**DEMENTIA ALLIANCE INTERNATIONAL**

**Professor Peter Mittler, Human Rights Consultant**

**Ms Kate Swaffer, Co-Founder, Chair and CEO**

Dementia Alliance International was founded in 2014 by persons with a diagnosis of dementia across the world and now has some 3000 members in 35 Member States. 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[[1]](#endnote-1)- 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 building by 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.

*We ask the Committee to consider the following comments on the draft General in the wider context of our contribution to the Day of General Discussion in April 2016.*

PURPOSE

For persons living with dementia, their care partners and members of their household, Article 19 lies at the heart of their aspirations to be supported by professional and community agencies to continue to live at home for as long as possible.

We therefore wish to register a formal objection to Paragraph 47 and to ask for it to be removed.

For the past 11 years, the Committee has insisted on the run down and eventual closure of institutions by all Member States and has opposed attempts to re-introduce them in different forms in community settings.

Persons with dementia are particularly vulnerable to decisions taken by others for a variety of reasons. In this context, the Committee’s insistence on supported decision-making in Article 12 is fully justified.

*Examples of the experience of persons with dementia are given in extracts from our submission to the General Day of Discussion on Article 19*

**DEMENTIA ALLIANCE INTERNATIONAL[[2]](#endnote-2)**

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

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

Professor Peter Mittler, DAI Member and Human Rights Adviser

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.*

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[[3]](#endnote-3) study that “dementia receives the worst care in the developed world” and a WHO[[4]](#endnote-4) 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[[5]](#endnote-5) 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 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[[6]](#endnote-6). 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 (Article 19b)

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[[7]](#endnote-7). A service along these lines in provided in the State of Queensland, Australia[[8]](#endnote-8).

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[[9]](#endnote-9)
* Social workers to consider family issues and provide access to community resources.

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

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.alz.co.uk> [↑](#endnote-ref-1)
2. <http://www.infodai.org> [↑](#endnote-ref-2)
3. <http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/addressing-dementia_9789264231726-en#page1> [↑](#endnote-ref-3)
4. WHO (2004) *Global Burden of Disease*. <http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf?ua=1> [↑](#endnote-ref-4)
5. Alzheimer’s Society (2016) *Fix Dementia Care Hospitals.* [www.alzheimers.org.uk/fixdementiacare](http://www.alzheimers.org.uk/fixdementiacare)

 [↑](#endnote-ref-5)
6. 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-6)
7. Swaffer, K. (2016) *op.cit* pp.165-166. [↑](#endnote-ref-7)
8. <https://www.health.qld.gov.au/cairns_hinterland/docs/gp-dementia-enablement-guide.pdf> [↑](#endnote-ref-8)
9. 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-9)