**ANNEX 1 TO DEMENTIA ALLIANCE SUBMISSION TO SPECIAL RAPPORTEUR**

**CRPD FROM A DEMENTIA PERSPECTIVE**

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The road to a diagnosis of dementia can be long, stressful, beset by unrealistic expectations, fears based on myth, unfounded hopes and certain confusion. We must change the approach of treating people with dementia as having lost capacity from the moment they are diagnosed; instead, it needs to be acknowledged that we are now living 20 years and more beyond diagnosis, and striving to live well. We are not invisible; we are not children, and we will not be ignored or shunted aside.

It is our right – whether at home, on a bus, at a concert, a sports event, a restaurant, a doctor’s office to be treated with dignity and respect. We still count, we are loved, sometimes well-educated, verbose, funny, and above all human.

 By creating a culture where our well-being and health are addressed, communities can establish a stable environment that improves our ability to live well with – and even beyond dementia. We deserve the same respect and high-quality care that would be given to a rocket scientist, a movie star, a surgeon, or a college professor – because that’s exactly who we are.

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| **CRPD Article** | **Expectations for States to Ensure our Rights** |
| **Article 1 Eligibility**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. **Article 4 General Principles** **Article 10 - Right to life**Every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others. | From a human rights perspective, the biggest barrier is the Iron Curtain that separates dementia from disability. This has led to the assumption that we are not included in CRPD and are solely a Health responsibility, rather than the joint responsibility of all government departments for the well- being of all their citizens. This has led to persons with dementia being excluded by Member States from their implantation of the Convention and to the absence of evidence of the use of CRPD General Principles and Articles in the regional and national |Dementia Strategies launched by Member States who have ratified it Seven of the eight General Principles are systemically disregarded in respect of persons with dementiaThe right to life is frequently breached by gross neglect, the high risk of falls and premature discharge from general hospitals, often at night without ensuring that appropriate care and support are available.  |
| **Article 25 - Health**25d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent. 25e. Prohibit discrimination against persons with disabilities in the provision of health insurance and life insurance…25f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. | Doctors should give me the full truth about my health condition, recommended medical procedures, and options. Doctors do not have the right to decide which information to give or withhold or whether to give it to me or a care partner, nor to insist on handing over my driving license. The government must provide the specialized physical and mental health care I need, including dietary requirements, vitamin and mineral supplements, regardless of my ability to pay, such that I may have the same opportunity to enjoy life as people without disabilities.  |
| Article 26 - Habilitation and rehabilitation1. Enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:26.b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas. | Doctors must start by prescribing rehabilitation for abilities I’ve lost. A body with dementia can still heal and the mind can still learn, sometimes to PhD level. I may need vocational and physical therapy, speech and language therapy, rehabilitative education, grief counseling, psychotherapy, an emotional support animal, yoga, meditation, acupuncture, an exercise regimen and more. My care partner and I may need support training, both individually and together. State and private providers, medical and non-medical professional staff. hospitals, libraries, and other agencies must provide information about access to community agencies providing education and re-education and to social and employment services. Support people will need to learn adaptive communication skills to speak with me; they need to slow down, give me time to think, acknowledge they understand me, keep out noise and distractions, and understand nonverbal messages.  |
| **Article 19 - Living independently and being included in the community**States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: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. …access to in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; | Post-diagnostic support for living well with dementia must include referral to community based organizations, support groups, DPOs, and a variety of rehabilitative pathways (see separate attachment for DAI submission to the UN General Day of Discussion on Article 19).  |
| Article 28 - Adequate standard of living and social protection1. The right… to an adequate standard of living for themselves and their families, including adequate food, clothing, housing, and to the continuous improvement of living conditions28.1b.To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection and poverty reduction programmes;28.1c.To ensure access by persons with disabilities and their families living in poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care.28.1d. …public housing programmes. | Assistive devices and services to help me achieve the maximum reasonable independence.The government must provide safe shelter to homeless individuals and their dependents. Many people with moderate to severe dementia are poor and homeless, as mental institutions have closed and many hospitals refuse to keep them unless they have urgent medical needs. Hospitals should not be allowed to “discharge” (drop off by taxi or ambulance on the side of the road) undocumented or homeless people with a diagnosed of dementia, unless to a responsible shelter, individual, or other medical facility agreeing to care for them.People with dementia should be able to benefit from “respite” in the same way as their care partners. The constant stress of having a degenerative brain disease merits attention to the psychological needs of the individual, who is striving to function on society’s terms every day. |
| Article 4 - General obligations4.1.f: To undertake or promote research and development of universally designed goods, services, equipment and facilities… which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;4.1.g … and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities… at an affordable cost;4.3 …  in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities… | With the focus on science and technology, there have been numerous science fairs, invention challenges, national competitions that have yielded considerable innovation in the field of disability design. Governments should sponsor such competitions in the field of disability research, and provide open-source software to allow competitors to design adaptive devices for people with dementia.Information may have to be provided in alternative terms and modes, other than through verbal communication. There may have to be illustrations, models, online videos, or other creative solutions, but access must be facilitated. |
| Article 9 - Accessibility9.1. To enable persons with disabilities to live independently and participate fully in all aspects of life… include the identification and elimination of obstacles and barriers to access…:9.1.a. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;9.1b. Information, communications and other services, including electronic services and emergency services.9.2b. private entities open or provided to the public… all aspects of accessibility for persons with disabilities;9.2.g. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet; | GPS or equivalent navigational devices should be available for persons with dementia at risk of getting lost. Signage, wayfinding systems, tactile landmarks, audio and visual cues, sensory gardens, translation apps that “read” signs aloud and in multiple foreign languages are easily available to install to facilitate access in public buildings.Closed captioning, and interpretation from written or spoken language into simple written or spoken language should be provided by trained interpreters for people with dementia as well as for those with other disabilities.  |
| Article 20 - Personal mobility20b. Facilitating access… to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, | Access includes information; I therefore need to have facilitated access to any official documents, news, advertisements, job offers, emergency announcements, etc. that the rest of the public enjoys, at no extra cost. |
| Article 21 - Freedom of expression and opinion, and access to information21a. Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost; | Vital announcements, warnings for my safety are needed, as is a full education, which refers not only to formal instruction in public or private institutions, but to life-long learning opportunities. People with dementia are on a long continuum of progressively-changing cognitive functioning. Even those with high cognitive reserve need to find alternative ways to deal with emerging problems. People with dementia must be told first (not at the same time as others, and certainly not last) about emergency contingencies, detours, and other changes of plans, to allow them extra time to adapt, understand, and accept the news. |
| **Article 24 - Education**24.1. …States Parties shall ensure an inclusive education system at all levels and life long learning directed to:1. The full development of human potential and sense of dignity and self-worth, strengthening of respect for human rights, fundamental freedoms and human diversity;
2. The development by persons with disabilities of their personality, talents and creativity, mental and physical abilities to fullest potential;

24.3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community.24.5. …to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others… [with] reasonable accommodation…. | As with information dissemination, the government must ensure that people with dementia continue to have access to learning opportunities beyond traditional schooling and college courses. These may include not only content knowledge, but life and social skills such as practical coping strategies, food preparation, budgeting, writing, exercise, games, software, smartphones. The myth that people with dementia cannot learn anything new must be dispelled. With proper instruction, most of us can keep learning all our lives, even in the advanced stages of dementia. If the brain is functioning, it can make neural connections.  |
| Article 27 - Work and employment the right of persons with disabilities to work, on an equal basis with others1.f. Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one’s own business; |  |
| Article 30 - Participation in cultural life, recreation, leisure and sport30.1a. Enjoy access to cultural materials in accessible formats30.1b. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats30.1c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.30.2. …Enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.30.5c. To ensure… access to sporting, recreational and tourism venues. | This is essential to the retention and development of quality of life in place of the stigma and social isolation which follows a disclosure of diagnosis.  |
| **Article 22 - Respect for privacy**22.1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation.22.2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis | It is not merely the government’s responsibility to protect my rights, but to create an environment conducive to *promoting* my rights, to *actively* combat stereotypes and prejudice against people with disabilities. It means teaching people not to be afraid of me or my medical condition. Dementia-friendly communities are a first step in that direction but have far to travel to become more rights-based.  |
| **Article 8 - Awareness-raising**8a. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;8b. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, 8c. To promote awareness of the capabilities and contributions of persons with disabilities. | There is precedent for widespread dissemination of critical global information. A documentary could be produced on the urgent need to educate the world on the rights of a billion people with disabilities, including the 47 million people with dementia whose numbers will double every 20 years and are the most likely to be Left Behind the 2030 Sustainable Development Goals because of the general but legally mistaken that are not persons with disabilities  |
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