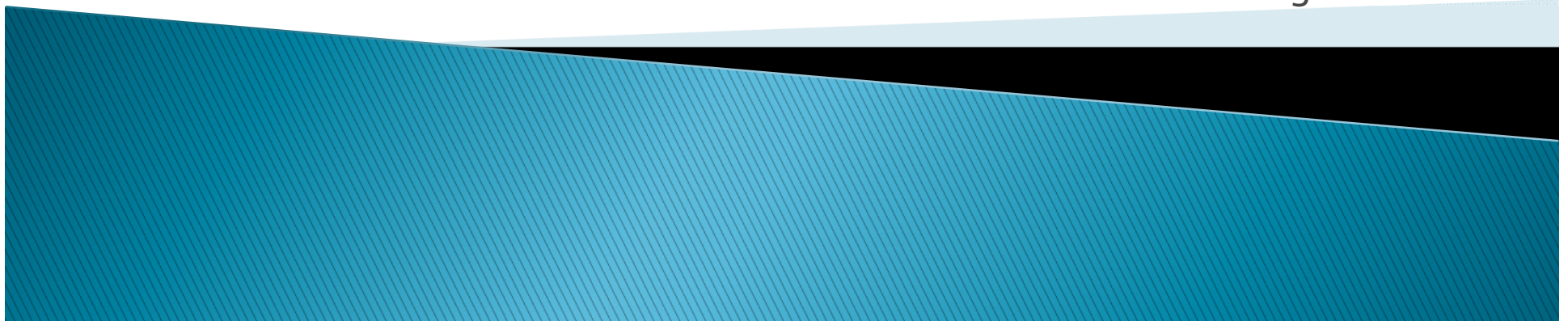# Young people's voices on 'disability' matters

Shanthi Ameratunga
Professor of Epidemiology
School of Population Health
University of Auckland

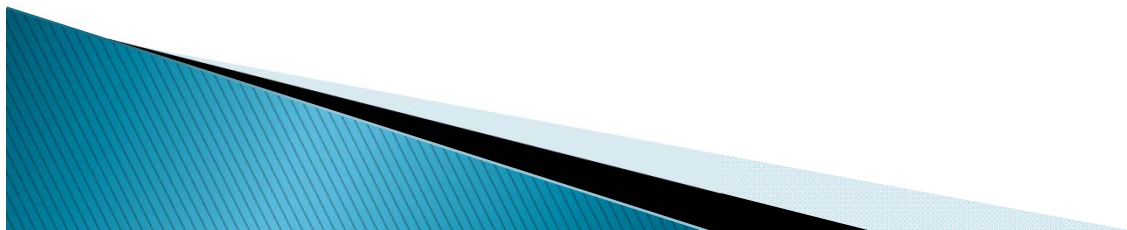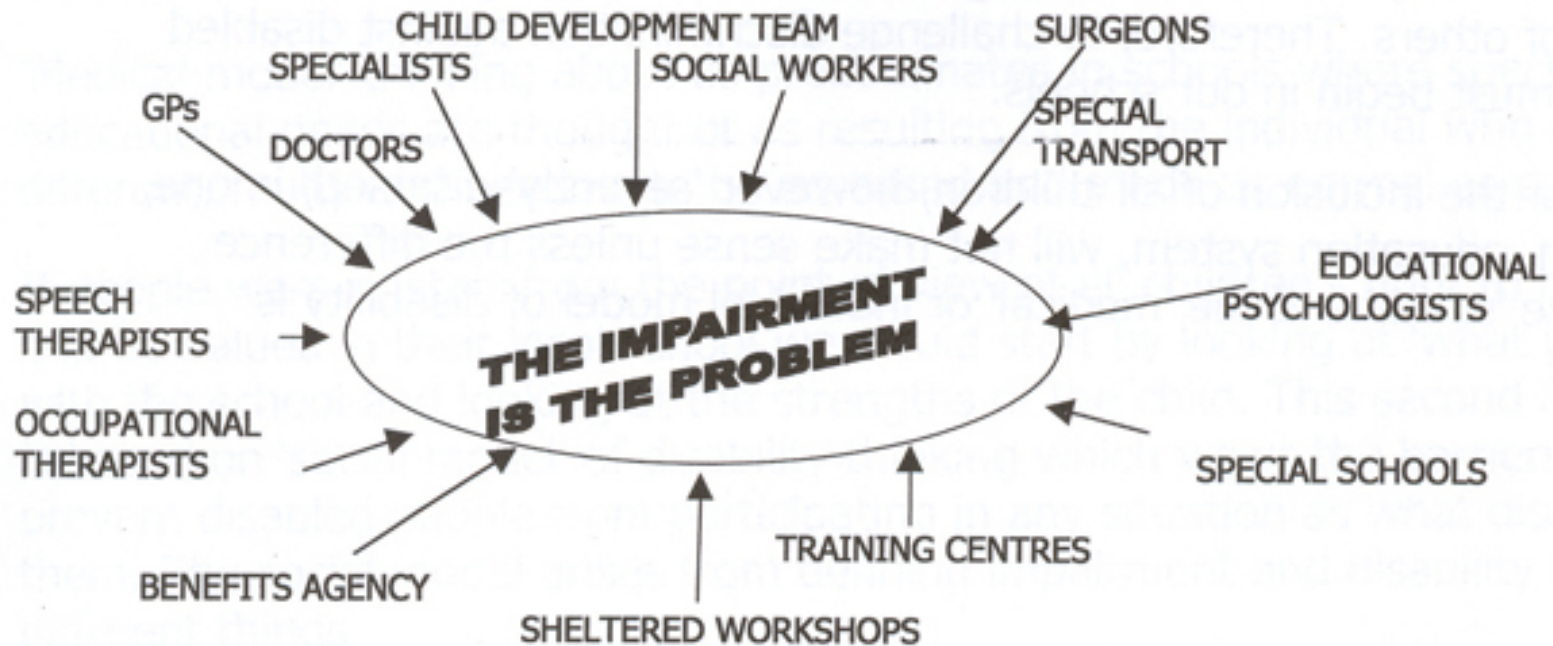PHA Annual Conference
4 August 2012

LIKE MINDS, LIKE MINE
Whakaitia te Whakawhiu i te Tangata

Disability prevalence is high & growing

- 15% global population
- Prevalence growing – due to ageing population, increasing burden of chronic conditions

- Increasing numbers of children living with disabilities surviving longer…

The Medical Model.

CHILD DEVELOPMENT TEAM
SPECIALISTS
SOCIAL WORKERS
SURGEONS
GPs
SPECIAL TRANSPORT
DOCTORS
EDUCATIONAL PSYCHOLOGISTS
SPEECH THERAPISTS
THE IMPAIRMENT IS THE PROBLEM
OCCUPATIONAL THERAPISTS
SPECIAL SCHOOLS
BENEFITS AGENCY
TRAINING CENTRES
SHELTERED WORKSHOPS

DISABLED PEOPLE AS PASSIVE RECEIVERS OF SERVICES
AIMED AT CURE OR MANAGEMENT

The Social Model

LACK OF USEFUL EDUCATION   DISCRIMINATION IN EMPLOYMENT

INACCESSIBLE ENVIRONMENT   SEGREGATED SERVICES

DE-VALUING   **THE STRUCTURES WITHIN SOCIETY ARE THE PROBLEM**   POVERTY

PREJUDICE

'BELIEF' IN THE MEDICAL MODEL

INACCESIBLE TRANSPORT   INACCESSIBLE INFORMATION
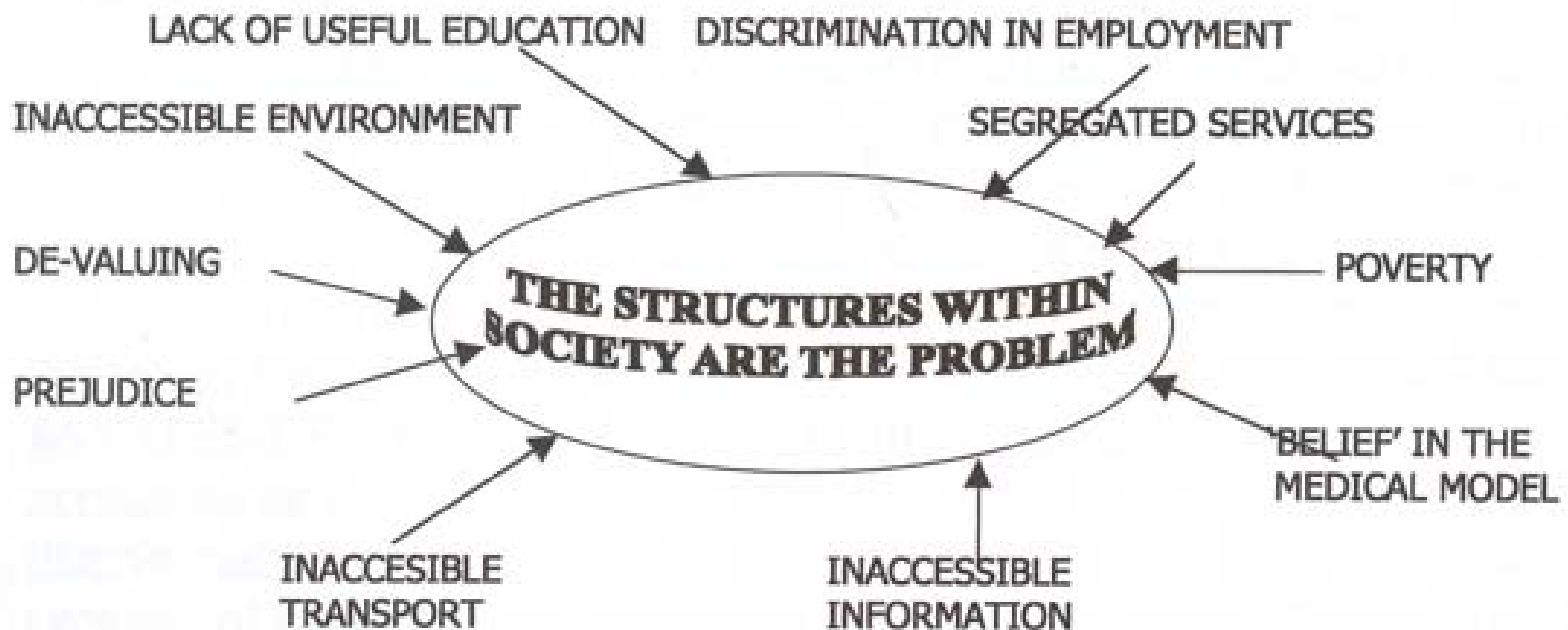
DISABLED PEOPLE AS ACTIVE FIGHTERS FOR EQUALITY WORKING IN PARTNERSHIP WITH ALLIES.

http://ukdisabilityhistorymonth.com

Paradigm shift in approaches to disability

▸ Move away from medical understanding towards social understanding.

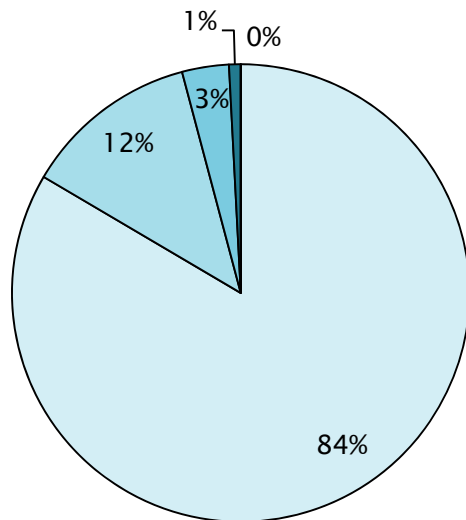▸ Disability arises from the interaction between people with a health condition and their environment.

▸ The CRPD focuses on removing environmental barriers which prevent inclusion.

People with disabilities face significant barriers

- Inadequate policies and standards, lack of service provision, inadequate funding
- Negative attitudes
- Lack of access
- Inadequate information and communication

- Lack of participation in decisions that directly affect their lives

Attitudes are the Real Disability

Nothing about us without us

Application of youth participation framework to Articles in *NZMJ, JPCH, ANZJPH* (2007-11)

Youth consulted and Informed	Youth assigned tasks	Youth involved in decision making
• Focus group • Pilot study • Youth-friendly research • Youth evaluation	• Youth facilitator • Youth recruiter • Youth shape survey • Youth interpretation of data	• Youth decide financial incentive • Youth decide on focus group topic

Pie chart: 1%, 0%, 3%, 12%, 84%

84% no evidence of youth engagement

Benefits of youth participation:

▸ Increased recruitment

▸ Appropriateness of methodology and interpretation of data affirmed

▸ Helps identify unique strengths and sources of resilience

▸ And many more....

Qin R, Ameratunga S, 2012

Youth2000 surveys

"New information and communications technologies can improve the quality of life for people with disabilities, but only if such technologies are designed from the beginning so that everyone can use them."
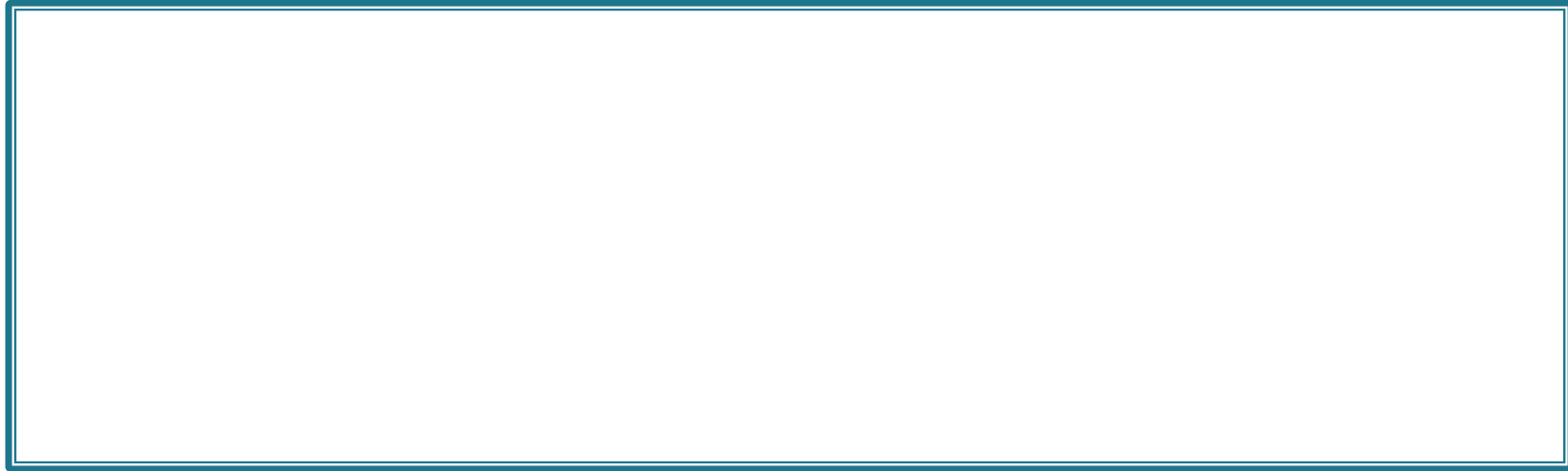
Bill Clinton

Implications

Attitudes are the <u>Real</u> Disability

- Adopt good practices and actively engage youth
- ask why participation is not happening and reduce barriers
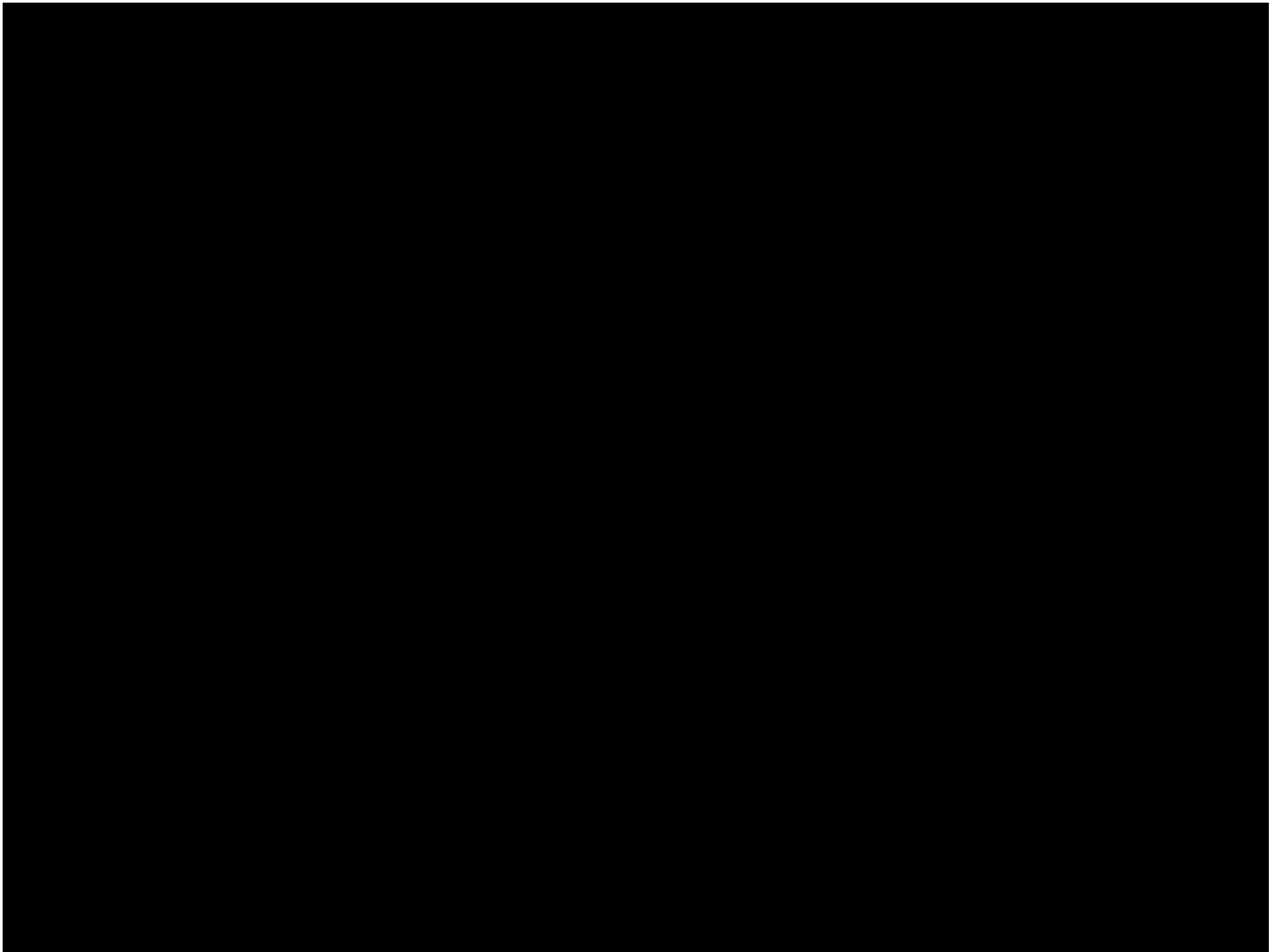

Nothing about us without us

What is the picture that our youth want to see portrayed in
Aotearoa/New Zealand?

▸ "No pessimist ever discovered the secret of the stars, or
sailed to an uncharted land, or opened a new doorway
for the human spirit."

Helen Keller

Reflections for the day...

- To what extent do you inform and educate others in your organisation about positive youth development?
- How can you increase youth involvement in your organisation? More meaningful participation?
- What can you do to make the physical and social climate of your organisation more supportive and welcoming to young people and their families?
- To what extent do you involve youth as primary resources in your agency's written material? In your policies or public relations material?

Adapted from: J Dotterweich, Positive Youth Development Resource Manual: ACT Youth

MEDICAL / SOCIAL MODELS

Medical And Social Model Thinking In Schools

MEDICAL MODEL THINKING	SOCIAL MODEL THINKING
Child is faulty	Child is Valued
Diagnosis	Strengths and Needs defined by self and others
Labeling	Identify Barriers and develop solutions
Impairment becomes Focus of attention	Outcome based programme designed
Assessment, monitoring, programmes of therapy imposed	Resources are made available to Ordinary services
Segregation and alternative services	Training for Parents and Professionals
Ordinary needs put on hold	Relationships nurtured
Reentry if normal enough OR Permanent Exclusion	Diversity Welcomed, Child is Included
Society remains unchanged	Society Evolves

http://ukdisabilityhistorymonth.com

Youth participation in Health Research (Framework)

▸ **Aim:** to investigate the extent to which youth actively contribute to the aim, design and execution of research about their own health

Adult has total control, youth take part in research Degree = 0	Youth consulted and informed Degree =1	Youth assigned research related tasks Degree = 2	Youth involved in decision making Degree =3	Youth initiates decision making Degree = 4

▪ (adapted from Shier's model and Green's guideline)

Qin R, Ameratunga S, 2012