMS:***

***Public examination systems in India still have a very antiquated mode of testing students. Just like those with no disabilities, our students are required to write through the long, narrative essay-type of answers. We***

***are struggling to change this format with the University authorities, but there is still a long way to go, especially as Vice-Chancellors are asking whether it is necessary for the disabled to do their degree.***

*The examinations we have so far attempted are the School-Leaving Certificate Examination, the Higher Secondary Examination and the Bachelor and Master of Arts Examinations. They have been long and ardous - each examination taking 4-6 hours. For communication, we have used* ***emmanuencies or writers****, as it is impossible for children with communication disorders to speak for so long. Results have been excellent.*

*At the sixteenth World Conference for the Disabled, John Busby of the British Computer Society said that the computer after the wheelchair has revolutionised the life of the disabled person.*

*Developments in electronic and computer technologies have dynamically changed the scenario with regard to the 'communication' needs of disabled persons. With the use of the hand-held Canon Communicators, portable light-writers which produce two way visual 'speech' on a small panel and speech synthesises a person with a severe speech disorder can efficiently hold conversations and, more than that, to hold down regular jobs.*

*If computers can be introduced in schools as a communication tool, instead of the typewriter, when the child*

*is about nine or ten, then by fifteen years of age, he is well-equipped to undertake a variety of computer application programmes and to expand the scope of its application to his individual aptitudes. Further, it will then be necessary for colleges and universities to set their examinations in a computer format.*

*The various computer hardware, related systems and software enable disabled students to engage in a variety of occupations including publishing, designing, architecture, engineering, etc.*

*Well-known users of electronics and computers today are Stephen Hawking, Christie Brown, Christopher Nolan and, nearer home, Malini Chib-Alur as well as many other disabled people.*

***Prof. Stephen Hawking***

*The most eminent astro-physicist who has no speech at all but holds the Newton Chair of Physics at Cambridge University and is invited to lecture all over the world. He uses a voice synthesizer for his lectures.*

***Christie Brown***

*A famous author with cerebral palsy who wrote "My Left Foot" which is now a very successful film.*

***Christopher Nolan***

*With no speech and no hand function, Christopher received the Whitbread award for his book, "Under the Eye of the Clock" where he made this poignant statement: "Accept me for what I am and I'll accept you for what you're accepted as".*

*I end with the person who has been my inspiration, Malini my daughter - severe spastic, wheelchair-bound, poor hands - with only the left hand working. She's used all the systems of communication mentioned earlier.*

*With very severe communication problems, she used typewriters and writers and obtained her B.A. Degree with History Honours from the University of Bombay, and continued her studies at the Oxford Polytechnic, gaining a diploma in advanced publishing.*

*With severe communication disorders, she has communicated the following:*

*"A relationship between a normal and a disabled person should be like all other relationship - based upon mutual respect rather than pity. I move away when it is the latter. Life is a challenge - these are many mountains to climb. But for me, the most important thing is to climb it with a smile".*

*"Of all my handicaps, I find the most trying is the fact I cannot speak easily like all of you, and cannot get myself understood quickly, the pain of not being understood is like a storm in my heart".*

*The major lesson I have learnt from living and working with people who have severe speech and communication difficulties is not to be judgemental and to avoid stereotypes...to try and remember that there is substantial research around the world showing that, despite their speech difficulties, they can have very powerful minds.*

*In conclusion, if specialists do more work in the area of communication, with the purpose of mainstreaming people with speech disorders into colleges, universities and, finally, jobs, they will become better professionals.*

*As professionals and parents, it is up to us to be innovative and sensitive to their needs, at all levels, so that the outside world becomes exposed to their minds - those minds that work, even if their bodies don't.*

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