

## Early Intervention in Resource Poor Nations What, Why and How? Can it be done?

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Early Intervention (EI) sounds self explanatory. It sounds simple. Of course, EI – what else? You have a problem brewing – nip it in the bud. Nothing could be easier to understand, it seems! But do we? Is it really that simple?

The first challenge in EI seems to be in Early Detection (ED). For example, healthy looking normally born babies may also be harbouring deadly diseases (asymptomatic new born)! To fight this menace, the western world has started New Born Screening Program since Seventies. These are a set of tests, which can pick up the possibility of any underlying diseases in the apparently healthy looking new born. The reason these have to be picked up so early in their lives is that their problems will show at a predictable period later in their life. But, by that time, effects of hidden damages by the on-going disease process will render further management harder or impossible.

One such example is congenital hypothyroidism. Unless detected at birth, every day of delayed treatment may result in permanent drop in IQ points of 1 to 2 scores, which was preventable.

Newborn screening tools are constantly refined. In developed countries, there are Newborn screening programmes which run continuously to pick-up children early to prevent or reduce the burden from their diseases. Gradually, in centres across India, such programs are adopted increasingly.

Once Early Identification is done, preventive measures or Early Intervention can save a child's future sufferings from the consequences of delayed pickup. Unfortunately, it is not possible to identify all conditions before they start showing their symptoms.

Clinicians and workers on the field need reliable screening tools. Researchers are constantly at it. For example, in case of cerebral palsy, where there is holes on both sides of the brain (bilateral PVL), doctor can predict cerebral palsy with complete certainty. EI before the spasticity sets in by 9 – 12 months of age may prevent the visible disability later in life. Hence, it is important to start EI without delay. Neuro-Developmental Therapy for an at-risk neonate can be started within days of birth from the New Born Care Unit itself for the best results.

Similarly, screening tools have been laboriously designed for childhood autism also. Modified Checklist for childhood Autism in Toddlers (M-CHAT) is an example where autism may be genuinely suspected in a baby as early as fifteen month of age. Screening using early identification tools and suspicion by an expert paediatrician or another experienced health care professional are all access to EI. The idea is to spot a possible preventable burden early and to intervene quickly, while expert are scratching their heads to establish a diagnosis!

During my long experience abroad, in one of the more progressive child development centres in London, UK, I learnt how early intervention changed the course of a child's life-chance for the better.

### Why Early Intervention?

If believability were high in our society, none of us needed to worry.

Even a child could understand the importance of intervening early, if we could all believe what the doctors and the health professionals say. Please refer to the “how” section later. But for the time being, let us consider that all doctors have gone saint and that they are all highly competent in what they are doing. Even in that scenario one may feel defensive if someone suggested that one's loving child might have a problem. In situations where a professional is genuinely worried and presents find it impossible to accept, one should understand that the mechanism of “denial” is in operation.

Denial is a strong psychological reaction to cope with your inner fears. One does not want his or her child to have anything wrong. So, one feels rather protective. This feeling somehow misdirects one to act out the ostrich phenomenon where the bird dips its head in the sand during sand storm assuming that there is no sand storm, as it cannot see the storm anymore!

In our society, the awareness label is rather poor even amongst the professionals who have the awareness to be concerned in face of a ‘red flag’ sign or symptom. He may be unaware of the availability of early Intervention and the requisite resources nearby. For the sake of awareness, it must be emphasized that there are high quality early intervention enters of excellence in India now. The numbers may be very small at present. But success stories of a handful of high quality early intervention need to be percolated, if we want to spread this good work around as for the benefit of our suffering children in any nation.

Thus, going back to our question of “why”, I think, we can emphatically say that we should adopt EI, because EI pays in the long run. If I am a child with cerebral palsy, I would rather have people helping me never to become a cripple rather than wait until I go cripple and then try to repair my damages. But getting this concept take a foothold is rather like trying to turn the proverbial Titanic!

If I am autistic, I would rather want experts to show me what the world around me expects me to do from the very outset instead of telling me off later when I have developed my own methods of communication which no one else understood but me and where I have learnt how to cope with various sensory stimuli by flapping my hands, putting hands against my ears and shirking in joy or fear, of which others have no understanding and others start calling me “odd”.

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If I were a child with specific reading difficulties, I would rather have my remedial manoeuvres as soon as I could start, rather than being put in “special” class after being stigmatized as a “problem child” who is “mentally slow”. The cost saved in terms of financial resources, emotional burden and disability limitation are incalculable. The concept of “Social Capital” is only gaining grounds. Once a frame work of calculating the cost effectiveness of EI is formulated, there will be no dearth of takers, I am sure. But as a country we should emphasize on the needs of improving awareness, training, service development and implementation. We should intervene early. And we should do it expertly.

#### How to do EI?

In the field of child development, the best is the minimum! Unless the full expertise of the high quality training and experience in this discipline is brought forward, one cannot expect to produce result and improvement of a magnitude which are visible or appreciable by the parent and carers. Once high quality intervention became the norm, appreciable result will be produced from all corners of our country.

The finest bits of our humanity are being challenged when you are faced with a family where you find a child with disability is suffering. Parents are usually highly anxious. They want improvements in the minimum cost; way below what is required as a minimum. They often expect miracles. They shop around for that promise of miracle cure. They speedily start losing hope and a helpless child is left to suffer where a lot of meaningful help could have been brought forward. Parents want their child to get better and not suffer. That is why they take the child to the doctor. They do not like what is being said or how the doctor spoke to them about their child’s diagnosis or prognosis. They find it almost objectionable that instead of giving the child injection, medicines and putting the child in to “most modern equipment” which should bring out a “fully cured” child from the other end, doctors are referring that child to a number of professionals. They are disgruntled by the fact that no “hi – fi” stuff is brought about in their child’s ‘such a big’ problem.

Instead, the health professionals start playing with the child with toys and start stretching the child’s limbs and fingers. They get angry, feel frustrated and lose hope further. Unfortunately non-experts and sometimes con men (people who take advantage of someone else’s grief and misfortune) compound the hurt.

Therefore the word that is out there is in the line of “Oh! Well we have tried everything. None of these came to anything if you ask me”.

Expert step wise approach of counselling, making everything crystal clear at every step of the way helps them to accept the treatment. If you can bring forth high level of quality in your interventions you can deliver palpable results in short time too.

At our Child Development Centre, Apollo Gleneagles Hospital, Kolkata, a typical parental comment is “after two or three meetings the child is showing improvements that we can feel and see”. Without quality in every member in our team this would have been the mirage that so many colleagues in Developmental Paediatrics had lost their way in. I know of 3 or 4 such good centres in India where you can expect such good results. Our mantra being Early Intervention, we leave no stones unturned keeping the “child first and always” to ensure that the child will enjoy the benefit of its interventions.

It has been an uphill task to ensure that not only we have well qualified high ability professionals, they also had to learn how to be a good human being and a caring individual in the first place (professional of a “Good Standing” template).

Meeting all the minimum conditions for enabling “Early Intervention” is a challenge and it is going to remain challenging at least for another half a decade. But, if even a handful of good centres like ours can keep producing the good result, I expect mushrooming of Child Development Centres (simple supply demand economics) minimum acceptable standards of which will be at a level where these make some difference. Our job is therefore; to keep raising the bar at the centres of excellence. Watered down emulated versions of which must not go below an acceptable standard, in that case.

All professionals should know that there are experts who can help in such situations of Educational/Emotional, Behavioral and Developmental (EBD) problems in children (please refer to Pediatric Symptom Checklist, page 59, Indian subcontinent version of Nelson’s textbook of Pediatrics, 19<sup>th</sup> edition). The sooner you pick up a problem, the better it is, only if you did something about it. “Early Intervention” will reduce a lot of suffering. Experts deliver better standard of care. From our CDC, AGH, Kolkata, we make it a point to refer back the child to the original referrer. A disability may be inevitable, but there is no place for losing hope. Every child can be helped. In our current state of affairs, we can bring big improvements in a very short period of time. It is extremely gratifying to see the smiles of real success in those tiny individual’s divine faces. That is what keeps us charged up to continuously champion the cause of “Early Intervention”. As India’s first Child Development Centre in a corporate healthcare set up, CDC AGH, Kolkata is already making significant contribution by embracing EI and putting up a model for the entire resourced poor nations by being in formal existence for more than 3 years (informally for 5) and setting up a standard so that others emulating it can still manage to deliver the care, which was hitherto believed to be unattainable. Good quality EI remains the mantra.