The level of awareness of international human rights underpinning rights-based advocacy for dementia

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#ADI2016
Parallel Session 2 - Law, ethics and the rights of people with dementia
Meeting room: Liszt II-III.
22ND April 2016 - 2 pm
Budapest, Hungary
Dworkin (2011) – “Justice for hedgehogs”
"basic idea" of a rights-based theory:

“distinct individuals have interests that they are entitled to protect if they so wish."

A “human rights based approach” is about making people aware of their rights, whilst increasing the accountability of individuals and institutions who are responsible for respecting, protecting and fulfilling rights.

“A human rights based approach” Alzheimer Scotland,
“rights based consciousness”
• “Survey Monkey” in late 2015
• Link shared through Twitter – potentially international jurisdiction
• Bias amongst Twitter respondents?
• 55 respondents (18% declared themselves as disabled)
How important do you view the following legal instruments in protecting rights? 1 = most important; 4 = least important

Answered: 54  Skipped: 1

- human rights act
- mental capacity act
- UNCRPD
- equality act
<table>
<thead>
<tr>
<th>Question</th>
<th>YES</th>
<th>NO</th>
<th>DON'T KNOW</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is a right to a personal budget one of the legal ‘rights’ under the European Convention of Human Rights?</td>
<td>34.62%</td>
<td>17.31%</td>
<td>48.08%</td>
<td>52</td>
</tr>
<tr>
<td>Is a right to privacy and family life one of the legal ‘rights’ under the European Convention of Human Rights?</td>
<td>81.13%</td>
<td>1.89%</td>
<td>16.98%</td>
<td>53</td>
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<tr>
<td>Is a right to a medical diagnosis one of the legal ‘rights’ under the European Convention of Human Rights?</td>
<td>39.62%</td>
<td>22.64%</td>
<td>37.74%</td>
<td>53</td>
</tr>
</tbody>
</table>
There is neither a right to a personal budget nor a right to a diagnosis under the European Convention of Human Rights ("ECnHR").

A right to privacy and family life is enshrined under article 8 of ECnHR.
Do you feel dementia should be considered as a ‘disability’? 0 (not at all) to 5 (very much)

Answered: 55  Skipped: 0
EQUALITY ACT!
Dementia Alliance International

Dementia: From words to action

Recently, Dementia Alliance International (DAI) appointed DAI member Professor Peter Mittler as its Advisor on Human Rights. He has a wealth of expertise in the disability sector on which we can draw in claiming access for people living with dementia to the UN Convention on the Rights of Persons with Disabilities (CRPD).

We are also especially delighted with the commitment from Glenn Rees, Chair of ADI to this Convention and its relationship to 'dementia friendly'. His recent speech in Singapore declared; “I detect that the concept of dementia friendly communities is being given practical expression in at least four different ways. The first of these is Human Rights”. Glenn also said, “... the Board of ADI has asked the CEO to approach Alzheimer Scotland with a view to setting up a working group on human rights, together with people with dementia. The aim is to develop a strategy on the recognition of dementia within the Convention.”

Peter Mittler has been appointed as a member of this group representing DAI which is fully committed to working in close cooperation with ADI to make full use of the CRPD. What follows now is Peter Mittler’s introduction to the Convention, with suggestions on how we can begin now to get to know how we can benefit from it.

Kate Swaffer, Co-chair, Co-founder and editor, Dementia Alliance International
Which of the following principles is most important for inclusive systems?

Answered: 54  Skipped: 1

- Participation
- Accountability
- Non-discrimination and Equality
- Empowerment
- Legality of rights

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Non-discrimination and equality - A human rights based approach means that all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated.

“A human rights based approach” Alzheimer Scotland,
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<th>NO</th>
<th>DON’T KNOW</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is a right to <strong>accessibility</strong> available under the UN</td>
<td>9</td>
<td>36.36%</td>
<td>10.91%</td>
<td>52.73%</td>
<td>55</td>
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<tr>
<td>Convention of Rights for People with Disabilities?</td>
<td></td>
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<tr>
<td>Is a right to <strong>access to justice</strong> available under the UN Convention</td>
<td>13</td>
<td>41.82%</td>
<td>5.45%</td>
<td>52.73%</td>
<td>55</td>
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<tr>
<td>of Rights for People with Disabilities?</td>
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<tr>
<td>Is a right to <strong>live independently and be included in the community</strong></td>
<td>19</td>
<td>49.09%</td>
<td>3.64%</td>
<td>47.27%</td>
<td>55</td>
</tr>
<tr>
<td>available under the UN Convention of Rights for People with Disabilities?</td>
<td></td>
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<tr>
<td>Is a right to <strong>work and employment</strong> available under the UN Convention</td>
<td>27</td>
<td>42.59%</td>
<td>11.11%</td>
<td>46.30%</td>
<td>54</td>
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Dementia Friendly Communities (DFCs)
New domains and global examples
The Right to Health
Health—an explicit human right

“The past year severely tested the international system’s capacity to respond to crises and mass forced displacements of people, and found it woefully inadequate.” So begins Amnesty International’s annual report for 2015, The state of the world’s human rights, published last week. Set against the backdrop of unprecedented and worldwide migration, recurring themes include access to health services, the effects of conflict on health, women and children’s health, sexual rights, and the denial of health care in prisons. In this comprehensive review of human rights in 160 countries, health is an explicit and constant underlying thread.
The right to health is a fundamental part of our human rights and of our understanding of a life in dignity. *The right to the enjoyment of the highest attainable standard of physical and mental health*, to give it its full name, is not new. Internationally, it was first articulated in the 1946 Constitution of the World Health Organization (WHO), whose preamble defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. The preamble further states that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”

The 1948 Universal Declaration of Human Rights also mentioned health as part of the right to an adequate standard of living (art. 25). The right to health was again recognized as a human right in the 1966 International Covenant on Economic, Social and Cultural Rights.
A mixed picture?
Glenn Rees #ADI2015

Disability advocates have shown us the way. We need to ensure that the rights of people with dementia of all ages are protected and to ensure that they have the opportunity to participate in society as well have a purpose in life – which is what we all seek in our different ways.
WELCOME TO BUDAPEST