A human rights-based approach of disability

Developing Innovative Good Practices for dementia in the community.
Meanwhile… (2016)
Structure

- Need for Human-rights based approach
- CRPD and Human Rights
- Voice of People with Dementia
- Zero Draft for the Global Action Plan on the public health response to dementia 2017-2025
- Scaling up Community Care
- Dementia care in the community: The Example of Dementia Consultation Stations in Athens and Cyclades islands
THE NEED FOR A HUMAN RIGHTS-BASED APPROACH (WHO, 2015)

- It is widely recognized that people living with dementia are frequently denied their human rights both in the community and in care homes.

- In many countries people living with dementia are often physically and chemically restrained, even when regulations are in place to uphold their rights.

- Furthermore, people living with dementia can also be victims of abuse. For example, they may be beaten for being "stubborn" or exhibiting challenging behavior.

- Third parties may also use a diagnosis of dementia to their own benefit, such as using deceit to acquire a person’s assets. This reflects the ethical challenges inherent in the support and protection of people living with dementia, and legislation alone will not be sufficient to ensure the protection of their rights.
Human-rights approach to Dementia

PANEL+ provides a framework with important elements to keep in mind if we want to promote the respect for the rights of people living with dementia approved by the UN.
People with psychosocial disabilities experience a wide range of human rights violations.

Increased rates of physical victimization.

Restrictions in the exercise of their political and civil rights as well as their participation in public affairs.

Disproportionate barriers in accessing essential health and social care!

People with psychosocial disabilities are assumed to lack capacity to take charge of and make decisions concerning their own lives. CRPD signed by 151 countries promotes full inclusion and participation in community life and access to quality health care services as close as possible to people’s own communities.

The CRPD affirms that people with psychosocial disabilities have the right to exercise their legal capacity on an equal basis with others, and that supports must be put in place to enable them to exercise this right. (Natalie Drew, WHO, 2012).
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:
  
  (a) 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;
  
  (b) Persons with disabilities have access to a range of 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;
  
  (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.
Isolation, Quality of Life and Human Rights

At the end of this island, alone, secluded, long away from the human contact, he has lived his live carrying the burden of a disaster for which he had no responsibility, living without hope, without comfort, without meaning. Orphaned, childless, destitute, he developed this illness at a very young age. The fellow villagers forced him to seclusion, taking up the responsibility to keep him alive. It was not such a big cost for the community.

• Physical isolation
• Social isolation
• Denial of Equal Access and Participation in the Community
• Not accepted, but tolerated.
• Not a “citizen” but an object of “philanthropy”.

Inclusion in the community is directly linked with Quality of Life and is reported as a major unmet need by the users (Lavdas, 2016).

“At the end of this island, alone, secluded, long away from the human contact, he has lived his live carrying the burden of a disaster for which he had no responsibility, living without hope, without comfort, without meaning. No parents, not children, destitute he developed this illness at a very young age. The fellow villagers forced him to seclusion, taking up the responsibility to keep him alive. It was not such a big cost for the community. (Vikelas, “Papa-Narkissos”)
Human Rights and UN CRPD II

- Persons with dementia are included in CRPD Article 1 but have been excluded from its implementation by Member States.
- CRPD is not reflected in the dementia strategies and plans of 26 Member States.
- Example of systemic discrimination! (συστημική διάκριση για τα άτομα με άνοια)
- Underdiagnosed dementia rates
- Underestimation of the capacity of persons with dementia.
- Low access to support services.
# Evaluation of Greek psychiatric reforms: methodological issues

Evangelia Loukidou¹, Anastasios Mastroymannakis¹, Tracey Power², Graham Thornicroft⁴, Tom Craig³ and Nick Bouras*²

## Table 1 Planned and actually developed mental health units

<table>
<thead>
<tr>
<th>Mental health units</th>
<th>2001 (baseline)</th>
<th>2010 (target)</th>
<th>2010 (achievement)</th>
<th>Target achievement 2001-2010</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Psychiatric Hospitals*</td>
<td>9</td>
<td>125</td>
<td>4</td>
<td>-1</td>
</tr>
<tr>
<td>Psychiatric &amp; Child-Psychiatric Units of General Hospitals</td>
<td>75</td>
<td>55</td>
<td>41</td>
<td>-34</td>
</tr>
<tr>
<td>Psychiatric Units of General Hospitals</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child-Psychiatric Units of General Hospitals**</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health Centers</td>
<td>28</td>
<td>43</td>
<td>80</td>
<td>-46</td>
</tr>
<tr>
<td>Mental Health Centers for children **</td>
<td>22</td>
<td>68</td>
<td>73</td>
<td>-13</td>
</tr>
<tr>
<td>Mobile Units</td>
<td>6</td>
<td>95</td>
<td>40</td>
<td>-13</td>
</tr>
<tr>
<td>Day Centers</td>
<td>18</td>
<td></td>
<td>42</td>
<td>-2</td>
</tr>
<tr>
<td>Psychosocial Rehabilitation Units</td>
<td>196</td>
<td>52</td>
<td>407</td>
<td>-82</td>
</tr>
<tr>
<td>Guest Houses</td>
<td>95</td>
<td></td>
<td>170</td>
<td>-14</td>
</tr>
<tr>
<td>Boarding Houses</td>
<td>16</td>
<td>89</td>
<td>130</td>
<td>-14</td>
</tr>
<tr>
<td>Sheltered Apartments</td>
<td>85</td>
<td></td>
<td>107</td>
<td>-13</td>
</tr>
<tr>
<td>Socio-vocational rehabilitation units</td>
<td>102</td>
<td>69</td>
<td>148</td>
<td>-46</td>
</tr>
</tbody>
</table>

- Alzheimer’s Centers                                     | 5      | 180         | 9      |             | 4      |             |
- Drug abuse Centers                                      | 35     |             | 0      | -35         | 0      |             |
- Alcohol abuse Centers                                   | 15     |             | 0      | -15         | 0      |             |
- Social Enterprises -KOISPE                              | 55     |             | 18     | -37         | 18     |             |
- Home Care Unit                                          | ✓      | 33          | 1      |             | 1      |             |
- Autism Center for children                              | ✓      |             | 2      |             | 2      |             |

*Includes Psychiatric Hospitals full operation. Additionally the University Psychiatric Hospital “Aiginition” operates but does not have long-stay units.

**It is not reported in the First Revision of Psychologos (Ministry of Health & Social Solidarity 2001) neither the baseline number in 2001 nor the target-number for the development of Child-Psychiatric Units in General Hospitals. Therefore the success rate cannot be deduced.

***According to the First Revision of Psychologos (Ministry of Health & Social Solidarity 2001) the mental health centers for children were 22 in 2001. However, according to data provided by the Mental Health Directorate, in 2010 there were only 10 centers (mental health centers for adults that also provide services for children have not been included). Therefore the success rate cannot be deduced.
“The diagnosis for dementia or any other disease does not necessarily mean loss of legal capacity, simply because the presence of a disease does not necessarily mean a disability. A disability can result from a disease but it is important to evaluate the extent, the type, the stage, the symptoms of disability with a central point being functionality”  E. Fitrakis, Gen. Secretary for the Ministry of Justice
Kate Swaffer (2014) refers to the contrary to the empowerment model that is widely accepted in dementia as “Prescribed Dis-engagement”.

When the professionals along with the diagnosis tell the person with dementia “to give up work, give up study and go home and live for the time you have left”.

Family members are also given the same direction to become “full time carers”.

This “sets up to live a life without hope or any sense of a future and destroys our sense of future well-being; it can mean the person with dementia behaves like a “victim” or “sufferer” and many times their care partner as a martyr”.
Zero Draft for the Global Action Plan on the public health response to dementia 2017-2025

- **Human rights** of people with dementia
- **Empowerment and engagement** of people with dementia and their carers
- **Evidence-based practice** for dementia risk reduction and care
- **Multisectoral collaboration** on the public health response to dementia
- **Universal health coverage** for dementia
- **Gender equity**
- **Balance cure and care** for people with dementia and their carers
Collaborating to scaling up the effort (WHO, 2016)
Scaling up Community Care

Among the key findings of the World Alzheimer Report 2016 by Prince et al. (2016) is that dementia care is over-specialized and thus is rather difficult to be scaled up to sufficiently cover the growing number of people affected by dementia especially in low and middle income countries.

ADI also argues that task-shifting and task-sharing with primary care services will be the center of strategic planning for improved coverage of diagnosis and continuing care in dementia.

According to ADI task shifting is “delegating selected tasks to existing or new health professional cadres with either less training or narrowly tailored training. This may involve shifting tasks from higher- to lower-skilled health workers – for example, from a neurologist to a primary care physician – or creating new professional roles, so tasks can be shifted from workers with more general training to workers with specific training for a particular task– for example, from a primary care physician to a dementia case manager”.

Large body of evidence for task-shifting in mental health (Araya, 2009; Patel, 2012)
The pyramid diagram illustrates the different levels of care and services needed based on frequency of need and costs.

From the bottom to the top:

- **Self-care**
- **Informal community care**
- **Primary care mental health services**
- **Psychiatric services in general hospitals**
- **Community mental health services**
- **Long stay facilities and specialist psychiatric services**

The diagram shows a progression from low frequency and low costs (Self-care) to high frequency and high costs (Long stay facilities and specialist psychiatric services). The services are organized to match the needs and costs effectively.
Counseling services network (CSND) for promoting dementia prevention and non-pharmacological interventions within public local authorities

Dr. Sakka Voula, Athens Association of Alzheimer's Disease and Related Disorders, President of the Observatory for Dementia
Areti Efthimiou, Psychologist, Cand. Phd, AAAD
Michael Lavdas, Psychologist EPAPSY
Tasos Mastroyiannakis, Financial Manager, CMT Prooptiki

13 Dementia Consultation Centres

- Prevention and intervention programmes
- in Athens and Cyclades
Community Services!

- Integration in the community.
Dementia Consultation Stations: Objectives

- Dementia prevention: awareness campaigns, cognitive screening, cognitive training groups of healthy elderly
- Interventions for people with dementia: diagnosis and follow-up, non-pharmacological interventions for people with Mild Cognitive Impairment and dementia
- Interventions for carers: seminars, psychoeducational interventions, counseling services
- Training of health care professionals already employed by the municipalities
Intervention for the prevention and treatment of Dementia in the Community

- 13 Consultation Centres
- 1868 Screening tests
- 1991 Users
- 14 cognitive empowerment groups
- 361 sessions
Dementia Consultation Station responding to expressed need.

- In total, 1991 people visited the Dementia Consultation Centres (October 2014 – April 2016), a number that exceeds in a percentage of 153% the initial users estimation (1300 users in total). The services that were provided during the lifetime of the project included:
  - **Neuropsychological screening and neurological examination**: 1868 screening tests were conducted by trained psychologists of the implementation team and 592 neurological assessments at the Dementia Consultation Centres in Athens.
  - **Cognitive Stimulation groups of people with Mild Cognitive Impairment and normal Cognition**: 14 groups of cognitive stimulation have been organised, further analysed into 361 sessions and 198 participants in total.
  - **Carers psychoeducational support**: 132 individual sessions have been organised, with the participation of 105 carers and 23 group sessions with the participation of 43 carers.
  - **92 care professionals have participated in training sessions** about dementia issues and the Dementia Consultation Centres Model. Furthermore, almost half of them have participated on the job training in order to facilitate the sustainability of the Centres after the end of the project.
  - **236 care professionals from all over Greece have registered to the eLearning course** developed in the framework of the project.
  - During the lifetime of the project, 207 networking and dissemination actions were organised in an effort to communicate the aims of the programme.
Profile of Users in Dementia Consultation Stations (N=1991)

- Dementia: 51%
- Memory Disorders: 0%
- Mild Cognitive Impairment: 7%
- Mood and Anxiety Disorders: 24%
- Normal: 17%
- Other Neurological Disorders: 1%
Registration for E-Learning Courses

http://elearning.dementia-community.gr/

You can access the elearning course through the website of the programme: http://dementia-community.gr/ clicking on E-Learning
“Persons with disabilities are widely considered as patients with a diagnosis and not persons who are entitled to a full enjoyment of human rights”.

Jan Jarab, Regional Representative for Europe of the UN High Commissioner for Human Rights
Care is not always costly, yet it requires political will and rational allocation of resources!

Thank you for your attention!