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LIVING WELL WITH DEMENTIA: A FUNDAMENTAL HUMAN RIGHT

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**DEMENTIA
ALLIANCE
INTERNATIONAL**

Support and Advocacy: Of, by and for people with dementia

“Dementia receives the worst care in the developed world”

**Organisation for Economic
Cooperation and Development
(2015)**



"When making policy for dementia, don't forget to listen to the real experts - the people who live with it."
Hilary Ratner
Chair, European Working Group of People with Dementia

The Human Rights of People Living with Dementia: from Rhetoric to Reality

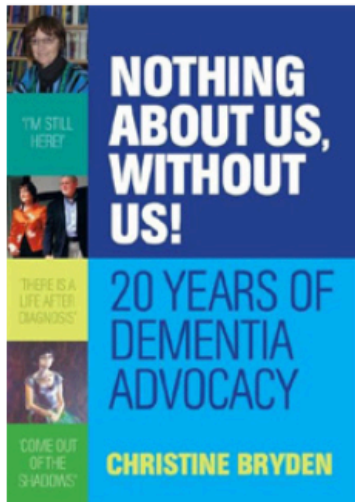


HOLDING GOVERNMENTS TO ACCOUNT

- ASK US
- What Matters to Us
- What changes do we want to see?
- LISTEN TO US
- WORK IN PARTNERSHIP WITH US
- WE ARE EXPERTS BY EXPERIENCE



NOTHING ABOUT US WITHOUT US



Bryden, C. (2015). *Nothing About Us Without Us*. London: Jessica Kingsley.

IN 2015, DAI'S CHAIR KATE SWAFFER DEMANDED:

- **Policy and practice should be based on UN Convention on the Rights of Persons with Disabilities**
- **That research should focus as much on care and support as on cure**
- **A more ethical pathway of care, including pre and post-diagnostic support from a wide range of professionals in the community**

BOOKS BY PEOPLE LIVING WITH DEMENTIA

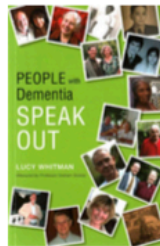
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Swaffer, K. (2016). *What the Hell Happened to My Brain?: Living beyond dementia*. London: Jessica Kingsley.



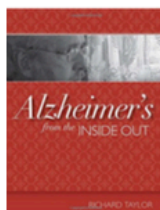
Rohra, H. (2016). *Dementia Activist: Fighting for Our Rights*. (translated from German original). London: Jessica Kingsley.



Whitman, L. (ed) (2015). *People with Dementia Speak Out*. London: Jessica Kingsley.



Bryden, C. (2015). *Nothing About Us Without Us*. London: Jessica Kingsley.



Taylor, R. (2007). *Alzheimer's From the Inside Out*. Baltimore, Md: Health Professions Press. 5th printing 2015.

ADI 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

Towards a Rehabilitation Pathway: A THOUGHT EXPERIMENT

- **You have sustained a severe brain injury as a result of**
 - stroke, road traffic accident, penetrating bullet wound, etc.
- **What services and supports would you expect to receive**
 - in hospital
 - prior to discharge
 - at home?

Rehabilitation Team

- **Specialist in rehab medicine**
- **Physiotherapist –restore mobility, balance**
- **Speech and language –communication, swallowing**
- **Clinical psychologist – cognitive functioning**
- **Social worker- plan transition to home**
- **KEY WORKER appointed at time of diagnosis**
- **Occupational therapist- adaptations to home, PC**
- **Other specialists from all relevant agencies**

PEOPLE WITH DEMENTIA ARE INCLUDED IN CRPD DEFINITION BUT NOT IN ITS 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).*

USING CRPD TO PROMOTE THE RIGHTS OF PEOPLE WITH DEMENTIA

GENERAL PRINCIPLES

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination e.g. age, gender, race, disability
- Full participation and inclusion in civil society
- Respect for difference; acceptance of disability as part of human diversity
- Equal opportunity
- Accessibility
- Equality between women and men

CRPD ARTICLES

- Right to Life
- Accessibility at all levels
- Equal Recognition Before the Law
- Freedom from torture, cruel, inhuman or degrading treatment, exploitation, violence and abuse
- Living independently and participation on in the community;
- Respect for home and family
- Health
- Rehabilitation
- Employment
- Adequate standard of living and social protection
- Participation on in political and public life, cultural life, recreation, leisure and sport

HOW CAN THE CONVENTION BE USED BY ALZHEIMER ASSOCIATIONS AND SELF-ADVOCACY GROUPS?

Lobbying to ensure that regional, national and local dementia policies and future plans reflect CRPD Principles and Articles

Insisting on the right of people with dementia to participate as equals in the development of policy and in the implementation of the CRPD (Art. 33.3)

Using their right to submit parallel reports when their country is reporting to the CRPD Committee

Publicising the Committee's Concluding Observations to advocate for the implementation of its Recommendations.

TWO PLANETS

PLANET DISABILITY

PLANET DEMENTIA

“The UN Disability Convention is a mirror to society. It makes us face up to our own values and it forces us to acknowledge the large gap that still exists between the ‘myth system’ of our own values... and the ‘operations system’ of how these values are dishonoured in daily practice.

Thus the Treaty is a force for rationality as well as a vehicle for carrying these values squarely to the heart of the disabilities field.

As with all mirrors, we can refuse to look into them; we can look at them but ignore their reflection or we can take notice of our reflection and *commit to a process of change*”.

(Gerard Quinn 2009)

NEXT STEPS

- ADI-DAI will meet the CRPD Committee in August
- Support AS societies in developing HR policies &
- submitting parallel reports to UN
- DAI will promote human rights approach at next regional conferences- Europe & Asia Pacific
- Raise our concerns about human rights of persons with dementia in WHO Disability Policy, CBR and regional and national dementia strategies.

THANK YOU



**DEMENTIA
ALLIANCE
INTERNATIONAL**

The global voice of dementia