



**EUROPEAN FOUNDATIONS’
INITIATIVE ON DEMENTIA**

European Foundations’ Initiative on Dementia (EFID)

Conference “Valuing the expertise of people living with dementia in the community”

4-5 December 2019

**Talent Garden Fondazione Agnelli
Via Giuseppe Giacosa, 36-38 Turin, Italy**

Background

Since 2012, EFID supported organisations working on creating inclusive environments in communities across Europe. EFID partners are convinced that communities are the places where citizens, policy-makers, business and civil society can join forces with people with dementia to create sustainable boroughs and promote active citizenship. With the increasing number of people diagnosed with dementia and no known cure on the horizon, communities play a crucial role in supporting people to live well with dementia. According to the WHO¹, people with dementia, their carers and organizations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research of dementia. This means that the expertise of people with dementia should be valued and mainstreamed across multiple sectors such as health, social services, education, employment, justice, and housing, as well as partnerships with relevant civil society and private sector entities. Along the same line, a comprehensive and coordinated response to dementia requires collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment and care. Achieving such collaboration requires the engagement and empowerment of people with dementia, to speak up and be valued as experts with the condition. EFID’s mission for 2019-2020 is to deepen the work on dementia-friendly environments and promote the expertise of people living with dementia to empower them as individuals living with the condition. This goes hand in hand with an empowerment of the community to value and promote the expertise of PwD.

Aims of the conference

Drawing from the previous workshop on valuing the expertise of people with dementia, this conference will address the topic of empowering people with dementia as experts as they live with the condition with a particular focus on the community they live in.

The conference is expected to provide a stimulating networking and learning space for the EFID network of practitioners and provide an opportunity to reflect on methods and initiatives to value the voice of people living with dementia in the community, empower them and respect their autonomy, dignity and the right to self-determination.

In addition to this individual peer-group learning opportunity, the conference participants will work together on the co-development of the EFID quality framework. This is a flexible tool providing the awardees with a common language to assess their work.

Beside the co-creation of the quality framework, the workshops will offer space for the awardees to spend quality time to learn from each other and strengthen the EFID network.

¹ . Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017

The specific objectives of the conference are:

1. Increase participants' understanding of what makes good practice when empowering people with dementia as experts by experience and thus strengthen their confidence in scaling what works:
 - a. analyse good practices across Europe on empowering people with dementia as experts by experience
 - b. understand the role that the community plays in enabling the empowerment of people with dementia as experts
 - c. investigate the potential for replicability of successful models
 - d. Visit the awardee Rifugio Re Carlo Alberto and learn from their experience
2. Fine-tune the quality framework and learn from the piloting phase in order to agree on a common approach and commit to its implementation
3. Exchange experiences among awardees and strengthen the network to further enable future peer-group support

DRAFT AGENDA

Day 1 – December 4, 2019 at Talent Garden - Fondazione Agnelli, via Giuseppe Giacosa, 36-38

09:00	<i>Registration</i>
09:15	Welcome <i>Saida Sakali, King Baudouin Foundation, EFID Chair</i>
09:30	Framing the meeting and getting all participants on board <i>Natasha Walker, workshop moderator</i>
09:50	Key note – how do I value and increase my expertise? <i>Agnes Houston, MBE dementia advocate</i>
10:15	How can communities value and empower people with dementia as experts by experience? Mini-Pecha-Presentation for each case-study (10 slides with pictures of the community in 5 minutes) followed by a 20-minute panel discussion <i>Community leaders working towards inclusive communities</i> <ul style="list-style-type: none"> • <i>The experience of a community leader in Italy: Silvia Torresin, Passo Social Point Turin</i> • <i>Six steps to participation in the community. Insights from Vienna, Petra Rösler, Kardinal Koning Haus (Austria)</i> • <i>The Town Hall Meetings Project, Stefanie Wiloth, University of Heidelberg</i>
11:00	<i>Coffee break</i>
11:20	World café How do we enable the community to become more inclusive? <i>Participants discuss about the success factors and challenges of the 3 case studies presented. The rounds are guided by questions such as 'how can we</i>

	<p><i>replicate this in our context?; What is the impact of the case study on the community/pwd? ‘</i></p> <p><i>2 rounds of 30’ each – 2 tables per case study. Each participant will choose 2 cases</i></p>
12:20	<p>Feedback from the world café using slido</p> <p><i>Facilitated by Natasha Walker, moderator</i></p>
12:45	<i>Lunch</i>
13:30	Departure for the site visit
14:30	Site Visit: Rifugio Re Carlo Alberto, Luserna San Giovanni (TO), località Musset, n. 1
16:30	<i>Coffee break and departure to Restaurant “Le Cose Buone”, Luserna San Giovanni, via Fuhrmann 23</i>
17:00	<p>Key learning messages from the site visits</p> <p><i>Small group discussion and plenary debriefing facilitated by Natasha Walker, moderator</i></p>
18:00	<p>Wrap-up</p> <p><i>Natasha Walker, moderator</i></p>
19:00	<i>Dinner at “Le Cose Buone”</i>
20:30	<i>Return to the NH hotel Torino Centro</i>

Day 2 – December 5, 2019 at Talent Garden - Fondazione Agnelli, via Giuseppe Giacosa, 36-38

9:00	<p>Welcome to the second day</p> <p><i>Natasha Walker, moderator</i></p>
9:30	<p>Co-creation of the EFID quality framework</p> <p><i>Emma Harte, ODS</i></p>
10:40	<i>Coffee break</i>
11:00	<p>Fine-tuning the EFID quality framework</p> <p><i>Working groups</i></p>
12:00	<i>Lunch</i>
13:00	<p>Speed dating</p> <p><i>The awardees and stakeholders exchange learnings</i></p>
14:15	<i>Coffee break</i>

14:45	Story-telling on how communities can evolve to be more inclusive and value the expertise of PwD from the viewpoint of PwD
15.45	Wrap up and lessons learnt for the EFID Conference 2019 <i>Facilitated by Natasha Walker, moderator</i>
16:00	Closing of the conference <i>Saida Sakali, King Baudouin Foundation, EFID Chair</i>

EFID is an initiative by:

Robert Bosch **Stiftung**



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