

Child, Family, Community



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TGIR

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TGIR

- My foolishness (stupidity)
- Conferences, Workshops
- Possibly my Disability (that I want to help)

- Summarise & chart our direction forwards
- The next step – the community

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Overview – We are on A Journey

- Size of the problem & Service Needs
- Progress over time
- Whose Responsibility?
- Obstacles to Community Involvement
- How Can Communities Change
- The Role of Families
- Impact of a child with a disability on the community

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A Digression

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Mission & Vision of the Paediatric Department of Ipoh Hospital (HRPB Ipoh)

Vision

All children should be assured of an excellent standard of health and wellness. **The diverse needs of children should be met in the context of a wholesome family and stable community.**

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Mission & Vision of the Paediatric Department of Ipoh Hospital (HRPB Ipoh)

Mission for Paediatric services in Perak State is to:

1. provide quality care for all children
2. maintain the dignity & enhance the full potential of all children
3. **work with parents as partners** in the care of their children
4. **motivate the community to recognise and promote child wellness as a means towards the well-being of society**

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Mission & Vision of the Department of Paediatrics Ipoh Hospital (HRPB Ipoh)

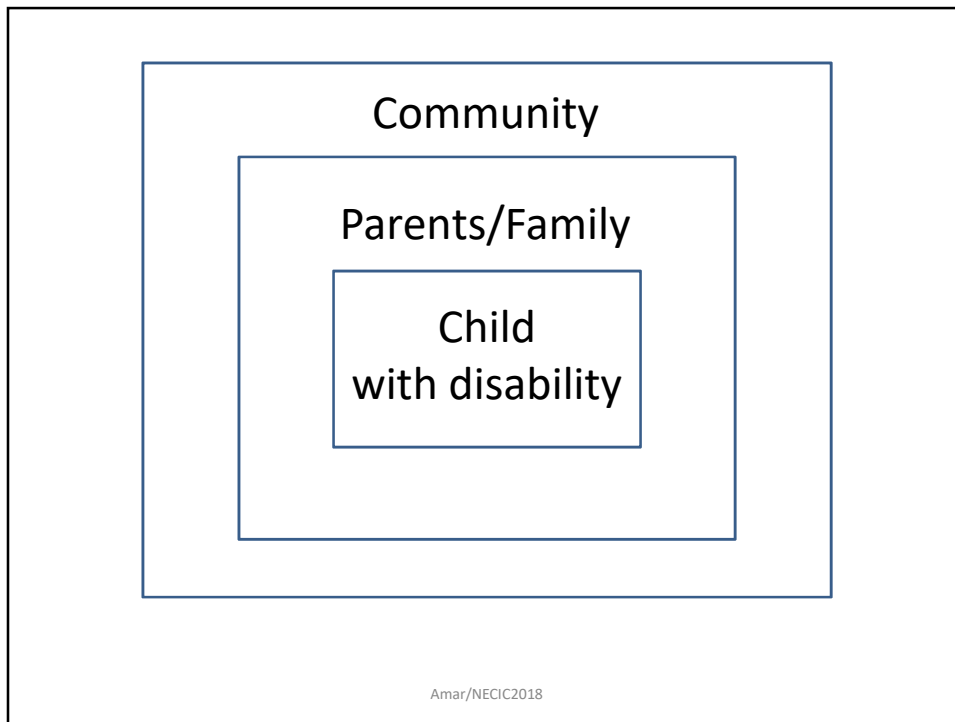
Well Child
Wholesome Family
Stable Community

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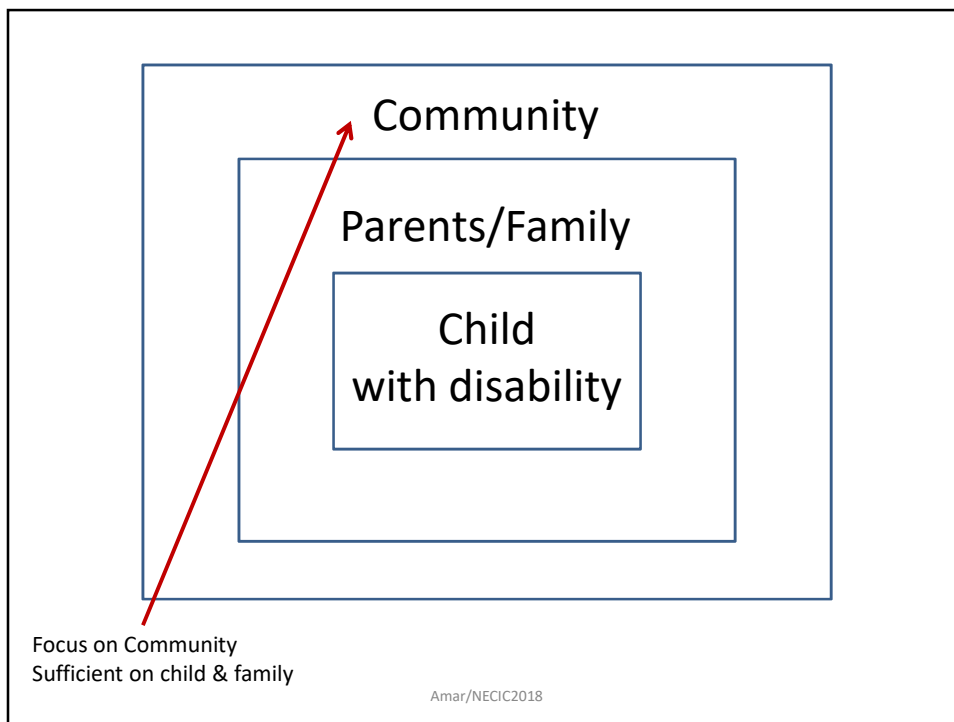
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We need to anchor
the child with a disability
in the context of the family
and the community

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Size of the Problem

Children with disabilities form a considerable part of our society

- 1:100 Sensory impairment (vision, hearing impaired, etc)
- 1:100 Physical disability
- 1:100 Intellectual Impairment
- 1:100 Autism (growing)
- 1:20 ADHD
- 1:7 Learning Disability (including Dyslexia)
- 1:5 Disabled

NCHS Data Brief, Nov 2017
CDC 2016
New Zealand Disability Survey 2013
Hall 2003; Bhasin 2006; Rydz 2005; Amar 2006

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5 Key “Stages” in a PWD’s Life

1. Diagnosis/Assessment
2. Preschool needs
3. School
4. Employment
5. Long term care



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History of disability services for Children in Malaysia (1960-2017)

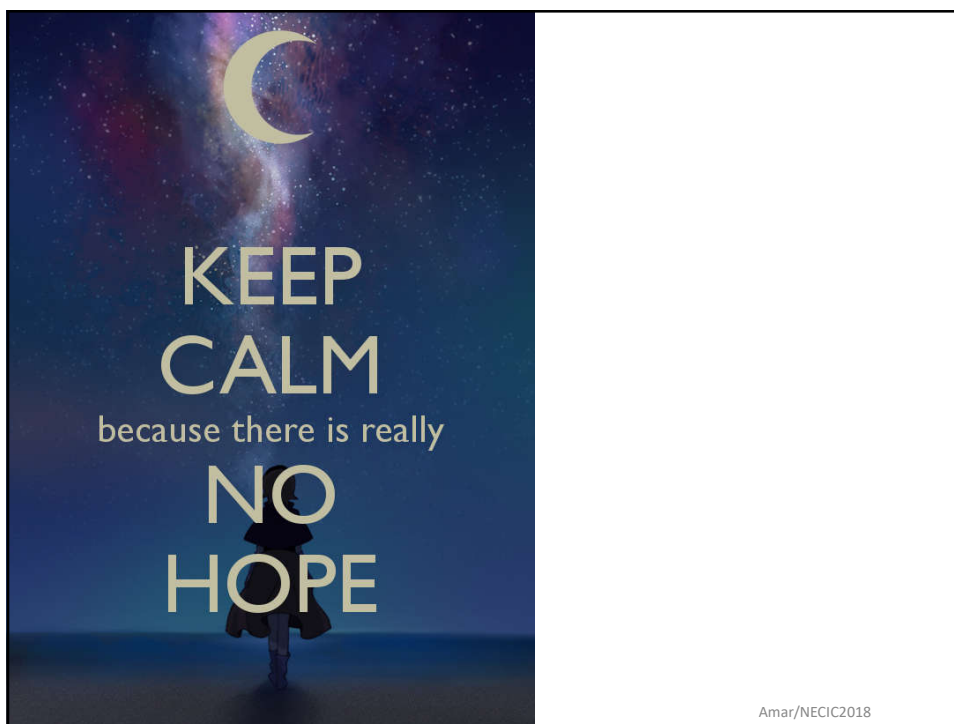
1. Movement from residential based to ambulatory services
2. Movement from physically disability to learning disability
3. Movement from NGO based to government based (swung back)
4. Movement from charity model to a social or rights model (still limited)
5. Movement from provider led to family-focused, empowering & advocacy based (still limited)
6. Movement to Community Responsibility? (nil)

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Is there Hope? Will the Systems Defeat Us?

1. How can parents/families have the energy to support their child in the face of many challenges?
2. How can a person with disabilities overcome the many societal and system barriers?
3. How can the system work with passion instead of just performing a task?
4. How can therapists, professionals and those in policy be encouraged to go beyond the narrow confines of their system restraints?
5. How can communities be proactively galvanised to take responsibility to include the disabled in all aspects of life?

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“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
by JRR Tolkien

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Whose Responsibility?

- Parent/Family
- Professionals/Therapists/NGOs
- Government
- Community



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Whose Responsibility?

- Strong thrust over years to develop family-centered early intervention & support
- Little emphasis given to community-centered early intervention (CBRs limited abilities)
- Often responsibility for child with disability placed on family (Resilience, Strength, Coping, Impact, etc)
- Some responsibility shared by professionals/therapists & government agencies
- But few communities take on this responsibility and become accountable for the needs of the child & family

- **Ownership is the key**

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Service Needs for a PWD

1. Diagnosis/Assessment - reasonable
2. Preschool needs - reasonable
3. School – fair (far behind expected)
4. Employment - poor
5. Long term care - dismal

Lots of energy put in but limited outcomes
Because we have little community ownership
Especially for areas 3-5

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Why Communities Fail or Are Disinterested?

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Obstacles to Community Involvement & Ownership What Limits Fully Community Involvement?

- **Charity/Welfare based model** (pity)
- **Medical model** (making it a disease)
- **Social model** (remove barriers, improve attitudes, enable inclusion by society)
- **Rights based model** (a fight for system change, to offer access to the privileges people would otherwise have had if they were not disabled)

Key Reason: We are still a nation that views disability as a charity issue

Medical personal to deal with it as a disease

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How Can Communities be Encouraged to Change?

1. Systemic or Community advocacy
2. Inclusion in all areas is key (fight discrimination)
3. Social & rights-based approach
4. Making Government policy work
5. Private sector engagement useful
6. Families are critical
7. Use critical events/media frenzy
8. Work on visibility & understanding (information & community engagement)

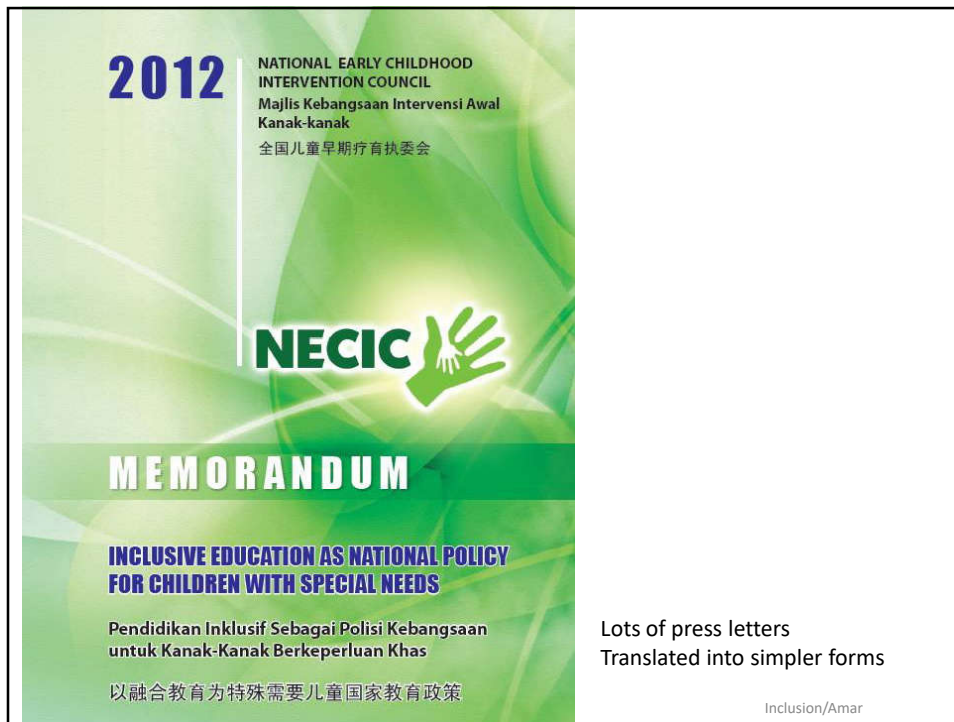
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Work on Visibility & Understanding

(information & community engagement)

- Print media stories
- Social media
- Autism/Disability Walks
- Dinner with PWD (Peter Young's example)
- Policy documents/Memorandums

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Use critical events/media frenzy

- Individuals do it better than organisations
- But organisations have more say
- Example (Black Print)
- We don't write or speak up enough

THE STAR ONLINE

Impact of this letter

News Business Sport Metro Tech Lifestyle **Opinion** Videos Property Jobs Autos More

Letters Home > Opinion > Letters

Tuesday, 21 April 2018

A black print for children with disabilities

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Popular Now in Opinion

- Why the LRT isn't worth the switch
- Finding father again
- Doing it the 'Johor way' in Pahang
- A high income reality check
- A dream for a better Malaysia

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.

Latest News

- A dream for a better Malaysia
- Real problem in getting the right number
- Clear the air over logging
- Looking back at my cup of tea.
- More parks, fewer condos

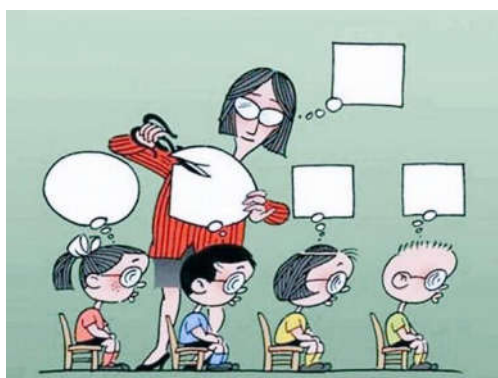
Most Viewed

- Why the LRT isn't worth the switch
- A high income reality check
- Blind to Malibus at airport

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Inclusion in all areas is Key Fight Discrimination

- Social & rights-based approach
- Our right, not a privilege



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Private sector engagement useful

Example Sook Yee, Edmund Lim, Jaden & Branden



Making Government Policy Work (maintain pressure)

Ministry of Health

- Medical student's curriculum for disabilities poor (esp. learning disabilities)
- Growth in medical rehabilitation but institutional
- Quality of services not uniform, not family focused, not in rural regions

Pressure universities to change curriculum

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Making Government Policy Work (maintain pressure)

Welfare Department

- CBRs professional quality limited
- Staff remain poorly paid
- Some CBRs have “lost” their way

Revamp CBRs & make them NGOs

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Making Government Policy Work (maintain pressure)

Ministry of Education

- Enormous growth in services but failing children with learning disabilities
- Commitment to inclusive education for learning disabilities limited
- Children still ‘victimised’ by Education Act
- Quality of special education teachers varies enormously

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Making Government Policy Work (maintain pressure)

Ministry of Education

1. Have a real policy to support inclusive education
2. Remove the pressure from teachers to achieve literacy KPIs
3. Include parents in decision making for education choices for their children
4. Change Unit Pendidikan Khas to Unit Pendidikan Inclusive
5. Have a commitment to a teacher aide programme

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

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Making Government Policy Work

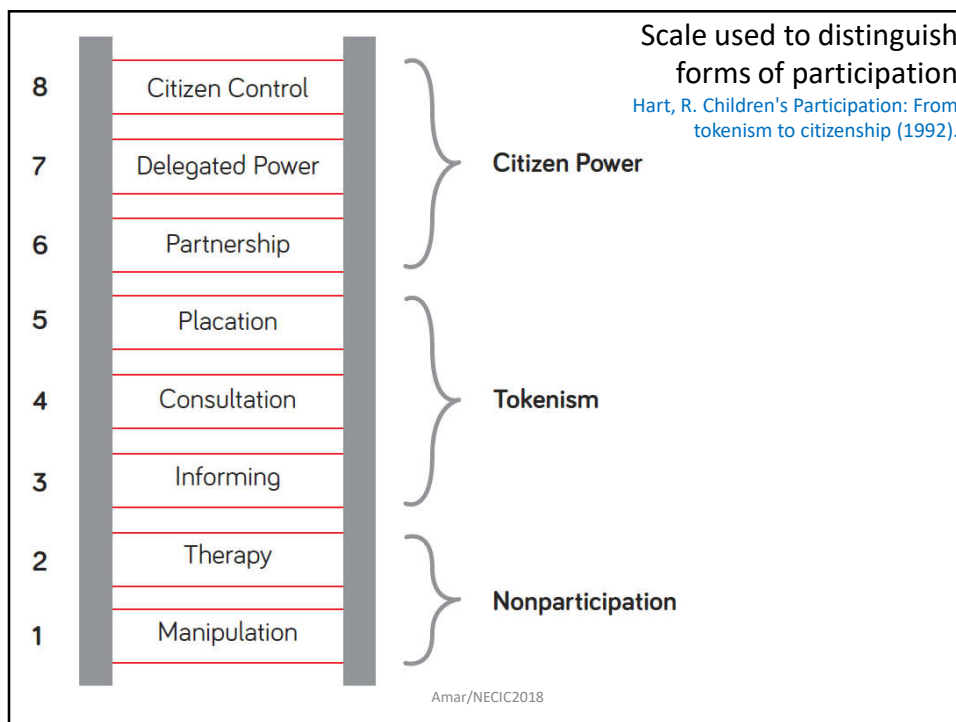
(maintain pressure)

Too many Requests/Demands on New Government

Keep it Simple, Short, Repeat It

1. Pressure universities to change curriculum
2. Revamp CBRs & make them NGOs
3. Change Unit Pendidikan Khas to Unit Pendidikan Inclusive
4. Have a commitment to a teacher aide programme
5. Real Participation/Involvement

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Families are Critical

(The Role of Families)

- Parent engagement
- Two-way-street type of relationship

1. Families supporting other families
2. Families as activists
3. Families as contributors to therapy/education
4. Families, schools, and the community as partners
5. Family involvement in governance & management

[Open File on Inclusive Education, UNESCO 2001](#)

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Child, Family, Community

(the message)

Every Child Belongs

No differentiation between disable & able

Our Strength in Diversity (Accepting & Using)

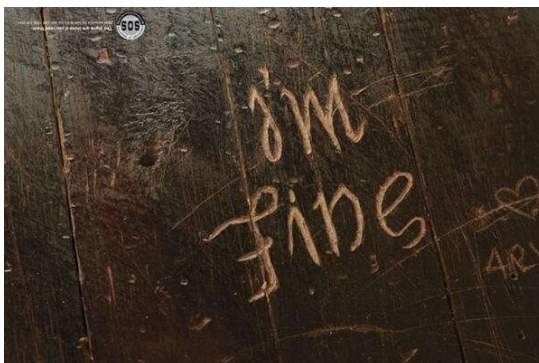
Recognise the many positive impacts and meaningful contributions that children with disabilities make within their families in society

<http://vanierinstitute.ca/children-disability-positive-impacts-children-family/>

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Impact of a child with a disability & families on the community

- Our societies are lost, fragmented, disintegrated & have a loss of hope



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Impact of a child with a disability & families on the community

- When we accept a person with a disability & include them
-
- We are able embrace people with different outlooks, genders, ethnicity, etc in the community

We are more able to bring inclusion to society & integrate society

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Impact of a child with a disability & families on the community

- When we recognise & appreciate the value, potential & strengths of a person with a disability
- We are able to offer same support to everyone in the community & recognise the value, potential & strengths of others

We bring hope especially those who feel worthless

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Impact of a child with a disability & families on the community

- When we (PWD or families) grow our character through hardship & struggle and become "better people" with real value systems
- We are able to bring that character & value systems into the communities we live & work in

Bring meaning to relationships & life

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Impact of a child with a disability & families on the community

1. Integrates/Unifies the community
2. Offer communities an opportunity to find purpose & hope & joy
3. Offer meaning to relationships & life

This is how we will change communities
I have changed & become an agent of change

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What **True** Community Involvement Means

- More than supportive policies at national level
- More than adequate funding for programmes
- More change in infrastructure at the local level

- Complete change in the outlook of communities towards disabilities and an integration of the child with disability and their family in the community
- No longer an 'us-and-them' outlook/reality that socially excludes but a wholesome community that embraces and enhances all diversity in society

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Working with Communities: The Final Frontier

- Professionals/Therapists/NGOs need to go beyond the provision of quality care, therapy, intervention, and working with parents as partners in the care of their children

Professionals/Therapists/NGOs need to

- Integrate children with disabilities and their family into the community
- Motivate the community to recognise and promote the family's need for wellness as a means towards the well-being of society
- Maintain the dignity and enhancing the full potential of all children in the community

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Working with Communities: The Final Frontier

Children with disabilities
and their families
have much to offer
society
if communities are
willing to
listen, accept them and
learn from them



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The “Face” of Disability is Changing

We need to be imaginative in meeting new challenges



Passive Recipient
Hidden

Active/Directing Change

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The “Face” of Disability is Changing and Continues to Change

Need to communicate this



Passive Recipient
Hidden

Active/Directing Change

Joyful Acceptance
Celebrate who we are

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