

## **The LWIEN Service – community outreach work to identify and provide support to hard-to-reach family caregivers of the mentally ill in their self-empowerment process.**

(LWIEN in Maltese means colours and hues)

[The report below featured in the compilation of best practices of civic participation in health published by the Active Citizenship Network (ACN) as part of the 5th European Patients' Rights Day, April 11/12, 2011. All the best practices collected and the criteria are available on ACN website: [www.activecitizenship.net](http://www.activecitizenship.net)]

### **1. Actors of the Best Practice**

#### *Civic Organization(s):*

The St Jeanne Antide Foundation (registered NGO with remunerated professionals and a cadre of around 51 volunteers).

The Mental Health Association Malta (registered voluntary organisation made up of relatives of mentally ill persons with caring responsibilities) affiliated to EUFAMI. Some members are professionals in the health, mental health, & social work fields.

#### *Public Institution(s):*

The Ministry of Health, Care of the Elderly and Community Care

#### *Other Subjects involved*

Family caregivers of mentally ill persons

### **2. Who initiated the Best Practice? Public Institution /Civic Organisation**

Civic organisation

### **3. Location**

City/ Region: mainly in South-East

Country: Malta

### **4. Duration**

Starting and ending dates: 2010 to 2012

### **5. Objective/s**

#### Broad aims:

To reduce isolation amongst family caregivers of mentally ill persons.

To reduce self-stigma.

To prevent burnout and depression of family caregivers and breakdown of supportive family systems.

To stimulate a readiness for advocacy work.

#### Specific objectives

To identify a highly underserved category of citizens - family caregivers of mentally ill persons.

To provide family-focused consultations on issues that have become family stressors.

To facilitate self-empowerment processes.  
To highlight the key role that family plays in providing care and support.  
To stimulate family caregivers to advocate on behalf of very vulnerable others.  
To identify issues of common concern and to transmit these to policy makers.  
To work in partnership with other NGOs and public entities active in the fields of health and mental health.

#### Resources:

An experienced Psychiatric Nurse.  
A Community Social Worker.  
Collaborative work with Mental Health Association for media promotion and support work.  
Joint development of publications for family caregivers.  
Community outreach workers.  
Welcoming premises for support work with family caregivers.  
Start-up funding from the Ministry of Health, the Elderly and Community Care since the initiative complements government policy to invest in community-based mental health clinics and day centres for sufferers.  
Psychiatric practitioners provide free consultations over the phone.

#### Outcomes:

- **Weekly outreach** work in depressed neighbourhoods leading to identification of vulnerable families & a number of mis-diagnosed sufferers.
- **Family Consultations** on two weekdays.
- **2 radio programmes.**
- **3 Support Groups** for family caregivers with a high level of anxiety.
- **Joint publications with Mental Health Association:** Stars shine brightly in the dark, **written by family caregivers** out in February.
- Supportive CBOs.
- **Case-studies** for evidence-based evaluation and training.

#### Analysis

**Policy Field:** Mental Health

#### **Type of Best Practice**

Partnership with another civil society organisation – the Mental Health Association Malta - with start-up funding from the Ministry responsible for health and community care. Community outreach used as a tool to identify vulnerable families at risk of breakdown and social exclusion. Family focused holistic support, advocacy, and groupwork combined with educational radio programmes and joint publications.

#### **Development of the initiative**

Two stated principles of the St Jeanne Antide Foundation are to identify un-served or under-served categories of vulnerable citizens and to avoid duplicating services that already exist. Through its community outreach work, the Foundation came in touch with a significant number of overwhelmed informal carers struggling to cope with their caring responsibilities without any support from mainstream health service provision. Carers who self-administered a questionnaire to determine their level of anxiety showed maximum level. A highly competent psychiatric nurse was engaged to provide family consultations. The Ministry responsible for health and community care was contacted to provide start-up funding for this innovative initiative. The Ministry agreed immediately. The Foundation stepped

up its collaborative work with the Mental Health Association. 3 support groups were started. Radio programmes were aired from August to December.

### **Obstacles found**

1. Lack of funding due to the economic meltdown.
2. There is always a primary informal carer who absorbs all the caring responsibility when other family members shirk sharing the responsibility, standing comfortably back.
3. Self-stigma amongst relatives of mentally ill; stigma nationally is still rife.
4. Poor and vulnerable families cannot afford to pay for a private consultation – as carers - with a psychiatrist.
5. The fact that family caregivers have as yet not formed lobby groups as has been done in other sectors.
6. The health and mental health system is yet to extend its support mechanism to family caregivers who shoulder the main burden of day-to-day care of a family member.

### **Means to overcome obstacles**

1. The Ministry responsible for health accepted the justifications presented to it and provided start-up funding for the initiative.
2. Whole family consultations enables a frank discussion of the family dynamic and the key role of each member.
3. Combating stigma and self-stigma through radio programmes and publications through which family caregivers share their experience.
4. Provision of free whole-family consultations to at risk families.
5. Partnership with the Mental Health Association which has the potential of becoming a robust lobby group.

### **Factors that facilitated the process**

1. Outreach work has proved to be a crucial tool in the identification of many suffering families who have no means of accessing the kind of support they desperately need.
2. The fact that hardly any public health service exists that targets family caregivers of the mentally ill.
3. The readiness of family caregivers to write/speak out to combat stigma.
4. The readiness of Foundation professionals to knock on doors in depressed neighbourhoods to reach out to families, even during weekends when whole families are at home.

### **Impact on the participants**

The passion of *Partner NGOs* to support a vulnerable sector of society and to advocate is bearing fruit and is leading to innovative actions.

#### ***Vulnerable socially excluded Families:***

- express surprise that there are professionals who reach out to them in this manner.
- overcome mistrust and access services they need or re-engage with them.
- view support groups as a self-care space & encourage their children to similarly connect.
- express gratitude for support to understand treatment regimen side-effects & how they can be counteracted, and mapping out a cognitive behaviour therapy plan whose outcomes benefits the whole family.
- are poignantly emotional seeing their family breakdown being prevented, especially where mis-diagnosis, resistance to treatment, lack of a diagnosis, and lack of support threaten family relations.
- shed stress and anxiety when a mis-diagnosis identified by the team is confirmed and changes in medication result in recovery.
- Families say “this service is like a dream come true for us.”

## **Evalutaion**

### 1. Reproducibility

Any organisation can replicate or adapt the model as long as personnel are ready to carry out outreach work in neighbourhoods with a concentration of social problems and to work in partnership with other organisations at both community and other levels.

### 2. Innovativeness

No such service existed where overstressed vulnerable caregivers could sit down as a family with a professional to collectively thrash out their concerns.

EUFAMI will edit the English version of the book for relatives by relatives being published in Maltese.

### 3. Added value

- Both organisations are helping a community-based group to survey the incidence of mental illness so as to identify needs for community-based support. Other localities will become interested.
- A passion for reaching out to most hard-to-reach socially excluded families.

### 4. Appropriateness

- Giving a voice to a very vulnerable and unrecognised significant segment of society.
- Enabling family caregivers of the mentally ill to become well-informed, more skilled and ultimately more ready to support othe carers themselves.

### Other information:

It is hoped that the LWIEN initiative becomes a centre of excellence on working with families of mentally ill persons. A small house close to the Foundation's premises is being refurbished by a group of prisoners. The work is slowly creating an awareness among practitioners in community-based services of the importance of carrying out outreach work to identify and support hard-to-reach families who are socially excluded or at risk of becoming so. It is also creating an awareness of the link between (a) mental illness and how vulnerable families slide into poverty as well as mental illness; (b) mental illness and domestic violence. It is also hoped that policy makers will factor in such work in existing service provision mechanisms.

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