**DEMENTIA ALLIANCE INTERNATIONAL[[1]](#endnote-1)**

**POSITION PAPER: UN GENERAL DAY OF DISCUSSION ON CRPD ARTICLE 19**

**THE RIGHT OF PERSONS LIVING WITH DEMENTIA TO BE SUPPORTED TO LIVE INDEPENDENLY IN THE COMMUNITY**

Professor Peter Mittler, DAI Member and Human Rights Adviser

SUMMARY

This submission invites the UN CRPD Committee to take steps to ensure that persons living with dementia are fully included in the implementation of the Convention and the UN 2016-2030 Sustainable Development Goals in order to enable them to fulfil their stated aim “to be helped to live as independently as possible in the community[[2]](#endnote-2).

This is a world-wide priority for 47.5 million people now living with dementia and a policy imperative for those who will be diagnosed in the decades to come, especially in Low and Middle Income Countries.

INTRODUCTION

Dementia Alliance International was founded in 2014 by people with a diagnosis of dementia across the world and now has 1500 members. It provides a unified voice in claiming their fundamental human right to supports and services to enable them to live well in their community for as long as possible on the same basis as their fellow-citizens.

Dementia Alliance International is the voice of people with dementia. It works closely but autonomously with Alzheimers Disease International[[3]](#endnote-3)- the global voice for people with dementia.

Our joint aims are to

* Use the CRPD to secure the recognition of the human rights of persons with dementia- internationally, regionally, nationally and locally
* Ensure that CRPD implementation by Member States includes people with dementia
* New developments in policy and practice for people with dementia are based on CRPD Principles and Articles
* Build awareness, commitment and capacity among self-advocates and organisations for persons with dementia to use the CRPD as a tool for change
* Encourage and inform submissions to the CRPD Committee to secure the inclusion of the rights of persons with dementia in its List of Issues and Concluding Observations and in its relationships with other UN and international agencies in the implementation of the UN 2016-2030 Sustainable Development Goals.

BACKGROUND

Until recently, neither persons with dementia nor national Alzheimers Societies have used their right of access to CRPD to which they are legally entitled in the characterisation of disability in Article 1.

*“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 active participation in society on an equal basis with others”*

It is against this background that DAI Chair and CEO Ms Kate Swaffer included ‘Access to CRPD’ as one of its demands at the WHO First Ministerial Conference on Dementia in March 2015. In addition, a strong, human-rights based resolution submitted by Alzheimers Disease International on behalf of 38 national Alzheimers Associations was reflected in the first of the General Principles of the Call for Action by WHO Director Dr Margaret Wang[[4]](#endnote-4).

Although 163 Member States and the European Union have ratified the Convention, there is no evidence that persons with dementia are being included in its implementation at national level. This reflects a pervasive assumption that dementia is the sole responsibility of Health ministries, rather than a joint responsibility across all Departments of State, including Housing, Social Care and Protection, Transport and Justice to enable persons with dementia to have access to the whole range of supports, services and amenities available to their fellow-citizens (Article 19c).

OBSTACLES TO CONTINUED PARTICIPATION IN THE COMMUNITY

*Persons with dementia have ‘lived independently and been included in the community’ all their lives but encounter deep-rooted and systemic attitudinal and societal obstacles to continue to do so following diagnosis.*

DISENGAGEMENT BY DIAGNOSIS

Exclusion from the community frequently begins with the first disclosure of a diagnosis of dementia. Accounts by persons with dementia in books[[5]](#endnote-5), DAI weekly support groups and the social media include numerous examples of the ‘good, the bad and the ugly’ in ways in which the diagnosis is communicated by clinicians. A book by the late Richard Taylor[[6]](#endnote-6), a former clinical psychologist, includes a classic chapter based on his personal as well as professional experience contrasting good with bad practice in ways of communicating a diagnosis of dementia.

Kate Swaffer[[7]](#endnote-7) uses the term ‘Prescribed Disengagement® to characterise the advice that she received to “give up work, give up study, go home and *live* for the time you’ve got left.” Her husband was told he would soon have to give up work to care for her.

Legal capacity and fitness to drive are immediately threatened by a diagnosis of dementia, rather than evaluated by independent assessment of functioning. This can be particularly traumatic for people with Younger Onset Dementia in mid-career and with responsibilities for young children and elderly parents.

SOCIAL ISOLATION

Many people with dementia have described the loneliness and social isolation which they experience when friends and even family members stop visiting and neighbours cross the street to avoid meeting them. Their isolation is increased by fear of failure and humiliation in going out. Loss of self-identity and self-esteem can occur when household tasks and responsibilities are taken over by the care partner, sometimes on the advice of a professional.

STIGMA

Dementia has now replaced cancer as the illness most feared by the general public and is the reason why many people hesitate to seek help if they are worried about their memory or cognitive functioning. The stigma surrounding dementia is fuelled not only by the media but by politicians and clinicians who talk about time bombs and tsunamis and commit to a ‘world without dementia’ within a generation.

In the meantime, stigma is reflected in the conclusion of an OECD[[8]](#endnote-8) study that “dementia receives the worst care in the developed world” and a WHO[[9]](#endnote-9) statement that the disability arising from dementia is higher than in almost all other conditions, with the exception of spinal cord injury and terminal cancer.

PREMATURE RESIDENTIAL CARE (Article 19a)

Most people with dementia in High Income Countries continue to live with a care partner, with supports ranging from zero to daily visits from a support worker, funded by themselves or a publically-funded agency. The 30 per cent of people with dementia who live alone miss out on even more support due to their single status and inability to register a family carer. In many Low and Middle Income Countries the only alternative is a distant institution.

A person admitted to hospital for reasons not directly connected to their dementia is likely to stay in hospital for much longer than a person without dementia, due as much to the poor care which they receive as to their partner being unable to care for them at home.

A recent UK report[[10]](#endnote-10) based on information collected under the Freedom of Information Act reports that

* People with dementia stay five to seven times longer in the worst performing hospitals than other people over the age of 65
* 52-71 per cent of people over 65 who had a fall were people with dementia
* Thousands of people with dementia are being discharged between 11pm and 6am each year.

The risk of transfer to residential care could be reduced by contingency planning with a key worker familiar with the person’s home circumstances. Once in residential care, isolation from the community is compounded by the possibility that some family members and friends will stop visiting, especially if the person with dementia does not appear to recognise them or is uncomfortable in their presence.

THE CARE COUPLE

Many professionals and policy makers generalise about ‘carers’ as if they were a homogeneous group, despite evidence of their individuality in the social media and in the rich variety of their writing[[11]](#endnote-11). Because care partners are the main source of support for the person with dementia to live at home and to remain a member of the community, they too have the right to whatever support is needed to help them to do so.

25 per cent of persons with dementia and 50 per cent of care partners are clinically depressed. Richard Taylor’s account of crying for weeks following diagnosis reflects a need for crisis counselling both for him and his wife. His discussion of the impact of the initial impact of his diagnosis and difficulties on his relationship to his wife suggests that both might have been helped by couple counselling.

REHABILITATION PATHWAY

Poor support for people newly diagnosed with dementia is in strong contrast to rehabilitation programmes tailored to the specific needs of people who sustain severe brain damage as a result of a stroke or traffic accident. Kate Swaffer contrasts the current medical model of care with a support pathway based on CRPD[[12]](#endnote-12). A service along these lines in provided in the State of Queensland, Australia[[13]](#endnote-13).

The concept of ‘post-diagnostic support’ needs to be reconceptualised as a rehabilitation pathway which begins at the time of diagnosis with the offer of a follow-up visit to the hospital or memory clinic where the diagnosis has been given and provides opportunities to ask questions and discuss ways in which support can be given.

From this point, a qualified key worker needs to be appointed to maintain contact with the person with dementia and family members to discuss needs and priorities and provide links to necessary services and supports from all relevant services and community supports.

A rehabilitation pathway should provide access to a wide range of specialists. These include:

* Occupational therapists to discuss possible adaptations to the home and domestic appliances, television sets and personal computers
* Physiotherapists to maintain mobility and strength
* Speech and language therapists to promote language and communication
* Clinical psychologists to advise on adjustment to diagnosis, improving and maintaining cognitive functioning, maintaining independence and quality of life[[14]](#endnote-14)
* Social workers to consider family issues and provide access to community resources.

PLANNING FOR THE FUTURE

INCLUSION IN UN 2016-2030 SUSTAINABLE DEVELOPMENT GOALS[[15]](#endnote-15)

The UN 2016-2030 Sustainable Development Goals were launched with a commitment to Leave No One Behind. As a consequence of sustained advocacy, persons with disabilities are now clearly included in the 17 SDGs and 169 implementation indicators. Although the needs of older persons are recognised, persons with dementia are in grave risk of being overlooked.

COMMUNITY-BASED REHABILITATION

Persons with dementia in Low and Middle Income Countries should be able to benefit from the long established WHO Community-Based Rehabilitation Programme which aims to provide a home-based, first line of support to persons with disabilities and their families from local health and community workers, as well as persons with disabilities and family members.

The most recent revision of the CBR Training Manuals[[16]](#endnote-16) was co-written with Disabled Persons’ Organisations and draws on CRPD Principles and Articles to inform policy and practice. The Convention has also been used to underpin the WHO 2014-2021 *Disability Action Plan[[17]](#endnote-17)* but it is not clear whether persons with dementia will benefit from either of these initiatives.

REGIONAL AND NATIONAL DEMENTIA STRATEGIES

As a result of G8 and G7 leadership and the WHO Global Dementia Strategy, Dementia Strategies have been launched by the European Commission, the Pan-American Health Authority and several Member States. Although nearly all participating governments have ratified the Convention, we can find no evidence of it being used to underpin policies.

**RECOMMENDATION**

**Dementia Alliance International requests the CRPD Committee to take steps to raise awareness of the rights of persons with dementia among Member States and at all levels of the United Nations to ensure that they are included in its monitoring and implementation.**

**ARTICLE 19: GENERAL ISSUES FROM A DEMENTIA PERSECTIVE**

1 Dementia is one of several health conditions that suggest the need for greater consideration of the impact of impairments on day to day functioning (e.g. epilepsy, Parkinson’s’ Disease, Motor Neurone Disease). Although dementia is a progressive disorder, the rate of deterioration over a period of years is highly variable and levels of functioning also vary from day to day in ways that cannot be captured by routine assessments which influence decisions on legal capacity. There is often a mismatch between performance on tests and everyday life.

2 Other commentators have pointed out that Living Independently does not mean Living Alone. Article 19 is one of several where the focus is on the individual without sufficient regard to those with whom they share their lives - in particular the person who will lose their identity as a life partner and be automatically designated as ‘the carer’ at the time of diagnosis. Service planners, providers and supporters need to have regard to the dynamics of the ‘care couple and to the distinctive needs of each.

3 Early versions of the social model of disability conceptualise the environment in terms of obstacles that need to be overcome (e.g “parents are our enemies”) rather than the opportunities it can or could provide to support the person to live independently and be included in the community.

Peter Mittler

1. <http://www.infodai.org> [↑](#endnote-ref-1)
2. <http://www.alz.co.uk/sites/default/files/pdfs/global-dementia-charter-i-can-live-well-with-dementia.pdf> [↑](#endnote-ref-2)
3. <http://www.alz.co.uk> [↑](#endnote-ref-3)
4. <http://www.who.int/mental_health/neurology/dementia/call_for_action_en.pdf?ua>= [↑](#endnote-ref-4)
5. Swaffer, K. (2016) *What the Hell Happened to My Brain?* London: Jessica Kingsley Publishers; Taylor, R (2009) *Alzheimer’s From the Inside Out*. Baltimore, Md: Health Professions Press; Whitman, L.(ed.) (2016) *People with Dementia Speak Out.* London: JKP; Rohra, H. (forthcoming) *Coming Out of the Shadows: Why I Advocate for People with Dementia.* London: JKP. [↑](#endnote-ref-5)
6. Taylor, R*. op.cit.* If I were an M. and not a Ph.D. [↑](#endnote-ref-6)
7. Swaffer, K. (2015) ‘Dementia and Prescribed Disengagement’. *Dementia, 14*(3), 3-6. [↑](#endnote-ref-7)
8. <http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/addressing-dementia_9789264231726-en#page1> [↑](#endnote-ref-8)
9. WHO (2004) *Global Burden of Disease*. <http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf?ua=1> [↑](#endnote-ref-9)
10. Alzheimer’s Society (2016) *Fix Dementia Care Hospitals.* [www.alzheimers.org.uk/fixdementiacare](http://www.alzheimers.org.uk/fixdementiacare)

    [↑](#endnote-ref-10)
11. Whitman, L. ed.) (2009) *Telling Tales About Dementia: Experience of Caring*. London: JKP; Magnusson, S. (2014) *Where Memories Go.* [www.tworoadsbooks.com](http://www.tworoadsbooks.com) [↑](#endnote-ref-11)
12. Swaffer, K. (2016) *op.cit* pp.165-166. [↑](#endnote-ref-12)
13. <https://www.health.qld.gov.au/cairns_hinterland/docs/gp-dementia-enablement-guide.pdf> [↑](#endnote-ref-13)
14. British Psychological Society (2014) *A Guide to Psychosocial Interventions in Early Stages of Dementia; Clinical Psychology in the Early Stages of the Dementia Pathway.* [www.bps.org.uk/fpop](http://www.bps.org.uk/fpop) [↑](#endnote-ref-14)
15. UN Sustainable Development Goals. <http://www.undp.org/content/undp/en/home/sdgoverview/post-2015-development-agenda.html> [↑](#endnote-ref-15)
16. WHO, UNESCO, ILO & IDDC (2010) *Community Based CBR Guidelines: Introductory Booklet,* Geneva: WHO. <http://apps.who.int/iris/bitstream/10665/44405/9/9789241548052_introductory_eng.pdf> [↑](#endnote-ref-16)
17. WHO (2014) *Global Disability Action Plan 2014-2021: Better Health for All Disabilities.* Geneva :WHO <http://apps.who.int/gb/ebwha/pdf_files/EB134_16-en.pdf?ua=1> [↑](#endnote-ref-17)