

# Disability and CALD\* Families

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Presentation covers:

➢New Zealand framework for disability & models of disability

CALD Families and their challenges

>Overview of disability services

- ≻Tips for working with CALD families
- ≻Waitemata DHB cultural caseworkers
- ≻Evaluation of CALD CCW project





# **Medical Model of Disability**

- In the past western culture understood disability through what was known as the 'medical model'
- The emphasis was on cure and rehabilitation; the aim to make people as close to 'normal' as possible
- Focus was on what was 'wrong' with the person
- This was useful when people were ill, BUT most people with impairments are very healthy





# **Social Model of Disability**

- Came from the UK in the 1980s
- Challenged the medical model; the focus moved from the individual with the impairment and onto society
- Disability is what happens to people with impairments when society is built without including all people
- Focus is on inclusion and removing barriers

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# **New Zealand Disability Strategy**

- > Published in 2001, embraces the social model
- Vision is a fully inclusive society
- ➢ Based on 15 objectives
- Applies to government departments and agencies
- More information at www.odi.govt.nz





# United Nations Convention on the Rights of Persons with Disabilities

- Aims to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"
- Does not create new human rights for disabled people;
  it builds on what must be done to uphold existing
  human rights as they apply to disabled people





# **Emergence of a rights-based approach**

- New Zealand adopted the UN Convention in 2007 and ratified it in 2008
- All new legislation and policy must be consistent with the Convention
- New Zealand submitted its first report on implementing the UN Convention in March 2011
- More information at www.odi.govt.nz





# **Change takes time**

- New Zealand's approach to disability is moving towards a social model and rights based framework
- Language and terminology relating to disability in New Zealand is in transition e.g. impairment vs. disability
- There are many different views held by New Zealanders about disability





#### Who is included in 'CALD'?

- Culturally and Linguistically Diverse refers to  $\succ$ people who are classified by Statistics New Zealand at Level 2 as Asian NFD, Southeast Asian, Chinese, Indian, Other Asian, Middle Eastern, Latin American/Hispanic, African
- **Refugees: United Nations Human Commissioner** for Refugees (UNHCR) definition; New Zealand annual intake quota of 750 refugees, including 75 in the medical/disabled category





#### **Differences between Refugees and Migrants:**

- ➢ Refugees
- Refugees do not choose to leave their homeland. They flee in response to a crisis.
- Refugees, due to their hurried, or secret departure, are unprepared emotionally for leaving.
- Refugees often flee without any documentation whatsoever.
- Refugees must often leave family members behind.
- Refugees arrive in their new country illprepared and often traumatised with no financial resources.

## > Migrants

- Migrants choose to leave their homeland and settle in a country of their choice.
- Migrants have time to prepare emotionally for their departure and to farewell friends and family appropriately.
- Migrants take with them their travel documents.
- Migrants usually emigrate with their families.
- Migrants are usually well prepared and well motivated to settle in a new country





# How do CALD cultures view disability?

- CALD cultures are more based on family unit than Western culture which focuses more on individuals and individual independence
- Different cultures regard disability in many varied ways – for example: shame, karma, witchcraft, curse, punishment, God's will





# How CALD Cultures view disability?

- CALD families are not likely to be familiar with the social model of disability and the rights based approach being adopted in New Zealand
- CALD people with impairments commonly face discrimination and lack of acceptance within their own communities





# What are the challenges?

- CALD families may not understand how the New Zealand health system works
- CALD families may not know what disability support services are available and how to access them
- The family may have more pressing issue e.g. financial, housing, that need to be addressed first – more common with refugee families

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# What are the challenges?

- The services may be difficult to use (e.g. not culturally appropriate or difficult to understand or CALD parents may have different expectations of services)
- CALD families may have different understandings of disability and different ways of caring for people with disabilities





# What are the challenges?

- In some CALD cultures, families expect to solve problems within the family and do not want to accept help from services
- CALD families with children who have impairments may be isolated from community and this increases the risk of mental health problems as well





# **Disability Service/Support in New Zealand**

- Access to disability support services is through a referral to Taikura Trust (Needs Assessment Service Coordinator or NASC in Auckland region)
- Disability support services include: personal care, carer support, respite care, equipment, rehabilitation, vehicle and house modification, behavioural support, community residential service, etc



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## Many agencies provide disability support services

- Some examples
  - CCS Disability Action
  - IDEA service
  - Spectrum Care
  - > IRIS
  - Disability Connect .....





# Health sector services for children with impairments or developmental needs

- Each District Health Board has a Child Development Service which provides allied health services such as
  - Occupational therapy
  - Speech therapy
  - > Physiotherapists
  - Dietitians
  - Visiting Neurodevelopmental Therapists
  - Social Workers





#### **Education services for children with impairments**

- Ministry of Education
  - Early Childhood Intervention: 5% of children get special education support
  - School aged children: 4% of students get funding for special education





# Working with Children from CALD backgrounds

- ➢ Work with families to achieve their goals
- Identify the main caregiver and key decision maker – these may not be the parents
- Find a balance between the family's collective approach and western medicine's goal of individual independence





# Working with Children from CALD backgrounds

- Parents need support and training on how to manage challenges
- Special issues affecting refugee children and their families: malnutrition, intellectual delay, anxiety because of their horrendous experiences in countries of origin and prolonged journeys in refugee camps





- Funding from Ministry of Health under the Auckland Regional Settlement Strategy
- The 3 Auckland DHBs received funding for
  - Improving access to child disability services and responsiveness of services
  - Interpreter services in primary care
  - Cultural competency training for health staff





- Main purpose is to develop a model for CALD cultural caseworkers in DHB child disability services
- Established two CALD cultural caseworker positions





# **CALD Cultural Case Worker's role**

- Provide cultural support services to children and families from CALD back grounds
- Educate parents about NZ health system and NZ perspectives of disability
- Advocacy as needed to ensure the allocation of support services for children of CALD background





# **CALD Cultural Case Worker's role**

- Provide advice and support as needed to assist Child Health team members
- Assist teams with eliciting consumer feedback and supporting complaints resolution
- Provide information on cross-cultural resources and training, services available to CALD children and families; NASC system



# **Case Study 1:**

2 year old young girl who arrived NZ when she was 6 months old frm Middle East with very complex medical needs including:

- 1. Hypotonic CP
- 2. Microcephaly
- 3. Global developmental delay
- 4. Visual impairment
- 5. Difficult to control epilepsy
- 6. Poor weight gain
- 7. Previous barium swallow normal
- 9. Nasogastric feeding
- 10.Failure to thrive.
- 11.Epilepsy



## **Social Backgrounds:**

- This girl came to New Zealand with her mother who speaks no English through family reunification
- Mother is also very isolated socially and has no immediate family or friends in New Zealand..

# **Service Provision Now:**

- This child was referred to Waitakere Child Development Service by her Paediatrician, for input from the Speech Language Therapist (SLT), Visiting Neurodevelopmental Therapist (VNT), Dietitian and Cultural Case Worker.
- Other agencies that are involved include: Taikura Trust, Palliative care, Blennz and LifeWise.



# **CCW's Input:**

- Organise/reschedule Clinical appointments
- Organise MDT (Multidisciplinary team) meetings
- Helped to set up Individualising funding
- Help finding carer support workers
- Link with parent support groups for socializing
- ➢ Help with Disability Allowance with WINZ
- Helping with Housing NZ
- Cultural support and advocacy.
- Clarification of health professional roles,
- Eg: SLT, PT,OT, CCW etc as well as organizational



# Case Study 2:

14 year old boy with autism.

## Issues

- Severe intellectual handicap
- Sleeping problems
- Obesity and Poor school attendance
- Unhygienic living conditions
- Father is awaiting liver transplant and mother has thyroid disease

#### **Service Provision Now:**

OT and Cultural Case Worker from the CDS North, Home Care for Kids



# **CCW's Input**

> Arrange Warm Up insulation programme and nappy donation

- Education of the NZ disability service system for the father (Distrust for the NZ health system)
- Link with the cultural community support group
- Work together with the school for the boy to get back into normal sleeping pattern and go to school in the morning
- Organise a professionals' meeting or Strengthening Families Meeting





CALD Parent Education Seminars (3 seminars)







#### Parent Focus Groups (4 groups)







- ➢ Other work includes
  - Established Asian Family Autism Support Group
  - Translation of service brochures and consumer feedback form into CALD languages
  - Funded development of CALD training module Working with CALD Families – Disability Awareness (Oct 4 Lecture)





#### **Evaluating the cultural caseworker model**





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# **Evaluation findings (CRRC)**

#### What the cultural caseworkers were doing?

- Building relationships/trust
- $\blacktriangleright$  Education and information sharing
- > Advocacy
- $\succ$  Linking families to health and other services
- > Practical support

#### **Benefits to families included**

- $\succ$  improved access to health and other services
- $\blacktriangleright$  reduced isolation
- increased knowledge about a range of issues and topics
- > an improved living situation



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# Q & A

