



Agenda item 9

Human Rights

Dear friends,

ADI is partnered with Dementia Alliance International (DAI), the international self-advocacy group of people with dementia. We started this relationship last year at the conference in Perth and worked together on a number of topics.

One of the topics is exploring the opportunities that are created by the United Nations (UN) treaties on Human Rights. There is a Treaty on the Rights of Elder People in development and, already agreed in 2006, is the Convention on the Rights of Persons with Disabilities (CRPD) and most countries have ratified this convention since that time. That means that there is a regular process of reviewing the position of people with disabilities country by country at the UN and we believe this can be used to advocate for improvements in dementia care and services.

How this works is that the UN holds regular sessions where countries are asked to report on their progress in supporting people with disabilities and these reports are scrutinised by a UN Committee. At the same time, non-governmental organisations like Alzheimer associations can submit shadow reports to the UN, if they have complaints about the situation on their country.

In recent years there have been examples of success for other groups and we feel it is worth exploring how we can benefit as well.

If you want to learn more please look at the attached paper that was written by an external consultant, Neil Crowther, but with lots of input from a working group from ADI and DAI.

Next steps

ADI and DAI will work together on recommended steps internationally. At the national level you can consider using this as a tool as well. We would be happy to support that with information and tools. Canada will be the first country that is going to be discussed at the UN, in August 2016, and has agreed to be a pilot that we can learn from.

At the conference there will be a plenary speaker on this topic (Prof. Peter Mittler) and an ADI workshop to give further information about this topic for those who are interested.

We are aware that this is a new area and that lots of things need to be learned to use it successfully, but we believe that can be done.

Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia

Neil Crowther, 1 March 2016

Executive Summary

It is proposed that ADI in partnership with DAI should make active use of the Convention on the Rights of Persons with Disabilities (CRPD) as part of a suite of advocacy strategies to ensure people with dementia are able to enjoy their human rights and access services on an equal basis with others. These include the promotion of dementia friendly, accessible and enabling communities, the development of national dementia strategies in every country and the inclusion of people with dementia in the UN 2016-2030 Sustainable Development Goals.

The use of the CPRD as a tool for social change could be particularly useful in countries where the stigma associated with dementia is strong and more generally to achieve practical outcomes in access to health and everyday services, reduction in the use of restraints and anti-psychotic medication and the availability of high quality social care and support.

A course of action to achieve these aims is proposed for use by regional and national Alzheimer's Associations in partnership with people with dementia, their care partners and other stakeholders. Recommended actions include:

- Engaging with the United Nations Committee on the Rights of Persons with Disabilities, including through its policy making processes
- Seeking to develop productive relationships with the global network of National Human Rights Institutions
- Preparing and disseminating widely a paper on the UNCRPD and the rights of persons with dementia
- Encouraging and supporting national and regional Alzheimer's organisations to participate in the examinations by the United Nations Committee on the Rights of Persons with Disabilities of their own states.

What is the United Nations Convention on the Rights of Persons with Disabilities (CRPD)?

The CRPD is a global tool for achieving domestic social change. It is an international human rights treaty, adopted by the United Nations on 13th December 2006.

The CRPD does not provide persons with disabilities with new, different human rights additional to those already available to everybody else. It aims to:

- reaffirm the existing human rights of persons with disabilities, as set out in the ‘International Bill of Rights’.¹
- spell out the practical steps that need to be taken by countries to ensure that persons with disabilities enjoy their human rights on an equal basis with others.

These steps include:

- reforming discriminatory laws, policies and practices
- planning to remove barriers and to develop inclusive practices
- putting in place financial and practical supports
- tackling prejudicial attitudes and stereotypes.²

Why is the CRPD relevant to persons with dementia?

The Convention defines persons with disabilities as including *‘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.’* There can be little doubt that persons with dementia are addressed by this definition and are hence intended beneficiaries of the Convention.

The Convention is broad in scope. Of particular relevance to the situations experienced by persons with dementia are Articles concerning:

- **Awareness-raising:** The Convention requires that States take action, including at the family level, to foster respect for the human rights of persons with disabilities. This includes action to combat stereotypes, prejudices and harmful practices including those based on age and to promote awareness of the capabilities and contributions of persons with disabilities. This is particularly relevant to addressing the stigma, discrimination and social isolation that is a common experience of many persons with dementia and which acts as a major barrier to their participation in society and in achieving the social change necessary to secure their inclusion and wellbeing.
- **Equality and non-discrimination, including the obligation to provide ‘reasonable accommodation’:** The Convention requires that States ensure that persons with disabilities enjoy equality before the law and to guarantee legal protection against all forms of discrimination. This may include unlawful discrimination by healthcare and other service providers, driving license authorities, insurance companies and employers. ‘Discrimination’ includes the failure to provide ‘reasonable accommodations’ – that is, modifications and adjustments that enable persons with disabilities to enjoy or exercise their human

¹ This is the term commonly used to describe the combined Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Convention on Economic and Social and Cultural Rights which form the core of the international human rights framework

² More information on the Convention and which countries have ratified it can be found at: <http://www.un.org/disabilities/default.asp?id=259>

rights on an equal basis with others. This might include assistance when shopping or with personal banking.

- **Equal recognition before the law:** The Convention requires States to repeal guardianship laws and to replace ‘substitute decision-making’ with ‘supported decision making’ in order to protect and promote the legal personhood and autonomy of people otherwise deemed to lack capacity. This is particularly relevant to persons with dementia who commonly find their autonomy automatically undermined or removed following diagnosis or who do not presently enjoy access to independent advocacy for support with major decisions, such in relation to health, financial matters or their fitness to drive or travel.
- **Living independently and being included in the community:** The Convention requires States to ensure that persons with disabilities can choose where and with whom to live on an equal basis with others. To achieve this States are required to make available living and support options that prevent segregation and isolation from the wider community, such as can be created through placement in residential care or long-term institutionalization. Personalised post-diagnostic support to enable persons with dementia to remain in their own home and to prevent the isolation that they frequently experience is a top priority in public opinion surveys of the views of people with dementia.
- **Participation in public and political life:** The Convention requires States to take steps to ensure that all persons with disabilities can vote, be provided with modifications and adjustments to voting procedures and stand for election
- **Liberty and security of the person:** The Convention says that ‘the existence of a disability shall in no case justify a deprivation of liberty.’ The Committee on the Rights of Persons with Disabilities has issued a statement which clarified its view that ‘legislation...including mental health laws, still provide instances in which persons may be detained on the grounds of their diagnosis or actual or perceived disability, provided there are other reasons for their detention, including that they are dangerous to themselves or to others. This practice is incompatible with article 14 as interpreted by...the CRPD committee.’
- **Freedom from torture, inhuman or degrading treatment:**
The Convention reaffirms the rights of persons with disabilities to live free from torture, inhuman or degrading treatment. Other UN Treaty Bodies have interpreted this to include the disproportionate use of anti-psychotic drugs, physical restraint and being detained in psychiatric institutions and care facilities. without possibility of returning to the community
- **Freedom from exploitation, violence and abuse:**
The Convention requires States to take action to protect persons with disabilities from all forms of exploitation, violence and abuse, both inside and outside the home. This includes providing assistance to individuals, families and caregivers to recognise, avoid and report such behaviours and for States to ensure the effective regulation of facilities and services for persons with disabilities.

Implementing the Convention

The CRPD requires ratifying States to take actions to implement their obligations. Such actions include:

- Designating a clear lead department of government to oversee implementation
- Ensuring the active involvement of persons with disabilities in implementation
- Designating, strengthening or establishing one or more ‘independent mechanisms such as national human rights bodies to protect, promote and monitor implementation
- Adopting new laws, measures and practices and abolishing or modifying existing laws, policies, customs or practices which do not comply with the CRPD
- Taking account of the human rights of persons with disabilities in relation to all policies and programmes
- Refraining from acting in a manner that is inconsistent with the CRPD and ensuring that public authorities act in compliance with the Convention
- Putting in place plans to realize the economic, social and cultural rights of persons with disabilities – such as the right to health, to work and employment and to education – over time.

How can the Convention be used to bring about change in the lives of persons with dementia?

To date 161 countries and the European Union have ratified the Convention. This means that they have made a commitment in international law to implement it, abide by it and be subject to regular examination by the UN Committee on the Rights of Persons with Disabilities.

As a consequence, the Convention is playing an increasingly influential role in shaping and reshaping laws, policies, practices and legal case law globally with respect to the rights of persons with disabilities, including on issues that are highly pertinent to the situations faced by many people with dementia.

Involvement of persons with disabilities

The CRPD places particular emphasis on the involvement of persons with disabilities both in both implementation and in monitoring whether and how States are meeting their obligations.

At the national level this means:

- Government’s should be involving persons with dementia in steps being taken to implement the CRPD, for example in the development of a national action plan
- Persons with dementia should be fully involved in dementia friendly community programmes nationally and locally, including as employees
- Persons with dementia should be involved in the national independent framework tasked with monitoring implementation of the CRPD, for example via forums established by national human rights institutions

- Organisations of persons with dementia using the Convention as a framework for advocacy, including actions to influence public policy, in relation to strategic litigation and in raising awareness of the situation of persons with dementia.

At the international level this means:

- Persons with dementia and their organisations contributing to the examinations conducted by the Committee on the Rights of Persons with Disabilities of the States in which they live.
- Opportunities include:
 - submitting written and oral evidence to the Committee concerning the situation of persons with dementia to influence the ‘list of issues’ (priority areas) chosen by the Committee
 - attending the examination of their country’s government in Geneva and to lobby Committee members to propose recommendations to their home government
 - following the examination, raising awareness in their countries to follow up the Committee’s recommendations.
- Contributing to the evolving thinking of the Committee by contributing written evidence and through attending ‘General Days of Discussion’ which lead to ‘General Comments’ and Statements to spell out more clearly the precise meaning of the CRPD. The Committee has to date issued General Comments and Statements on issues pertinent to the human rights of persons with dementia in relation to legal capacity and the right to liberty, It is now developing a General Comment in relation to ‘living independently and being included in the community.’

87 countries have also ratified the ‘Optional Protocol’ to the Convention. This empowers their citizens to bring complaints to the Committee and enables the Committee to conduct investigations and carry out inquiries regarding ‘grave and systemic violations’ of human a rights treaty. . The United Kingdom is reported to be the first country to be the object of such an inquiry by the Committee on account of threats to independent living resulting from cuts to relevant support and welfare benefits.

Recommended steps for ADI/DAI regarding the CRPD

ADI/DAI the international level:

- Participation in the activities of the CRPD Committee, in particular General Days of Discussion’ and responding to Calls for Evidence and Recommendations
- A ‘side event’ on issues of particular importance to persons with dementia at a future CRPD Committee meeting in Geneva
- An engagement strategy with individual Committee members
- Engagement at the international level with National Human Rights Institutions through their regional offices in Europe and other regions (the Asia Pacific Region).

- Commission and widely disseminate a paper on the CRPD and the rights of persons with dementia as the basis for a global strategy

Regional and National Alzheimer's organisations

- Collaborate with or join regional and national alliances of Disabled Persons Organisations in order to ensure that the voice of people with dementia and their associations can be heard when decisions are being made about the rights of persons with disabilities.
- Engage in the upcoming examination of their States by the UN Committee on the Rights of Persons with Disabilities (a timetable of upcoming examinations is included in the annex)
- Engage with their National Human Rights Institutions

Other opportunities to promote the human rights of persons with dementia

ADI/DAI should strengthen its engagement with the UN Human Rights Council via the UN Special Rapporteur on the Rights of Persons with Disabilities and the Expert Adviser on the Rights of Older Persons whose mandate includes assessing gaps in how existing human rights law is being implemented in terms of older people's rights.

In 2010 the UN General Assembly established an 'Open-ended Working Group' to 'consider the existing international framework of the human rights of older persons and identify possible gaps and how best to address them, including by considering, as appropriate, the feasibility of further instruments and measures.' The group is considering the potential of an international human rights convention on the rights of older persons.

Opportunities exist for engagement at the regional level with other bodies advancing human rights. In Europe, these include the European Disability Federation, European National Network of Human Rights Institutions and the Council of Europe all of which have a keen interest in the rights of persons with disabilities -which must in future be understood as including persons with dementia.

The UN 2016-2030 Sustainable Development Goals (SDGs)

Following consultations with the world's governments, civil society worldwide and with countless individuals through Internet forums and the social media, the UN has recently launched 17 *Sustainable Development Goals* for everyone on the planet, with a commitment to LEAVE NO ONE BEHIND.

Disabled Persons Organisations, working together as the International Disability Alliance, have succeeded in ensuring that the indicators being developed to assess progress towards these Goals include specific references to persons with disabilities.

It is now necessary to ensure that people with dementia are included when the UN and the Disabled Persons Organisations are monitoring the extent to which persons with disabilities are benefiting from the SDGs. This is particularly important for the

majority of people living with dementia in Low and Middle Income Countries. This issue can be raised at national and regional level as well as with the CRPD Committee.

Publicity leaflets and infographics on ways in which the CRPD Articles and the SDGs can be used jointly by civil society have just been published and may/will be available at the Budapest and regional conferences later this year.

Timetable of UNCRPD Committee examinations 2016-17

List of issues

Country	Expected date
Ethiopia	March/April 2016
Bolivia	March/April 2016
Columbia	March/April 2016
Guatemala	March/April 2016
Uruguay	March/April 2016
Italy	March/April 2016
UAE	March/April 2016
Moldova	March/April 2016
Canada	August 2016
Honduras	September 2016
Iran	September 2016
Armenia	September 2016
Bosnia	September 2016
Cyprus	September 2016
Jordan	September 2016
United Kingdom (anticipated)	2017

Concluding observations

Country	Expected date
Uganda	March/April 2016
Chile	March/April 2016
Thailand	March/April 2016
Lithuania	March/April 2016
Portugal	March/April 2016
Serbia	March/April 2016
Slovakia	March/April 2016
Ethiopia	August /September 2016
Bolivia	August /September 2016
Columbia	August /September 2016
Guatemala	August /September 2016
Uruguay	August /September 2016
Italy	August /September 2016
Moldova	August /September 2016
UAE	September 2016

