NOTHING ABOUT US WITHOUT ALL OF US

Professor Peter Mittler
DAI Human Rights Adviser
Global Dementia Charter

“I CAN LIVE WELL WITH DEMENTIA”

I should have:

ACCESS TO A DOCTOR to check if I have dementia (25)
- medicine and treatment that helps me (25, 26)
- high quality care that’s right for me (9, 25, 26)

A SAY in the care and support I am given (21, 25, 26)

HELPED TO LIVE INDEPENDENTLY for as long as I can (19)

TREATED AS AN INDIVIDUAL: those looking after me knowing me

RESPECTED for Who I Am (3a, d)

MY END OF LIFE WISHES discussed with me while I can do so
QUESTIONS TO PEOPLE AFFECTED BY DEMENTIA

• What do you know about the disability movement in your country?

• Do organisations for different groups of disabilities work together to lobby governments to achieve change?

• Is the voice of people with dementia being heard?
QUESTIONS TO ALZHEIMER SOCIETIES

To what extent are your policies based on human rights?

How closely do you work with other disability organisations in your country or region?

Do you know how they have used CRPD?

Would you work with them to ensure that people with dementia are included?
PEOPLE WITH DEMENTIA INCLUDED IN CRPD

DEFINITION - BUT NOT IMPLEMENTATION

• ‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments

• which in interaction with various barriers

• may hinder their full and effective participation in society on an equal basis with others.’ (Article 1).
WHAT DOES THE CONVENTION SAY?

• **GENERAL PRINCIPLES**
  
• Respect for dignity, autonomy, freedom to make choices, independence
• **Non-discrimination (e.g. age, gender, disability)**
• Full participation & inclusion in society
• Respect for difference; acceptance of disability as part of human diversity
• **Equality of opportunity**
• Accessibility
• **Equality between men and women**
LIVING INDEPENDENTLY IN THE COMMUNITY
CRPD Article 19

- **19a**: Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

- **19b**: Persons with disabilities have access to a range of in-home, residential and other community services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

- **19c**: Community services and facilities for the general population are available on an equal basis and are responsive to their needs.
ARTICLE 25: HEALTH

Same range, quality and standard of free, affordable health care

Disability-relevant services:
• early detection & intervention
• services to minimise further disabilities - including older persons.

• AS CLOSE TO HOME AS POSSIBLE

• No discrimination in health insurance, denial of health care, food or fluids on the basis of disability
ARTICLE 26: REHABILITATION

• Based on early multi-disciplinary assessment of individual needs & strengths

• Use of assistive devices and technologies designed for persons with disabilities

• Promote initial and continuing training for professionals and staff
REHABILITATION PATHWAY

HOME VISITOR TO SUPPORT CARE COUPLE-FAMILY & LINK TO

- Occupational therapist- adaptations to home/appliances (PC)
- Family doctor: check on medications, general health, co-morbidities
- Specialist clinical nurses- eg palliative care
- Physiotherapist- maintain mobility, strength, prevent falls
- Speech therapist: promote language/communication skills
- Clinical psychologist: maintaining cognitive function, psychological interventions, well-being, quality of life
- Social workers: family issues, access to community services
WHO GLOBAL DISABILITY ACTION PLAN 2014-2021

OBJECTIVE 1: TO REMOVE BARRIERS AND IMPROVE ACCESS TO HEALTH SERVICES AND PROGRAMMES

Evidence of success

Existence of health policy based on CRPD

Universal health coverage inclusive of persons with disabilities
COMMUNITY-BASED REHABILITATION
A home-based first line of support

Can help to ensure that the benefits of the Convention reach people with disabilities at the local level through:

• familiarizing people with the Convention – actively promoting the Convention and helping people to understand its meaning;

• collaborating with stakeholders – working with nongovernmental organizations, including disabled people’s organizations and local governments, to implement the Convention;

• engaging in advocacy activities which aim to develop or strengthen antidiscrimination laws and inclusive national and local policies relating to health, education and employment and community supports.
CBR MATRIX

HEALTH
- Promotion
- Prevention
- Medical Care
- Rehabilitation
- Assistive Devices

EDUCATION
- Early Childhood
- Primary
- Secondary & Higher
- Non-Formal
- Lifelong Learning

LIVELIHOOD
- Skills Development
- Self-Employment
- Wage Employment
- Financial Services
- Social Protection

SOCIAL
- Personal Assistance
- Relationships
- Culture & Arts
- Recreation, Leisure & Sports
- Justice

EMPOWERMENT
- Advocacy & Communication
- Community Mobilization
- Political Participation
- Self-Help Groups
- Disabled People's Organizations

Support and Advocacy: Of, by and for people with dementia
DAI’S QUESTION TO WHO AND GOVERNMENTS

- Does WHO’S full commitment to CRPD include people with dementia?
- Do the 162 governments who have ratified CRPD include people with dementia in its implementation?
- If so, is this delegated to Health Ministries or seen as a responsibility of all Ministries?