

Passion has no Parameters

Amar-Singh HSS (Dato' Dr)

President, National Early Childhood Intervention Council (NECIC)

Cert Theology (Aust, Hons), MBBS(Mal), MRCP(UK),

FRCP(Glasg), MSc Community Paeds (Lond)

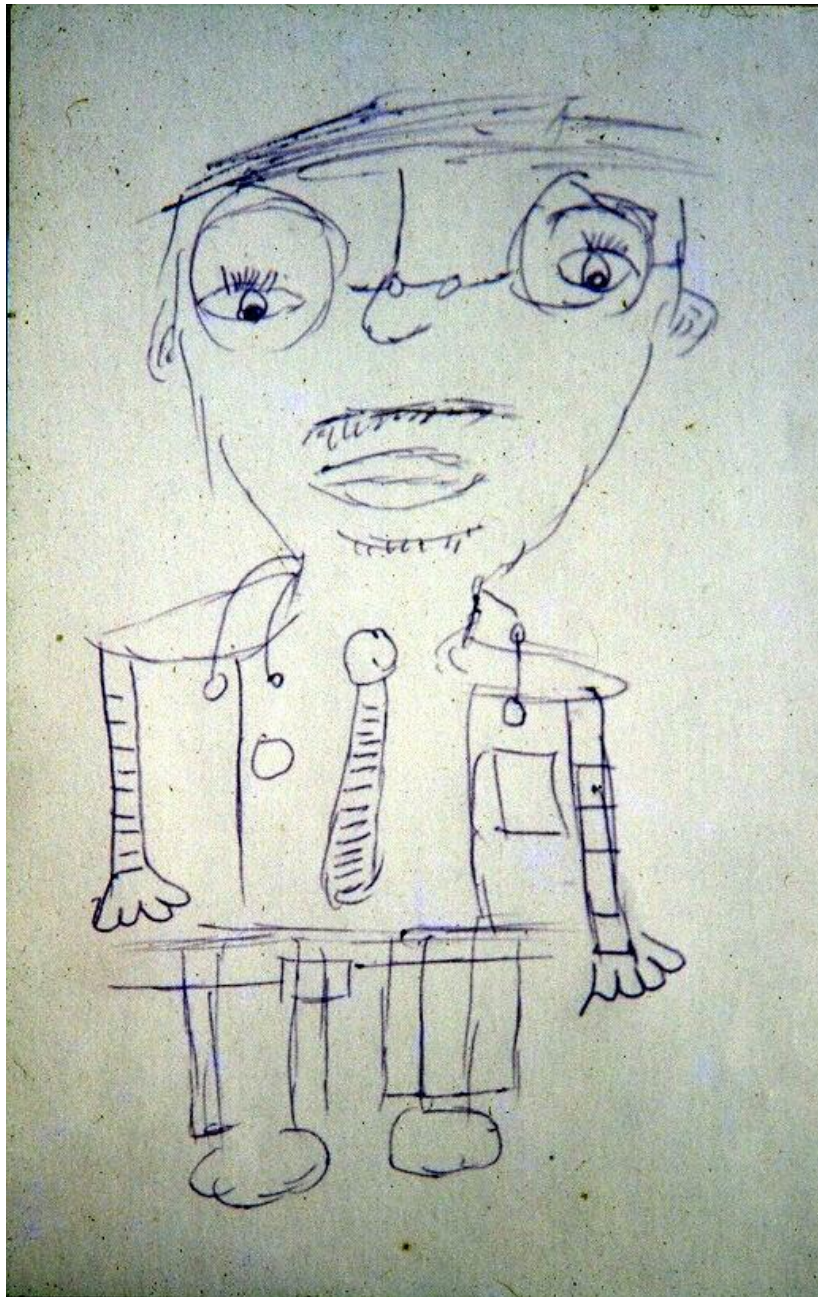
Head Clinical Research Center Perak

Senior Consultant Paediatrician (Community)

Head Paediatric Department, Hospital RPB Ipoh, Perak



<http://www.necicmalaysia.org/>



Who am I?
Who do I represent?

Outline of Dialogue

- Introduction on the Theme
- How to Develop Passion
- Three Movements
- The Cost of Change
- What disability teaches us



Introduction

- Theme: “Passion has no Parameters”
- Individuals, families, NGOs can make a difference
- No limits to what one person/group can achieve
- Everyone has an important role in promoting and advocating for children with disabilities and their families

Passion: “an intense desire or enthusiasm”

The difference one family can make



Example of Tn Hj Abdul Rahman, Parit, Perak

Key Message

Systems should support the child
Often individuals make the difference

Key Message

Much can achieved
Families and people with disability can lead
the way

How to Develop Passion?

- How can a parents have the energy to support their child in the face of many challenges?
- How can a person with disabilities overcome the many societal and system barriers?
- How can the system work with passion instead of just performing a task?
- How can therapists, professionals and those in policy be ignited to go beyond the narrow confines of their system restrains?

Three Movements

- No easy answers
- Suggest three movements in our lives
- ‘Movement’ (old word)
 - Implies a deep change within us that lasts
 - It speaks of a journey from here to there

1st Movement

From Despair to Hope

- Hope is vital when faced with disability
- Hope enables us to last the distance
- This movement requires:
 - Listening to the truth to find reality
 - Much time, space and solitude necessary for this change to take place





Art & Music Therapy



2nd Movement

From Looking at the Disability to Looking at Child & Family

- Requires a fundamental reorientation of our focus from a medical model to one that makes us human
- A change of our heart, not our mind, is required





Karthi, DMD

Key Message

See the Child first
Not the disability

3rd Movement

From Isolation to Community

- None of us can make it alone, we all need support
- This requires us to reach out, to build bonds with others, to share
- Can only happen when families and professionals deepen their relationship and understanding with each other (two way street)



Support Groups



Key Message

We need each other

Friendships will carry us forwards

(families, professionals, therapists, etc)

The Cost of Change

- ‘Passion’ comes from the Latin verb *‘pati’* which means to suffer
- Passion & change come with a cost, suffering
(grows us)
- Much politics, vested interest and financial motivation in the disability scene
 - Avoid this
 - Also speak out against false directions

An Appeal

- Keep eyes of our heart on the key issue:
 - Children and families
 - Systems need to change, not the child
 - See the child & those of us who care & the meaningful changes that are taking place and thereby be encouraged
 - Don't look at the negatives
- Let us ignite our passion to make real the dreams of children with disabilities

Our ultimate aim must be for the family and the person with a disability to live a meaningful life rather than allow the problem (disability) to run their life.

We need ... to see children with disability and their family as partners and offer them care in a way which dignifies, best meets the needs of the person with disability and takes into account his or her cultural and spiritual needs.

Meeting the Needs of Children with Disability in Malaysia
Amar-Singh HSS, Med J Malaysia 2008

Key Message

We need to move forwards as a nation
to accept persons with disability
and include them as part of society
(not a subset of it)

What disability teaches us

- Truth/Reality
- Meaningful relationships

Jean Vanier & L'Arche

The Cement that Binds Us

“In our fragmented, often broken societies, in our towns made of steel and glass and loneliness, people with disabilities can act as a kind of cement that binds people together. This is their role in society. They have a special part to play in the healing of hearts and in destroying the barriers which separate people from one another and prevent them from living happily and humanly.”

Jean Vanier, *Our Journey Home*, Introduction xi



Make the Right Real

Disability may make the right real



Three Movements

- From Despair to Hope
- From Looking at the Disability to Looking at Child & Family
- From Isolation to Community

It is not about how much we do
but about how much we love

<http://www.necicmalaysia.org/>

