

# Working with Families in Making Inclusion Possible



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# Outline of Discussion

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- ▶ Inclusion & local Reality
- ▶ Experience of Working with Families
- ▶ How to make Inclusion Happen
- ▶ How can we move Forwards in Partnership with Families for Inclusion?

Nothing new to say, only truths

# Inclusion & Acceptance

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Inclusion is at the heart of all humanity

We all want to be  
accepted for who we are

# Inclusion & Acceptance

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Inclusion is at the heart of all humanity

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# Inclusion & Acceptance

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Inclusion is at the heart of all humanity

We all want to be  
accepted **for who we are**

# Reality

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Unfortunately many people in society  
are in the habit of creating barriers and walls  
to exclude others  
based on their  
gender, ethnicity, social status or abilities

# MOE Target 2015 is 30% inclusion Reality: Current inclusion rates < 5%

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## Letters

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Tuesday, 21 April 2015

# A black print for children with disabilities

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WE, children with special needs, families, NGOs and professionals, had hoped that the National Education Blueprint 2013-2025 would result in better services and a true inclusion for children with disabilities.

However the reverse seems to be happening.

Teachers and headmasters, obsessed with the Education Ministry's (MOE) KPIs for achievement,

have increasingly been excluding children.

One of the important early targets set by MOE in the Education Blueprint is to have 30% of special education needs (SEN) students in the inclusive programme by 2015.

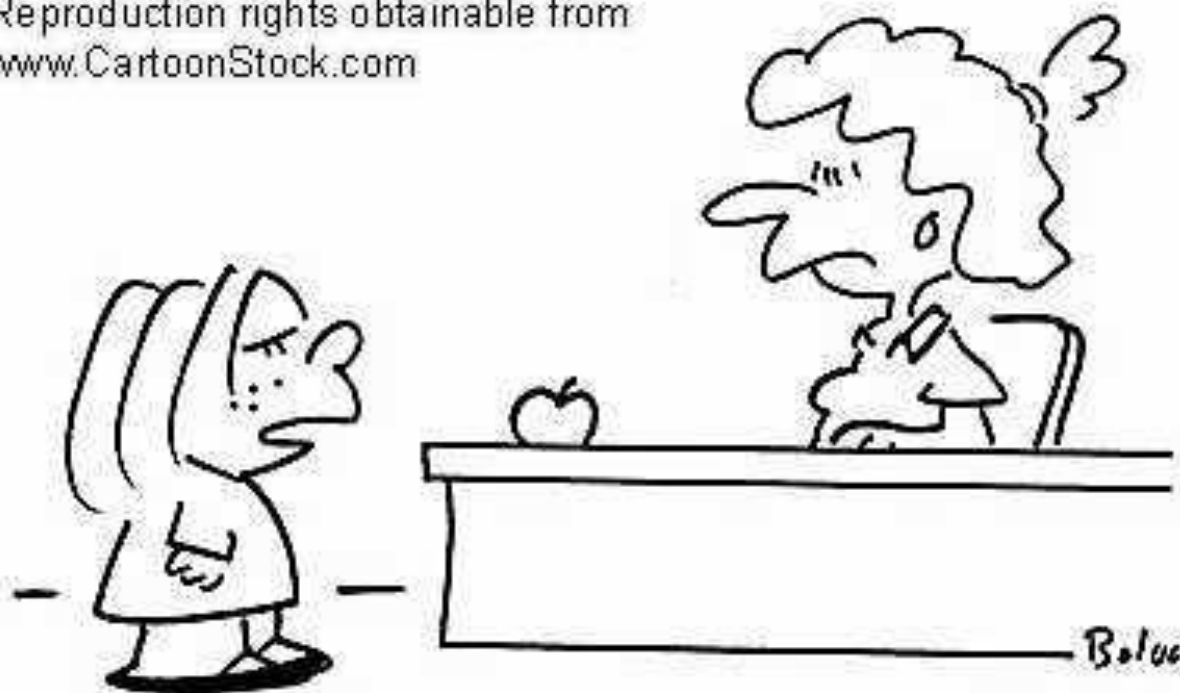
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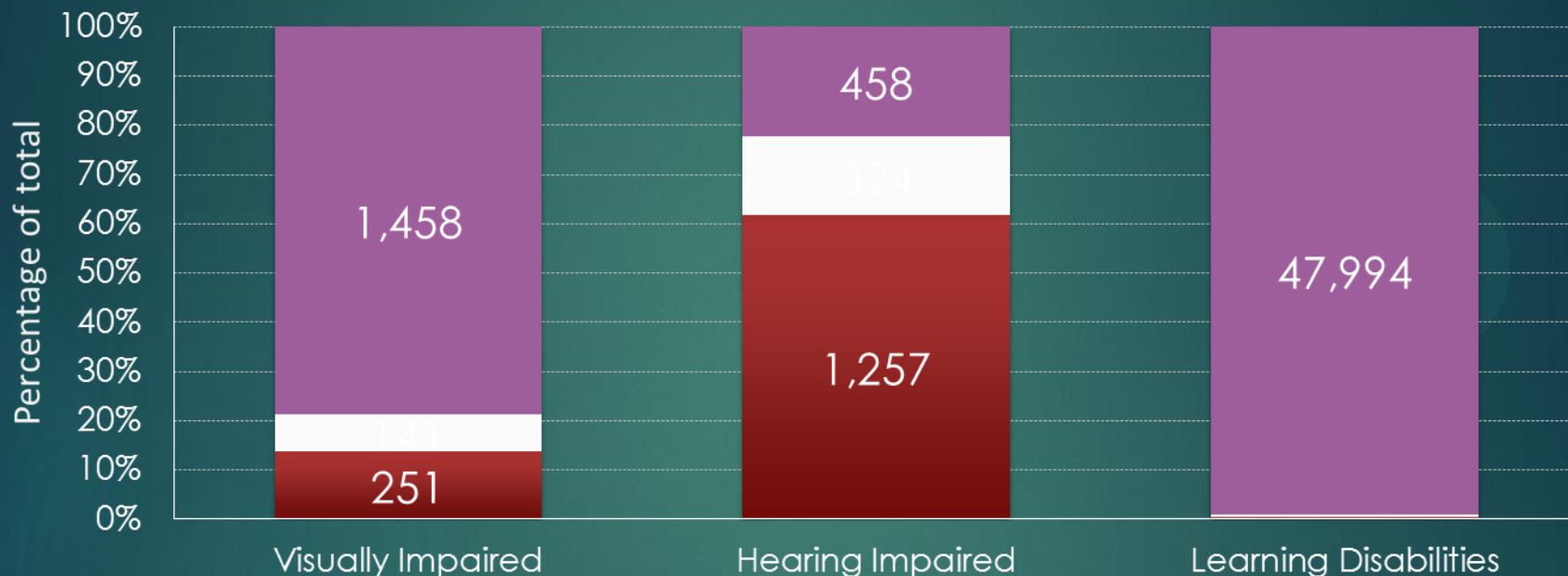
"How do you know I have a learning disability?  
— Maybe you have a *teaching* disability!"



# Composition of School Placement by Disability

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- **99.2% of learning disabled students** are enrolled in the **SEIP** – which integrates them into a mainstream school with supplementary classes
- **78% of hearing impaired** students and **21% of visually impaired** students are enrolled in **special schools**



**Children aged 0-12 years**

(pre & primary school age with special needs, assuming 10%):

**660,000**

	SKPK	Sekolah Kebangsaan Pendidikan Khas
	SMPK	Sekolah Menengah Pendidikan Khas
	SEIP	Special Education Integration Programme

**55,642 students  
in MOE**



KEEP  
CALM

because there is really

NO  
HOPE

“Alas that I spoke true!  
What hope have we ....?  
We must do without hope.  
Let us gird ourselves and weep  
no more! Come! We have a  
long road, and much to do.”

Aragorn, Lord of the Rings  
JRR Tolkien

# Experience of Working with Families

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**No Success without  
much Failure**

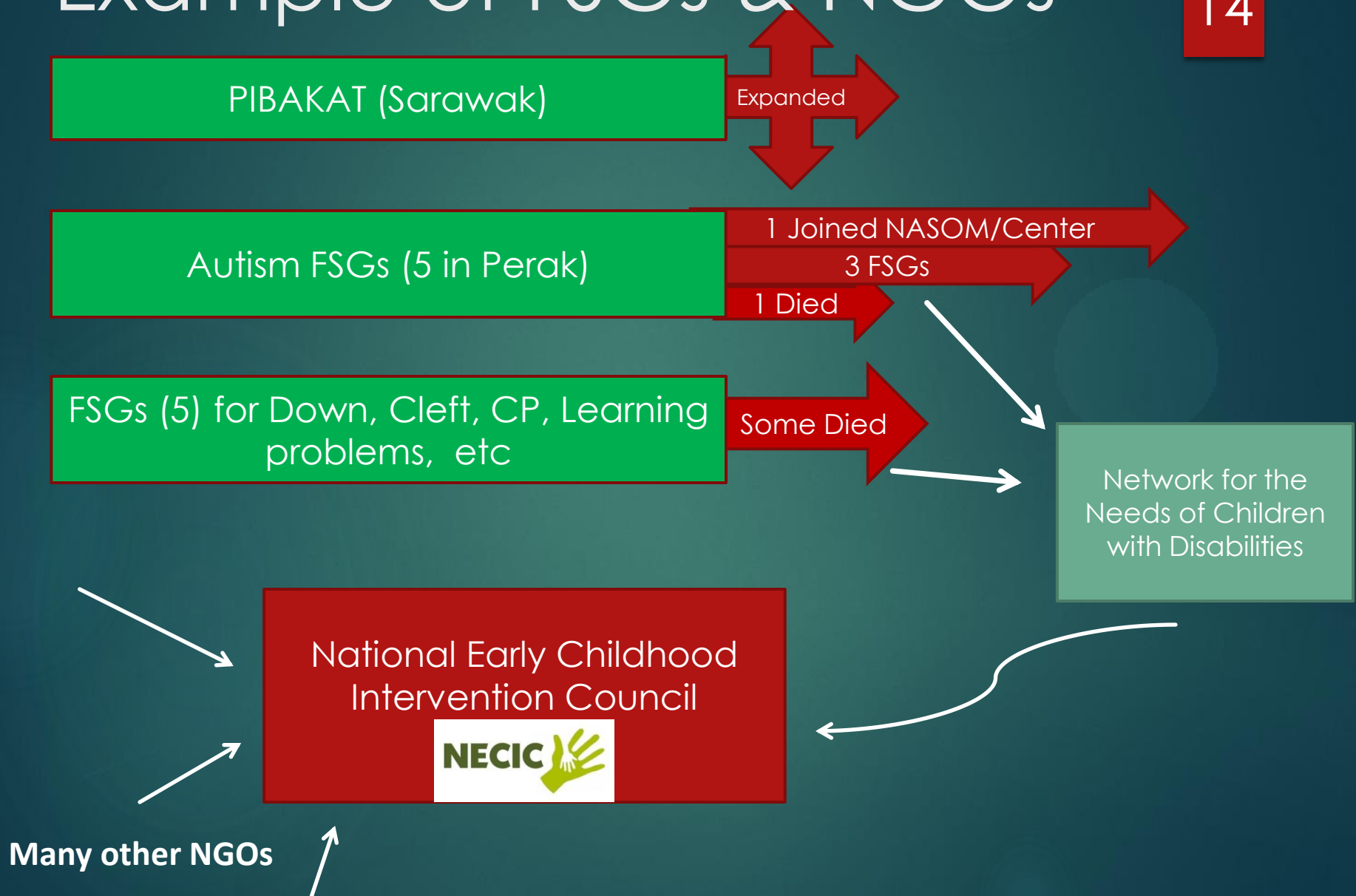
Learn more from failure than from success

# Experience of Working with Families

- Difficult to find families who will support others organizationally (1:1, FSG, NGO)
- Have to resolve their own struggles first
- Many feels disempowered (country's mind set)
- Some expect government or others to do it
- Some affected by societies negative views
- Professionals/Government/NGOs may be an obstacle (want to stay in leadership, decision making)

# Example of FSGs & NGOs

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# The Value Family Support Groups

(What are their functions?)

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Friendships /Strength & tears, Ideas, Organization, Advocacy

# Making Inclusion Happen

## Message 1

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**Be inspired by  
the Lives of Others:**

Children/Parents/Families

Professionals/Teachers

NGOs

Government Agencies



# Peter Young

The gentle giant

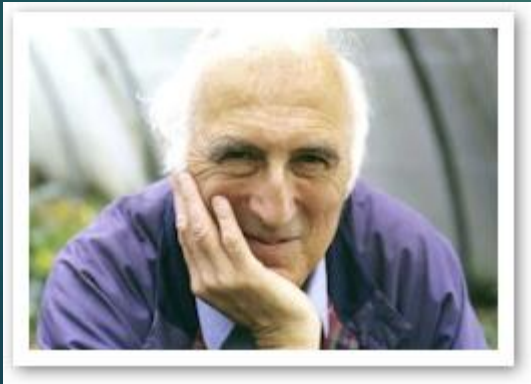
1981

One of the earliest voices for the disabled in the country

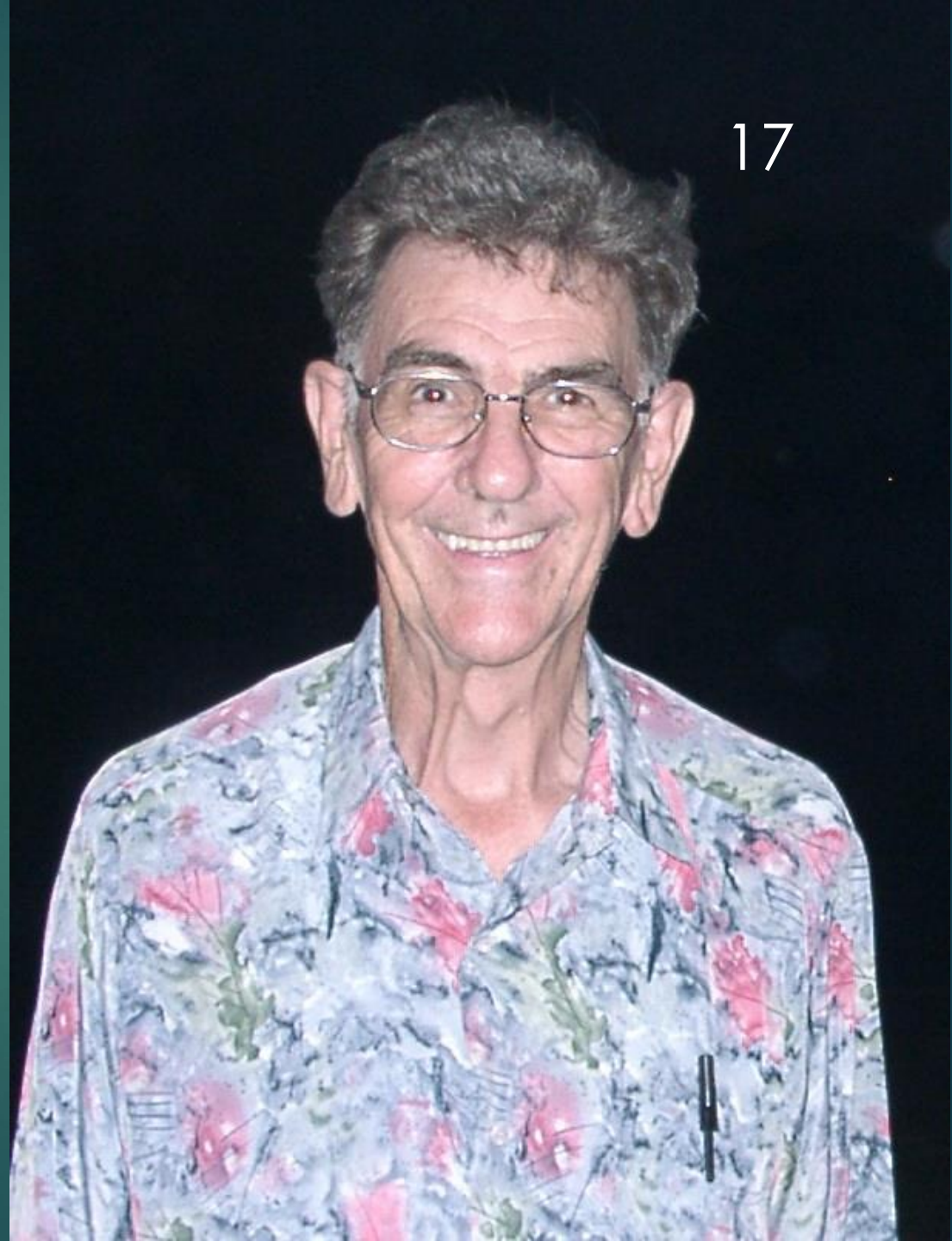
Rights based

Empowered others

“Catalyst for disability services”



Jean Vanier



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# Making Inclusion Happen

## Message 2

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## Network with like-Hearted Persons

Avoid the negative one

And the potted plant individuals (“politics” of disability)

# Making Inclusion Happen

## Message 3

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## People Work

## Systems not so well

Systems should support the child/family  
(but often don't)

Often individuals make the difference

# Moving Forwards in Partnership with Families for Inclusion

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Much can be achieved  
**Parents and people with  
disability  
can lead the way**

All of US (government, NGO, private)  
can work in partnership with them

# Moving Forwards in Partnership with Families for Inclusion

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One empowered family  
has no limits  
as to what they can do  
for the children in their care  
and for the children of other families



# 'Ernest' plea to realise a child's dream

THE recent 5th National Early Childhood Intervention Conference (NECIC) was a success not just because of the 1,000 children, parents, professionals, NGOs, etc who took part but because of the wonderful children who spoke or performed.

## Three children stand out:

- Natalie Dong, 10, was the MC for the VIP first plenary at which the Unicef director of Malaysia spoke. Natalie is profoundly deaf but, with the hard work of her family and a cochlear implant, she has great speech and attends a normal class.

- Ng Jun Yin, 11, was the second VIP speaker at the first plenary. He has autism but spoke flawlessly, without any text in front of him. He shared about his need to be seen as a child first, rather than as a disability. His parents' commitment has seen him do well academically in a normal class.

- Ernest Teoh, 14, gave a number of stellar violin performances. Ernest is blind but, due to the persistence of his family, is doing well academically in a normal class. He also passed his Violin Grade 8 at 11 years of age.

These delightful children impressed all of us with their capability and abilities.

During the open dialogue with managers from the Health, Education and Welfare ministries, Ernest made an impassioned plea. He is keen to become a scientist but Education Ministry policy is that visually impaired children cannot do science as they cannot participate in science experiments.

Ernest argued that some of the best scientists in the world are disabled e.g. Stephen Hawking. The representative from the ministry said his request would be considered.

The NECIC made a promise to Ernest that our collation of over 25 NGOs would strive to make his dream a reality, even if



Ernest is blind but, due to the persistence of his family, is doing well academically in a normal class.

we have to present a memorandum to the ministry.

This is an open letter to the prime minister and the ministry, a plea for Ernest. Do not let the dreams of any single child fail because we did not offer the chance to see them become a reality. Ernest has already overcome insurmountable odds to be included in a normal class. It is only a small

leap further to allow him do science and modify the environment to support him.

We trust that our leaders and the ministry will implement the Incheon Strategy (with the objective of improving the lives of persons with disability): "Make the Right Real". And do this by making real the policy of inclusive education on the ground, starting with Ernest.

Who knows, Ernest may be our first winner of a Nobel Prize in Science.

We await your positive response for Ernest, his family, the families of all children with disability and the Malaysian people to hear.

DATUK DR AMAR-SINGH HSS  
PRESIDENT, NECIC

# Moving Forwards in Partnership with Families for Inclusion

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To help your child you need to  
help other people's children

# Moving Forwards in Partnership with Families for Inclusion

## **Our change/outlook 1**

- Respect & Listen to their views
- Even if they contradict our own
- Act on them
- Ways to Listen (no agenda listening, audit services)



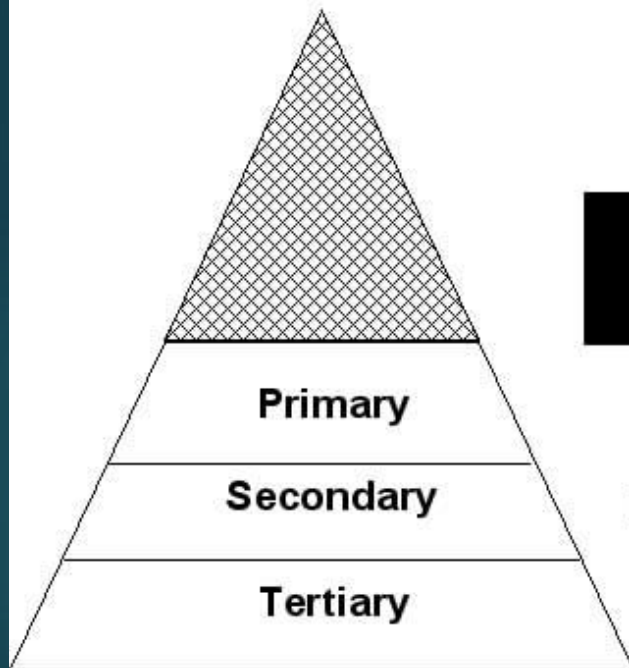
# Moving Forwards in Partnership with Families for Inclusion

## **Our change/outlook 2**

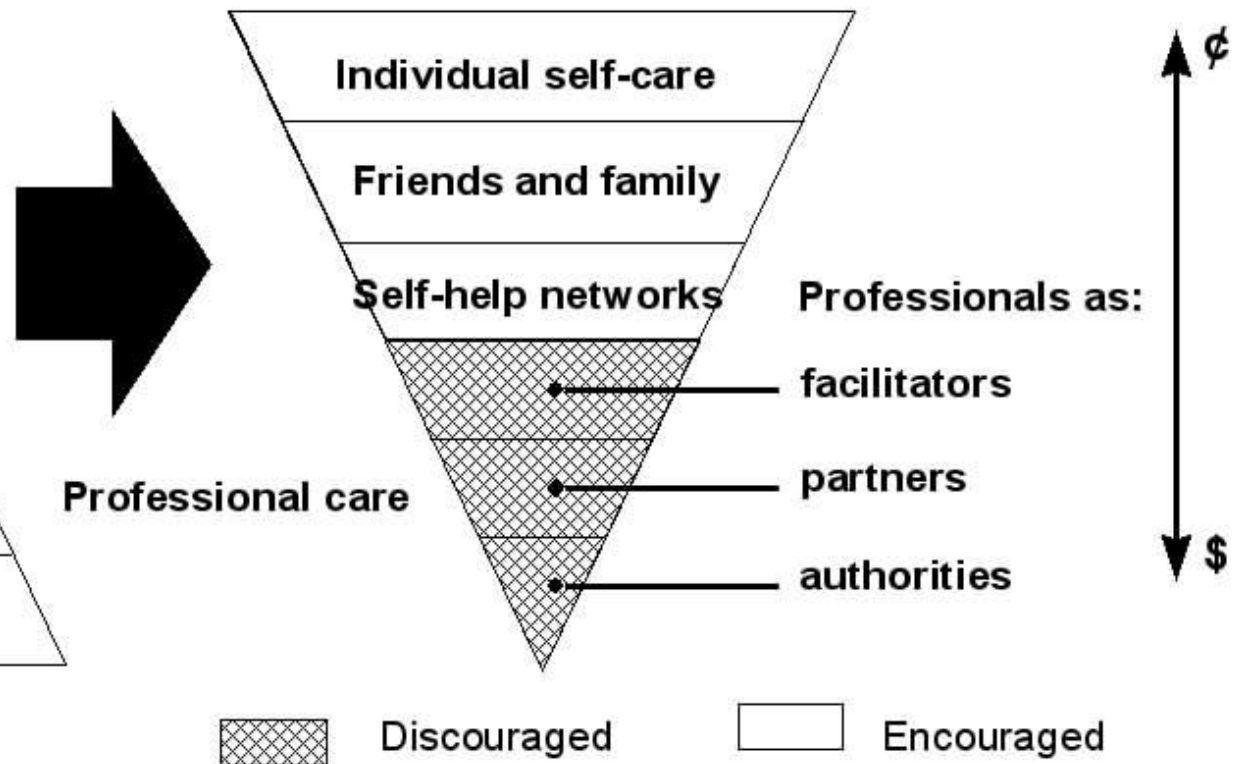
- Share power (empowering) with families
- In planning/decision making for services
- In open audits of services

# Figure 1: Transformation From Industrial Age Medicine To Information Age Healthcare<sup>6</sup>

## Industrial Age Medicine



## Information Age Healthcare



Ferguson T. Transformation from industrial age medicine to information age healthcare. Healthcare Forum Journal, Jan-Feb 1995. Note: Modified by the Technical Committee, Telemedicine, KKM - personal communication Mohan AJ.

# Moving Forwards in Partnership with Families for Inclusion

## **Our change/outlook 3**

- Keep our hearts always focused on the child's need
- Not the needs of organisation or system

**You cannot help others  
if you do not first find  
yourself**

Need to find God & self

# Ways to Live - Change in “work” outlook

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Work-Aholic (addiction, live to work)



# Ways to Live - Change in “work” outlook

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Work-Aholic (addiction, live to work)



Work Life Divorce (TGIF, OMGIM, work to live)



# Ways to Live - Change in “work” outlook

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Work-Aholic (addiction, live to work)



Work Life Divorce (TGIF, OMGIM, work to live)



Work-Life Balance



# Ways to Live - Change in “work” outlook

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Work-Aholic (addiction, live to work)



Work Life Divorce (TGIF, OMGIM, work to live)



Work-Life Balance



Work-Life Intergration (Work = Rest & Joy, All of life integrated, family at work)





# Developing Personal Capacity & Balance

- Lepak: Regular Solitude & Silence
- Journaling for emotional well being
- Accountable to a few good friends  
(a community of close friends)

# Have weekly screen free days\ with family

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- ▶ No TV, Tablet, HP, music, etc
- ▶ Turn off your wifi & data plan
- ▶ Silence all notification (except phone)
- ▶ Don't take any pictures – keep them in your heart
- ▶ Spend time with nature (not just food)
- ▶ Listen to each other







Our average weekend

“Inclusion is not about success  
but about acceptance”

Amar

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**Acknowledgment** (my trainers – children & parents)

6th National Early Childhood Intervention Conference



**NECI**  
Conference  
2016

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**Embrace Diversity Empower Families**

24 - 26 November 2016 | Pearl International Hotel Kuala Lumpur

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