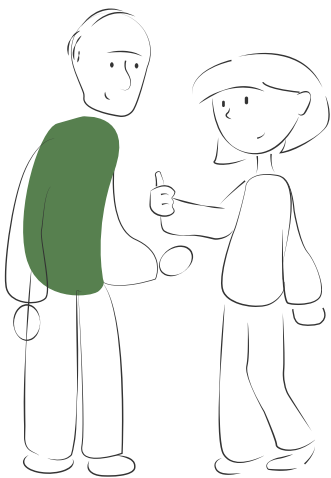


EFID **2010–2020** **10 years of** **transformative** **work on dementia**



EFID

September 2020



“I can’t believe
how far we have
travelled”

Molly, Rifugio Re Carlo Alberto, Italy

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Foreword

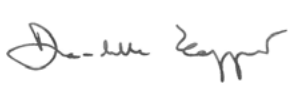
When diagnosed with dementia at the age of 57 in 2006, Agnes felt disempowered and lost. With no job, no purpose, no cure nor treatment, Agnes became a passive member of society with no identity. Is this part of the diagnosis or the society's reaction to dementia? Agnes asked at the past EFID conference.

Over the past 10 years EFID has worked to support the empowerment of local communities and their citizens to improve the lives of people like Agnes. Behind EFID there is a European partnership of foundations and their community partners, that are convinced that it is necessary to put people's life goals at the centre of the health and care interventions if we wish to build inclusive communities for all. Since its creation, EFID supported the scaling up and deep of the concept of 'dementia-friendly' communities. 'Dementia friendly community' concept was born out of the fact that dementia goes far beyond healthcare: citizens, family carers, the public, healthcare workers, social workers, volunteers, lawyers, political decision makers, government and a myriad of many others from local up to European level: we are all part of the community. Drawing from the different experiences and lessons emerging from projects, EFID and its award winners developed key values, such as the importance of involving people with dementia, that led to the evolution of the concept of 'dementia friendly communities', into 'inclusive communities'.

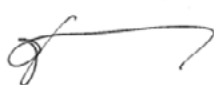
An inclusive community values all its members (with their assets, talents and capacities) and helps them to meet their basic needs so that they can live with dignity, engage actively, and contribute to their community. Indeed, a comprehensive and coordinated response to dementia requires collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment and care. Achieving such collaboration requires that people with dementia speak up and are valued as experts with the condition. The measures linked to the COVID-19 pandemic have heavily impacted people that are living with dementia, and the EFID network has mobilized extensively to find ways for breaking their isolation and maintaining their quality of life. We can only pay tribute to the dedication of all the community workers that worked relentlessly and found innovative ways to bring them care and emotional support. The current crisis amplifies the need for a holistic approach to health and wellbeing. It is essential that decision makers, in collaboration with the local community, commit to ensure adequate services and support to people living with dementia.

This report illustrates ten years of the EFID's activities in support of a 'dementia-friendly and inclusive society', by highlighting a number of initiatives, key achievements and recommendations for the way forward. The EFID journey is characterized first by many cross border encounters between community leaders, by many enriching and productive meetings, studies that fostered mutual learning. The "EFID Awardees" are the ambassadors of those experiences and the ones that will continue the work on dementia around Europe, to make the whole society and in particular the health and care services inclusive, culturally sensitive, accessible, goal-oriented for all people with dementia.

EFID partner foundations



Robert Bosch Stiftung
Bernadette Klapper,
Senior Vice-President



King Baudouin Foundation
Gerrit Rauws,
Director



**Fondazione Compagnia
di San Paolo**
Alberto Anfossi,
Segretario Generale



**Fondation Mederic
Alzheimer**
Alain Berard,
Deputy Director



Porticus Düsseldorf
Barbara von der Mark,
Country Manager

Introduction

EFID, the European Foundations' Initiative on Dementia, was founded in 2010 (through the Network of European Foundations) by four foundations: the Atlantic Philanthropies, the Fondation Médéric Alzheimer, the King Baudouin Foundation and the Robert Bosch Stiftung.

Its objective was to contribute to a better quality of life for people with dementia and their carers through a Europe-wide awards scheme. The theme of the first awards was “Living well with Dementia in the Community”, aimed at promoting social inclusion through context-relevant projects to build awareness about dementia. This remains the overall objective of the EFID awards.

In the following pages, we would like to share with you the road that EFID has travelled over the last ten years, from the creation of EFID and its first calls for projects, to the strong European network of NGOs and other organisations that it is today. But more than a group of organisations, EFID has become a network of talented and committed people, with a shared vision of inclusion, empowerment and community. We spoke to a number of them to see how they have experienced the EFID journey.

This brochure celebrates ten years of achievements of working with, and for, people with dementia, their families and carers. It describes how EFID and its award winners have evolved and developed key values, such as the importance of working together with people with dementia, as well as their carers, health practitioners, policy makers and local administrations, but also volunteers and a myriad of others in our local communities, from policemen and hairdressers to grocers, bakers and barmen. It also charts the path to ‘dementia friendly communities’, which later evolved into ‘inclusive communities’.

Like any journey, there have been hills to climb and bridges to cross, but there have been many moments when we have experienced fulfilment, relief and joy. Sharing and learning have been key to everything we have achieved to date.

More recently, Covid-19 has presented us all with significant problems and more than a few heartbreaks. Yet once again, a great challenge has resulted in some awe-inspiring initiatives as well as hope. There has been even more coming together of the EFID network in 2020 as we all appreciated the need for and the power of community. So we continue along the road and we look to everyone who reads this brochure to join us and work with us, in any way possible, to continue to create and sustain communities that are truly inclusive of people with dementia.

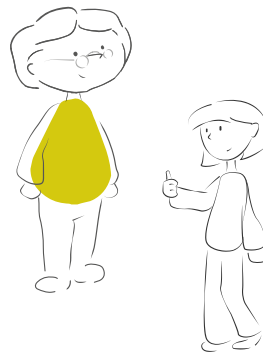
So let's begin with the start of our journey, with the birth of EFID ...

Section 1

Timeline



Timeline of key events



2007

Bernadette Klapper (Robert Bosch Stiftung) visits the King Baudouin Foundation

2008/10

Contacts between European foundations interested in working together on dementia

2009

King Baudouin Foundation Working group recommendations "Towards a dementia-friendly society"

2010



Dementia placed high on EU agenda during Belgian Presidency

Belgian research on frames and counter-frames for dementia published and discussed during a study day

25 November: EFID initiative officially announced at the EU conference on Dementia in Brussels

2011



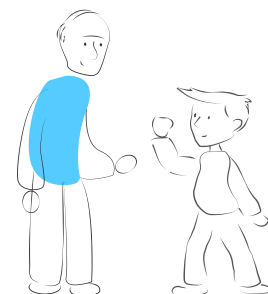
Workshop on framing dementia at Stirling University

6 April: Call for projects for the first EFID awards "Living well with dementia in the community"

May: Workshop at Stirling University on re-framing dementia

June: workshop in Dublin to discuss Belgian research report on re-framing dementia

2012



16 January, Brussels: First EFID awards presented in Brussels

EU Year of Active Aging and Intergenerational Solidarity

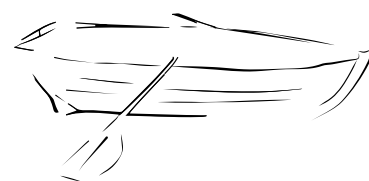
2013

Joseph Rowntree Trust (UK), Life Changes Trust (UK) join the foundations that set up the EFIDs and Genio Trust joins as representative of the Atlantic Philanthropies

March 25: EFID launches the second call for awards 'Living well with dementia in the community' (published in 8 languages, in an effort to attract organisations in Eastern Europe). People with dementia involved for the first time in selecting the award winners

30 May: EFID session at the European Foundation Centre's Conference 'Europe is growing older – why the dementia challenge can help build sustainable cities'

2014



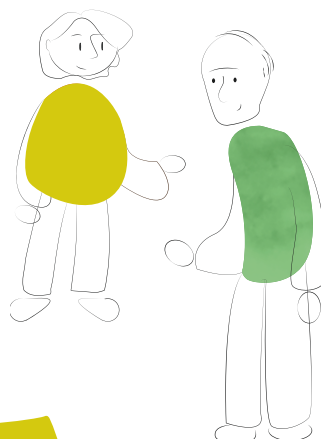
25 March, Brussels: Award ceremony for the second round of award winners and two workshops:

- 'From users to actors: involving people with dementia in your work'
- workshop on involving people with dementia from ethnic minorities and their families in the community

2015

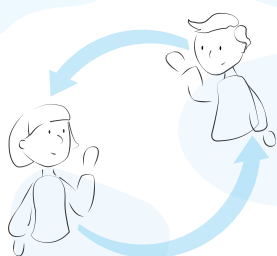
March: Dublin workshop 'Towards a network of Practitioners for Dementia-Friendly Communities – Innovate, collaborate, accelerate'

March: the EFID foundations decide to establish a ring-fenced Capacity Strengthening Fund to support EFID awardees to develop joint practices and go-and-see visits.



2016

10-11 May, Bruges: EFID Workshop in Bruges and Aalbeke, Belgium: on 'Exchange of practice and development of measuring tools to capture changes'.



2017

March: New EFID call for awards 'Valuing the expertise of people living with dementia' to be awarded to 12 organisations in 10 EU countries

2018

23 January, Sofia: 2018 EFID Awards presented in Sofia, Bulgaria under the flagship of the Bulgarian Presidency of the European Union

Workshop 'Valuing the expertise of people living with dementia'



2019

Series of EFID Webinars organised

4-5 December, Turin: EFID conference: 'Valuing the expertise of people living with dementia in the community'

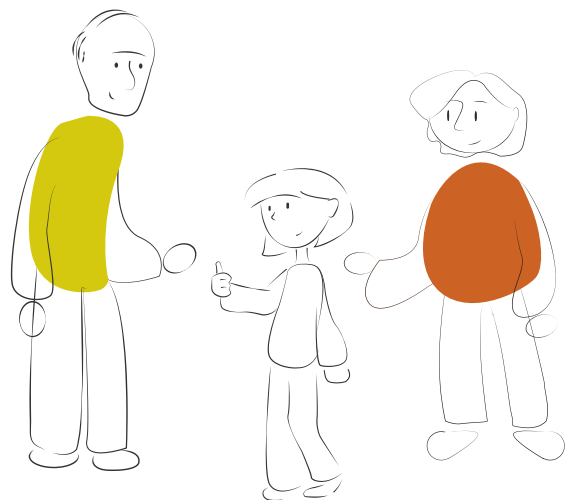
2019-20

The Fondazione Compagnia di San Paolo (Italy) and Porticus (Germany) join the Fondation Médéric Alzheimer, the King Baudouin Foundation and the Robert Bosch Stiftung as partners for EFID

2020

Covid-19 arrives and spreads quickly across Europe

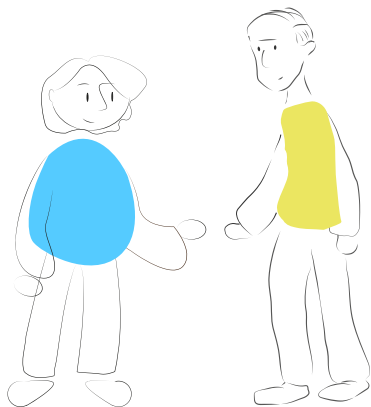
September: EFID launches the call for awards "Spreading a legacy for the future" to support best practices in the Covid-19 response and moving forward the EFID approach to inclusive communities



Serendipity in Brussels and Stuttgart leads to the creation of EFID

It is surprising how important, positive happenings often come about as a result of a chance meeting, but it seems that it was indeed serendipity that led to the creation of EFID. Dr Bernadette Klapper, today Senior Vice-President at the Robert Bosch Stiftung, had been working on dementia programmes at the German foundation's headquarters in Stuttgart since 2003 where, she said, "I wanted to spread the message that dementia is more than nursing and medicine; it's a task for the entire civil society".

In 2007, Bernadette was offered a two-week work programme with the King Baudouin Foundation in Brussels to see how they were working. She remembers, "In Brussels, the KBF was also looking at dementia and had created a working group of 13 experts that went on to do multidisciplinary research on the perceptions of dementia, its legal facets and advance care planning". While she was in Brussels, Bernadette met Gerrit Rauws and Saïda Sakali and they discussed the concept of dementia-friendly communities. Bernadette and Anna Miller, at the Robert Bosch Stiftung, continued the contact with the King Baudouin Foundation. It so happened that the foundations were also in contact with Marie Jo Guisset at the Fondation M d ric Alzheimer in France and thus the idea of working together in Europe was born. Shortly afterwards, The Atlantic Philanthropies joined this trio of foundations.



2010 Official announcement of EFID

On November 25, 2010 the inception of the EFID was announced at the high-level conference on dementia, *Improving the quality of life of people with dementia. A challenge for European society*, held under the auspices of the Belgian Presidency of the European Union. More than 20 European countries were present at the conference and the initiative received a warm welcome from everyone, including the institutions of the European Union.

The first call for projects came in March 2011, on the theme of *Living well with Dementia in the Community*. Why, however, was the idea to make what, in essence, were grants, into awards, accompanied by an award ceremony? Bernadette Klapper again, “We wanted to help our awardees to go a step further and develop further.” And further indeed they have gone. As one of the awardees concluded, “We are so small and have so few resources, so the awards are sort of prizes that give us money but also the energy to see a way forward”.

If the second decade of the new century was a propitious moment for the coming together of the EFID partner foundations, it is worth taking a brief look at what had been going on during the previous ten years, work that had ‘prepared the ground’ through the increasingly active participation of people with dementia, by research into ways of re-framing ‘dementia’ and early developments in the concept of dementia-friendly communities.

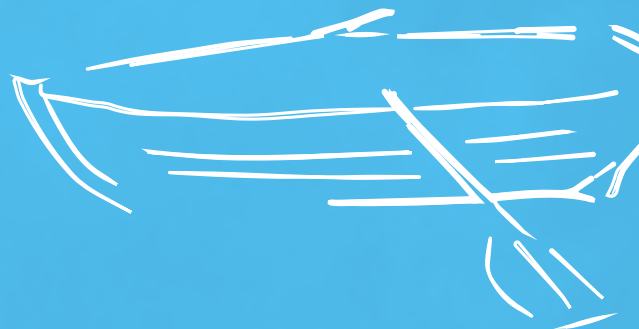


People living with dementia demand change

The first decade of the new millennium was a period “bubbling up with activism”, especially at grass roots. In what was considered to be rather revolutionary at a time when dementia was hardly talked about, this activism was being led by people with dementia, with towering figures such as James McKillop in Scotland and Helen Rochford-Brennan in Ireland, often initially getting involved through academic research. Soon other people with dementia began not only to demand change, but to actively promote changes in attitudes and behaviour towards people like them, including in organisations already active in the field of dementia. Helen remembers “In Ireland, I realised my rights were being totally violated! I couldn’t talk to anyone about dementia because there was such stigma around it. But we, the people with dementia, were and are the drivers who are changing all this and making sure we are as integrated as anyone and that the community has a duty of care towards us”.

The first decade also saw social researchers in various countries begin looking at how to get people to think differently about dementia, how it could be re-framed. Saïda Sakali at the King Baudouin Foundation remembers a Stirling University workshop on how people regarded dementia and people with dementia, “It was a real eye-opener for us all. It helped us to reach out to many more people and in a more meaningful way. I think it was the moment that brought the foundations together... there was so much activity at local level, but then suddenly there was this huge enthusiasm for working together across local level. I think that it was probably 2010 that marked the beginning of many exchanges between foundations and NGOs.”

In England, Philly Hare run a programme called “Dementia without walls” at the Joseph Rowntree Foundation, which looked at re-framing dementia and the concept of dementia-friendly communities, and set out to “push the boundaries” by working alongside people with dementia. In Belgium, the King Baudouin Foundation commissioned research on attitudes and the re-framing of dementia.



The creation of EFID: 'about care not cure'

When EFID was set up, there was still very much a bio-medical approach to dementia, but things were set to change because of this unstoppable osmosis of ideas and activity at national and increasingly international level. There was determination to re-frame dementia among policy makers, the media and society in general, to include people with dementia and to work on the ground to create dementia-friendly societies. As new data about the prevalence of dementia across Europe showed that some eight million people were affected by the disease, the beginnings of high-level recognition of the issue of dementia in the EU provided further impetus for change.

Some charitable organisations were reaching out to the pharmaceutical industry and fund-raising for scientific research into Alzheimer's and associated brain diseases; others were approaching governments and trying to influence public services in the care sector, through training and raising awareness about the needs of people with dementia. However, from the very beginning of EFID, as Bernadette Klapper now remembers, the foundations involved in EFID...



“ never sought to do structural work, but rather to inform, influence and support, inspire and train. From the beginning EFID was about care, not cure ”



There was already some collaboration between European foundations in 2010. Saïda Sakali remembers “It was just so heart-warming and easy to find partners at European level! The enthusiasm was amazing and 2010 marked the start of many exchanges between us... When we started, there was such a clinical view of dementia and we realized we had to focus on the person and the care of the person with dementia, while others looked at the medical side of things and for a cure. But we realized that things could be different, trying to keep people with dementia in contact with society, going shopping, having a coffee, cultural activities...”.

The EFID Awards: a pioneering model to induce change

And so it came about that on 6 April, 2011, four like-minded foundations, the Atlantic Philanthropies, the Fondation M  d  ric Alzheimer, the King Baudouin Foundation and the Robert Bosch Stiftung launched the first EFID awards on the theme *Living well with dementia in the community*. The objective was to raise awareness and improve perceptions of dementia, but it was also to stimulate solidarity at local level. The foundations strongly believed that people in the local community should be encouraged to take responsibility for the way in which people with dementia were integrated in and supported by society and that this would result in a better quality of life for people with dementia and their carers.

Ten community-based organisations¹ across eight countries were selected by an independent committee and the awardees received up to   10,000 each. The awards were presented by HRH Princess (now Queen) Mathilde at a ceremony in Brussels on January 16, 2012. Isabelle Donnio says of the award made to *Bistro M  moire* in Rennes, France, "Money was in short supply in those days, so it meant a lot to us, but the fantastic thing was that we discovered all those other innovative projects around Europe! It was a brilliant introduction to inspiration, networking and sharing across Europe. People were doing amazing things like working with the police, banks, shopkeepers, bars and restaurants!"

This networking aspect was highly valued by all of the award winners and, importantly, by the EFID organisers, so it was decided to hold a workshop for the award winners later that year at the 23rd Alzheimer Europe Conference in Vienna on October 2012, with the participation of Patrick de Rynk, author of the report *I'm still the same person*. At the Vienna conference, EFID also organised a symposium designed to give greater visibility to EFID and its community approach, as well as the changes needed in communication when journalists and others talked about dementia.

1 See <https://efid.info/projects/> for the list and descriptions of 2012 awardees

Typology of EFID projects and organisations:



Reaching out, building bridges

After the 2012 awards, the next three years marked a period of reaching out and building bridges, to people with dementia themselves as well as to other organisations, and further increasing the visibility of EFID and how it worked. The original organising foundations were joined by the Joseph Rowntree Foundation and the Life Changes Trust (UK), and by the Genio Trust (IRL) as representative of the Atlantic Philanthropies. All were very active with their own dementia programmes, but importantly, in what was becoming a step change for society, they all actively involved people with dementia in their work.

The second call for projects went out on March 25, 2013. This call had two crucially new aspects: firstly it appeared in seven languages, in an effort to reach out to organisations in Eastern Europe and secondly, EFID invited Innovation in Dementia to facilitate the involvement of people with dementia in the selection of the EFID prize-winners.

On March 24 2014, ten new organisations² were presented with awards (of up to € 10,000) in Brussels. The awardees also had the opportunity to meet, share and learn from each other during a workshop entitled “From users to actors: involving people with dementia in your work”. This principle of reaching out to people with dementia and to learn from other awardees and work together – “becoming a real family” as many of the award-winners have described what happened – was firmly taking root. Great new ideas emerged, such as conducting exchange visits and twinning, but the geographical scope of the awards remained limited.

Towards a ‘Dementia-friendly community’

EFID and the award winners were increasingly promoting the dementia-friendly community, a concept that involves promoting understanding of dementia and the needs of people with dementia in the local community, by involving organisations such as the local police, shopkeepers and cultural organisations. In 2014, EFID representatives attending a conference in Leeds visited York to observe on the ground a city that had already implemented good practices³ to create such a dementia-friendly city. Key aspects of the concept in York include making it easy to get around the city thanks to clear signage and easy-to-use public transport, ensuring that cultural and leisure resources are dementia friendly, training staff in the main community services such as banks and shops and finally using a forget-me-not symbol around the city to denote venues that are dementia-friendly.

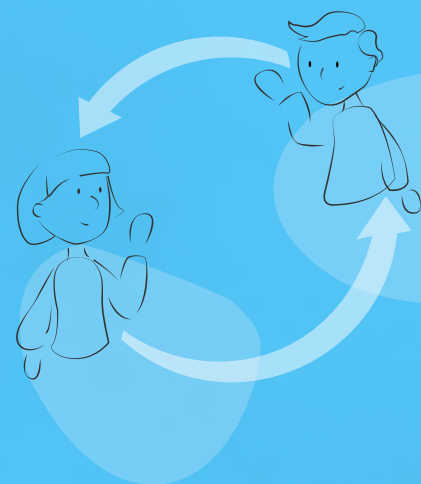
² See <https://efid.info/projects/> for the list and descriptions of 2014 awardees

³ <https://www.yorkcvs.org.uk/yorkdaa>

Other EFID events also spotlighted the community: a workshop in Dublin for awardees, on the theme *Towards a network of practitioners for dementia-friendly communities – innovate, collaborate, accelerate*, and the creation of a Capacity Strengthening Fund of €64,000.

The fund supported six local initiatives⁴ implementing good practices in the community to enable them to conduct joint projects and go-and-see visits, thereby further strengthening cooperation and synergy and creating new partnerships. Importantly, the projects that would benefit from the Fund were once more selected by a facilitated group of people with dementia.

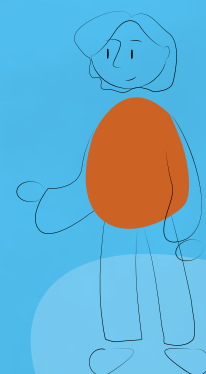
One of the six projects selected was ‘Go-and-see visit: Sharing European realities to mobilise change’ created by awardee Foundation Compassion Alzheimer Bulgaria. This involved the NGO’s staff, board and local council partners visiting another awardee, the Rifugio Re Carlo Alberto in Italy, which later paid a return visit to Bulgaria to help them on the ground with their projects. Tania in Sofia remembers:



“ Thanks to EFID we developed such fruitful close contacts and amazing exchanges. No other network offers this sort of cooperation. Local government now *asks us* to work with them! ”

In 2015 Luisa Marino joined the Network of European Foundations to coordinate and develop EFID, bringing with her extensive experience of working on European projects and coordination. Luisa remembers:

“ I was overwhelmed by the warmth, dedication and knowledge about dementia among my colleagues, the sector and the other organisations within the network and, above all, by the people with dementia ”



⁴ See <https://efid.info/projects/> for the list and description of 2015 initiatives supported

Disseminating knowledge about dementia-friendly communities

Workshops were becoming an increasingly important tool for EFID, enabling awardees and others to meet, learn and share knowledge and practices, particularly in relation to widening the concept of dementia-friendly communities. One such event, held in Belgium in May 2016, on the theme *Towards a network of practitioners for dementia-friendly communities* was a workshop about which attendees still speak with enthusiasm because they had the opportunity to visit the beautiful city of Bruges and see Foton's work there, where local partners including the police, healthcare services, restaurants and shopkeepers work with Foton to create a dementia-friendly community, as well as to visit the village of Aalbeke to discover the work of OCMW Kortrijk in creating *Reminiscence Promenades*, improving mobility and accessibility and intergenerational work.

2016 also saw the publication of *Mapping Dementia-friendly communities across Europe*,⁵ a research project commissioned by EFID from the Mental Health Foundation to analyse the concepts and practices of dementia-friendly communities across Europe and create an online collection of case studies⁶. The research also gathered information about policies and strategies and, interestingly, although it found some Europe-wide initiatives that included support for dementia-friendly communities, no agreed model of what exactly this was emerged. Moreover, EFID was the only comprehensive European programme supporting the development of such communities.

The research identified **four key factors** for the development of dementia-friendly communities:



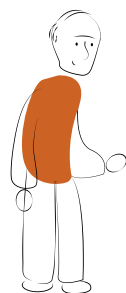
⁵ [Download the Mapping report here](#)

⁶ <https://efid.info/resource/dementia-friendly-community-case-studies-across-europe>

A taxonomy for 'dementia-friendly community' activity (DEM-FACT)

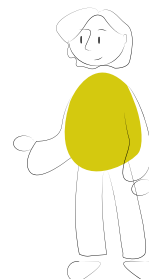
'Community support'

Focus of DFC activity is providing community care and support to people with dementia



'Community involvement'

Focus of DFC activity involves the wider community being supportive towards people with dementia



'Whole community and citizenship'

Focus of DFC activity are community partnerships co-ordinating a comprehensive 'whole community' and citizenship approach with the active involvement of a range of organisations, resources, and people with dementia

Focus on people living with dementia

As the decade progressed, increasing attention was being given by the media and by society itself to people living with dementia who continued to have an active life and indeed to contribute to society. A huge paradigm shift was taking place that had important repercussions, notably that people living with dementia were now becoming actively involved in the design, implementation and evaluation of projects and policies.

It was apposite, therefore, that the 2017 EFID call for awards was for '*Valuing the expertise of people living with dementia*'⁷, which was not only aimed at valuing the expertise of people living with dementia but also at creating the conditions for peer support and public expression. The 12 prize-winners, chosen once more by people with dementia, came from 10 countries across Europe.

The awards ceremony took place in Sofia, Bulgaria, in January 2018, and was an event that provided good press coverage and awareness-raising opportunities for everyone involved. Helen Rochford-Brennan, an internationally recognised spokeswoman for people with dementia, who was diagnosed with Younger Onset Dementia in 2012, gave the keynote speech.

⁷ See <https://efid.info/projects/> for the list and description of the 2017 prize-winners



“ People with dementia have the same human rights as everyone else, but we often face barriers to fulfilling these rights. Our rights should include the right to a timely diagnosis, to person-centred, quality care, and the right to be respected as individuals in our communities. We are citizens with inherent human rights. We are not sick. We are not clients. We are not patients. We are rights holders. I’m still me. I’m still a wife. I’m still a mother. I’m still a sister. I’m still a person. I’m still Helen and Helen has a voice. ”

The awards ceremony was followed by a workshop on the same theme, which once more generated close collaboration and the sharing of experience between the award winners and others working in the field, including people with dementia.

The event was hosted by the Bulgarian prize-winner, Foundation Compassion Alzheimer Bulgaria for its project ‘Together we respect, promote and act – inclusive society for all ages and all stages of dementia’. Tania in Sofia remembers,

“ The ceremony and conference in Sofia were one of our common achievements, because there are not so many events focused on dementia in Bulgaria. And the fact that it was organised within the framework of the Bulgarian Presidency of the EU Council was an additional support and factor of legitimacy for us ”



Strategic road map

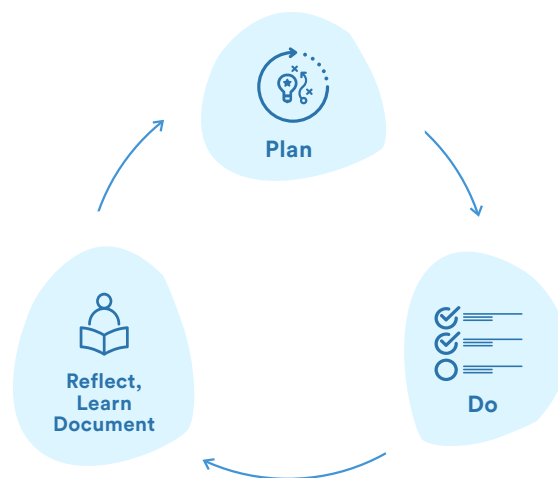
Disseminating the knowledge and good practice of awardees, along with valuing the expertise of people living with dementia and strengthening the dementia-friendly community approach across Europe became the three strands of EFID's strategy for 2019 to 2020. During this period, Porticus (Germany) and Fondazione Compagnia di San Paolo (Italy) joined the group of foundations.

Workshops played an increasingly important role in the dissemination of knowledge, ideas and experience in EFID. A second workshop *Valuing the expertise of people living in the community* was organised in Turin in December 2019. Once more, an invaluable part of the workshop was a visit to see the work of an award-winner (in 2014), that of the Rifugio Re Carlo Albert, specialised in both residential and day care of people with dementia and strong proponents of reaching out to other organisations. Molly explained: "We've worked with Het Ventiel in Belgium and Educate in Stockport, as well as with the Bulgarians and now we have a new project with Dement Talent in the Netherlands! ... It's amazing how EFID has created this network of skills and people actually involved in the heart of projects, who then take knowledge back to share with others as well."

In 2020, the diverse experience of awardees was used to co-create the EFID Toolkit for Planning, Reflection and Learning.⁸ A team of experts (Emma Harte and Rosien Herweijer) worked closely with EFID awardees, an advisory group of people with dementia and the partner foundations to develop the toolkit. Its objective was to help understand and monitor the effect of awardees' work on their communities by providing a common language to appraise the impact of work on dementia across Europe.

In addition to workshops, EFID began using technology as a means of reaching out to members of the network, creating a series of webinars to cover issues such as creating a quality framework, dementia and migration, and the EFID Tool Kit. This way of knowledge sharing and communication was of course to prove vital when the Covid-19 pandemic arrived in Europe.

EFID Toolkit



⁸ <https://efid.info/resource/download-the-toolkit/>

Section 2

Achievements



EFID achievements

When it was created, EFID's stated objective was to 'contribute to a better quality of life for people with dementia and their carers'. Over the last ten years, it has worked to achieve this through the creation of a highly professional and responsive network of like-minded professionals across Europe, who work towards raising awareness and reducing the stigma of people with dementia, and developing creative ways of integrating them into our society in a way that feels and is inclusive.

EFID and its awardees are, of course, among the many organisations working with people with dementia, helping them to "move out of the shadows and find a voice" in the community, the media and among policy makers, but EFID seems to have done this in a rather special way.

Focus on the person with dementia

Almost from the beginning, EFID directed its efforts towards getting society to see the person with dementia as a *person*, not a patient, and to reinforce the message that the person with dementia is someone who is often still able to enjoy life in the community and indeed to contribute to society. Key to this has been the involvement of people with dementia themselves in EFID's work.

Saïda Sakali, at EFID partner the King Baudouin Foundation in Belgium, says "My *coup de coeur* for EFID achievements is that we succeeded in having a different framing of dementia. It was such a clinical view before, but from the start, **we centred on the person**. Whilst others were focusing on cure, we focused on care. People started to forget about the word 'patient' and thanks to the projects EFID funded, to realise this is how it *could* be, keeping people with dementia in contact with society, even simple things like shopping, going for a coffee and cultural activities."

Cristian, at award-recipient Novilunio Italy, explains, "I think the main achievement of EFID over the last ten years is that **people with dementia are speaking**, saying what they feel and need, talking about their struggles. That's why we were attracted to EFID. People with dementia were *always* present, giving their experience, judging the projects, giving *us* advice. This is a major difference between EFID and other organisations that fund projects."

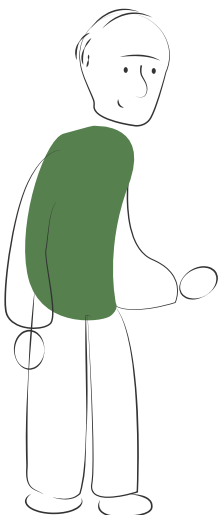
As a person with dementia herself, Helen Rochford-Brennan comments, "**EFID looks at the community** and it's how EFID put these groups together. They aren't necessarily Alzheimer's groups. There's such a range of groups and wonderful projects all creating awareness and things like holidays for families and lovely walks. There's nothing in a medical book that's going to bring that sort of enjoyment! At the end of the day, that's

all we (people with dementia) need: hope and a sense of purpose, that we can work, live well, enjoy the great outdoors, meet people from other countries. EFID has been so good at **reducing stigma** and it's not just one group, it's for the whole country, the whole of Europe”.

A European approach that engenders visibility and legitimacy

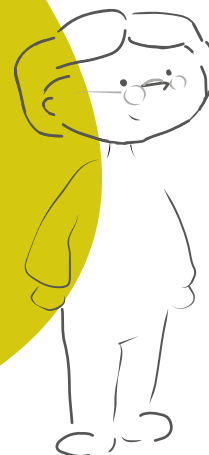
The European aspect of EFID's work can itself be considered as one of its key achievements of the last ten years. EFID is European to its core: it is backed by European foundations that share the same values and ideals and considerable effort has been made through its awards and activities to reach out across Europe, including to Eastern Europe in recent years, so as to include countries with different cultures and sometimes very different approaches to dementia too. Bernadette Klapper says:

“ I believe EFID's most important achievement has been to spread the idea of dementia-friendly communities across Europe and to have this nucleus of European cooperation. It's been wonderful over the years to spread Stirling's ideas to people with different cultures while also having the same humanistic approach towards people with dementia and the same goal and willingness to improve their lives. When we gave out funding, people came from across Europe to exchange experience and work with people with dementia. They were so encouraged in their work by the networking meetings, sharing ideas and exchanges ”



“(EFID) is a group of people who know about love, care, enjoyment and fun, like a family, giving people a great sense of purpose, things you don’t find in a medical book”

Helen, Ireland



The EFID awards and the award ceremonies provide visibility to dementia on several levels. First and foremost, the message is spread about the awardees and their work to people with dementia and their families, carers and the local community. However, and this is of critical importance, policy makers at all levels – local, regional, national and European – are informed of work being done with and for people with dementia. ‘Seeing is believing that things can be different for those with dementia.’

The European nature of EFID is felt to be of particular importance by EFID awardees, not just for the educational messages transmitted, but crucially because being recognised by an international award from a European body confers legitimacy on what are often small organisations, what they are doing and how they are working. This in turn helps them to seek further recognition, collaboration or financial support, especially from policy makers and public authorities:

“When we received the award for *Reminiscence Walks*, it was important recognition for everyone, for EFID, the people with dementia and our local government! It was a win-win for everyone, because it normalised small-scale working with people with dementia and it gave the local authority visibility and perhaps even votes!”

Jan, Belgium

“Our EFID award legitimised what we were doing and the fact we were doing things differently. We no longer had to be defensive. We became connected to a whole policy and operational world that enabled us to come back to our staff, our organisation, local councils, health authorities etc. and say ‘Look! What we’re doing is not off the wall, because the rest of the world is doing these sorts of things too!’”

Molly, Italy

“Our EFID award was good for everyone, it was good for the status of our project and the community. It highlighted working in and with the community and there was less negativity. We were less open to criticism for doing things differently.”

Martin, Germany

“ It’s about creating this community where everyone is rowing in the same boat, towards the same goal. It’s a network based on mutual help, professionalism, respect and friendship across borders, so we feel valued and trusted ”

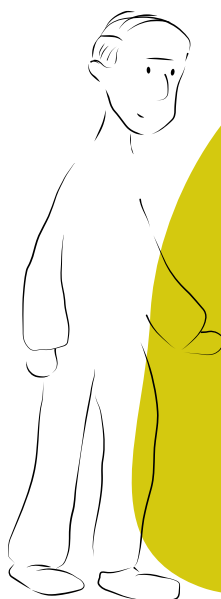
Tania, France



“ EFID and our award certainly contributed to us being asked to participate in a working group with the government to develop strategic guidelines for a national dementia plan... EFID also helped us realise another dream of ours, to participate in the day care service. Thanks to EFID and the Rifugio team who visited us in Bulgaria, we got knowledge and experience about issues for day care centres and last month we were granted a project with another Bulgarian NGO to set standards for day care centres! We’ll work directly with the Ministry of Labour and Social Policy in Sofia. ”

Tania, Bulgaria

The visibility and legitimacy conferred by EFID awards on NGOs working with people with dementia have two further important consequences. Firstly, they provide visible evidence that proper care in the community can enable people with dementia to live longer and better at home and this has a recognised positive impact on government finances. Secondly, they show that smaller structures for live-in and day care can offer significant improvements over large-scale institutional structures for people with dementia and their carers, in terms of finance and the quality of care.



“ For me, EFID feels like a safe, honest, and open space when we get together, so supportive of people who do different things. We have the same aims, values... we’re on the same page, so you feel comfortable with people who really know what the challenges are, a thriving community of people who want to be with each other ”

Andy, Scotland



“ It was so obvious from the start that EFID was really committed to the network. The shared values, the feeling of a family, so you can just pick up the phone and call anyone. I was blown away when I went to Turin and found they all knew each other! ”

Avril, Ireland

EFID Awardees: a European family with shared aims and values

A key achievement of EFID has been the creation of a remarkable network of people, all striving to see people with dementia fulfilling their role as members of an inclusive society. The feeling of being part of a European ‘family’, united by shared values and aims, is one that has percolated down from the EFID partner foundations to the awardees:

“ The partner foundations at EFID were and still are a very nice circle. We just like each other! It’s not just working together for a cause we all share; I think all of us are emotionally captured by it and this was what gave us the ‘glue’ as a group of foundations. There was this feeling of an important venture. I enjoyed that feeling too. There has been some change in the partner foundations, but this has never been an issue because we share the same goal and welcoming culture ”

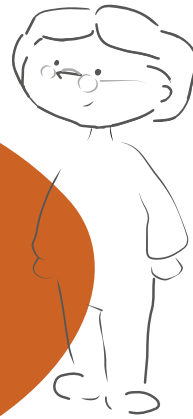
Bernadette Klapper

EFID awardees, the people with dementia and their families, as well as others they work with in the community, all consider themselves to be part of an incredibly effective network that generates “self-confidence and esteem” as well as the emotional bond of togetherness. They share a feeling of emotional and psychological support that is of huge value, because awardees work in challenging situations, often in very small teams, and the EFID network gives them the impression of being part of a bigger team on whose members they can call, at any time, about any subject.

This feeling has been created over the years not just by the awards themselves, but also by the many activities organised by EFID, such as workshops, ‘go and see’ and exchange visits and hugely important aids such as the EFID Tool Kit, developed to help awardees and other professionals to think through their approach to planning and implementing projects, and the sharing of material such as press releases, stories, videos and articles, all of which is invaluable particularly for smaller organisations operating with fewer resources and people.

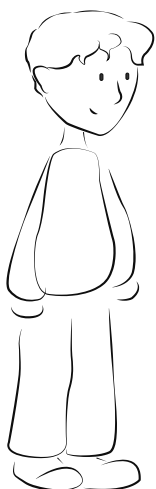
“ We sometimes forget it, but we all feel we are part of EFID and EFID is part of us. We have joint ownership of this network ”

Molly, Italy



Several awardees mentioned the fact that the ‘sharing-learning’ culture created by the EFIDs is of particular benefit for people with dementia, and indeed for everyone involved, because it enables them to be honest and open about what *doesn’t* work as well as what *does*.

Associated with this is a feeling that the EFID network “understands completely” the fact that different NGOs and countries are of different sizes, with different levels of awareness about dementia and the associated problems and they are at “different points along the journey of creating a dementia-friendly society”. So there is no ‘one size fits all’ in the minds of anyone involved. As Michael in Germany pointed out, this is of such importance for people with dementia too, “We still have to do a lot of education so that people understand the different types of dementia and how the disease progresses”.



“ EFID for us, and for me personally, means inspiration and reassurance, you feel that you’re part of a movement, where everyone is aspiring to change ”

Martin, Germany

Section 3

Recommendations



2020 Covid-19

First reactions: fear and isolation

With so many exciting projects and events in the pipeline for 2020, developed by so many skilled and dedicated people, no-one could have imagined how the third decade of the century was to create a very different world for us all. As wide-scale cases of COVID-19 began to be diagnosed in Europe in February, the huge impact on people with dementia and those in our organisations soon became clear.

Fear and isolation have been the most widely reported effects of Covid-19, emotions immediately experienced both by the people with dementia and their families and by the people working with them at home and in care. Over the years there have been so many brilliant efforts to persuade people with dementia to participate in the community, but now it seemed that much of the work would soon be rendered out of bounds as Europe was forced into lockdown: “People with dementia began to deteriorate physically and mentally and community projects became not just inaccessible, but irrelevant. It was, and is, so hard to bear”.

Self-help groups could no longer meet, face-to-face consultations with lawyers and psychologists, cafés and so many other initiatives stopped abruptly. There was anger too, “We got no help from the healthcare system, just no, no, no”, and “We were abandoned by the health system”, whilst for others, “It strengthened the ties between professionals in the care homes, and with the medical professionals working with people with dementia”. But there was also great anxiety about burnout among those working with people with dementia, particularly in care homes, and a “fear that a whole group of people would be forgotten. And indeed, many were”.

The EFID network responds

The EFID network instantly rose to the occasion with solutions that were fast, practical and professional, but also deeply caring and comforting for the people they served. “The situation immediately made us realise what were the most important, the most beneficial aspects of our work with and for people with dementia and how we could help and protect our staff.”

Communication, and of course online communication, was at the forefront: how to communicate with the people with dementia and how to maintain contact with the various professionals as well as everyone in the EFID network “We had to do

something to maintain personal and social relations”, “We thought it was key to create the stimulus of verbal communication and physical movement”.

Across the EFID network, e-mails and phone calls have kept everyone in contact as well as providing practical and moral support, ideas and help, and EFID organised a webinar on ‘Challenges and solidarity during the Covid-19 emergency’⁹. The vital role of technology became increasingly apparent, but problems as well as solutions soon surfaced for persons with dementia. Not everyone has access to the Internet; there was often competition for use of the computer or tablet between the person with dementia and parents working at home or children doing schoolwork; digital skills were often missing or insufficient among people with dementia or access was too complicated. Cédric at Delta 7, France, showed one of the ways forward, with a tablet programmed to facilitate easier use by people with dementia, working more like a TV set with a simple on/off switch.

One immediate reaction for many EFID partners was to install a telephone helpline for the people with dementia and their carers, “This was essential because our health system was totally overloaded and just didn’t – couldn’t – answer phone calls”. Newsletters and information sheets were sent out by mail as well as online, giving important phone numbers and places for help and information and, with limited time and resources available, creativity flourished across the EFID network to provide new websites, blogs, zoom meetings and online activities, with everything from physical exercises and memory games to story writing, concerts and musical request programmes. Michael in Hamburg explained how *Konfetti im Kopf* adapted their previous music-filled *Konfetti parades* to take *Konfetti Rock* to the care homes

“ We have to rid ourselves of the fear and stay positive, so we set up a new website with the time we had and since March, we’ve been doing little concerts in front of the care homes, four to six times a week until September and having a lovely time! ”



EFID and its awardees remain active, responsive and creative, but there is no doubt that Covid-19 is creating huge problems for people with dementia, their carers and those who work with them. It is also clear, however, that the pandemic has shown the importance of investing in networks and working in and with the communities. Despite the immense practical, emotional and physical implications of Covid-19 on the people living with dementia, their carers and indeed everyone in the community, it is where the sense of community is greatest that we have also witnessed the greatest resilience to the pandemic.

⁹ <https://efid.info/eng/webinar-series> (Webinar# 4)

The future path

Funding and technology will impact everyone's activities in the short and long term, but EFID's overall commitment remains to improve the lives of people with dementia by supporting local organisations that are active in dementia-friendly activities through awards, capacity development and networking and in this respect *people* will remain the key to continuing to improve the lives of people with dementia in the community.

Feedback from the EFID network during the Covid-19 pandemic nevertheless indicates a certain nervousness about the future path “because there is no real political roadmap for the future”. There was deep anxiety about care homes and day centres: “The pandemic has raised the issue of care homes needing to be *really* fit for purpose and of course we wonder whether day centres will re-open”, but there remains widespread hope that

“ perhaps governments would take a new look about supporting people with dementia at home and in the community, which is better for everyone and cheaper in the long run for the authorities! ”

As mentioned earlier, there is also hope that authorities will give more consideration to small-scale units of care, which offer significantly greater benefits for the people with dementia as well as facilitating significantly better management during periods of crisis.

Setting budget priorities will probably be different too for everyone: “What *should* we spend money on and how much?” Members of the EFID network fervently hope for continued close collaboration with policy makers and government in developing solutions. Future aspects for EFID of working with people with dementia are likely to be included in the Integrated Community Care movement.¹⁰

Continuing to reduce the gap in time between the diagnosis of dementia and access to services in the community and elsewhere is felt to be an important issue for future planning regarding people with dementia, as well as real issues of human rights, such as advanced care planning.

¹⁰ <https://transform-integratedcommunitycare.com/>

Communication via technology is, however, likely to be at the top of the agenda, because it has become essential for continuing to include people with dementia in the community. As Saïda commented “Inclusion in the community must remain the litmus test for everything we do for people with dementia” and, leaving the last word to Helen Rochford-Brennan, “Communication via technology is key for everyone associated with the community, for those in the EFID network, for exchanges at local level and for the volunteers to help those without access to the Internet. We must never leave anyone behind!”.

Guiding principles for building inclusive communities

In the absence of a cure, or universally effective treatments, for Alzheimer’s (and other forms of dementia) for the foreseeable future, there is both the opportunity and necessity for creative, positive community- and people-based solutions to support people with dementia, so that they can not only live well, but also be active participants in their communities.

This means strengthening the voice and interests of people with dementia and respecting and fostering their dignity and human rights throughout the course of their (care) path. People living with dementia are part of the community along with their talents, experience and challenges. They should receive the support they need in a way that empowers rather than disabling them.¹¹ Although European countries have different health and social care systems and institutional care for dementia, communities will remain the place where the majority of people with dementia live their lives. It is therefore in the communities that solutions will continue to be found and created, but as communities come in all shapes and sizes, it is perhaps inevitable that community-based solutions that enable people with dementia to live well will also be highly diverse – one size does not fit all¹².

Drawing from its work over the past 10 years and on the 7 effectiveness principles of Integrated Community Care (ICC)¹³, EFID has identified the principles we believe to be essential to building inclusive communities for all, with a special focus on people living with dementia:

11 Final report EFID Conference “Valuing the expertise of people living with dementia in the community”, Turin, 2019 <https://www.efid.info/wp-content/uploads/2020/02/Final-Report-EFID-Workshop-2019-Turin.pdf>

12 “Mapping dementia-friendly community across Europe”, EFID, Toby Williamson, 2016 <https://efid.info/resource/mapping-dementia-friendly-communities-across-europe/>

13 “ICC 4all: New Principles for Care. A strategy paper to move ICC forward”, TransForm, Authors: Philippe Vandenbroeck, Tom Braes (shiftN), March 2020 <https://transform-integratedcommunitycare.com/integrated-community-care/>



1. Dignity and quality of life

Enable the highest quality of life to be made possible for people with dementia, with the fewest restrictions on their **personal liberties**. Every effort should be made to **preserve their dignity** and **independence** throughout all stages of the condition, in a living space that provides safety and comfort.

2. Inclusion and Involvement

Foster the active inclusion and involvement of people living with dementia in all aspects of (community) life, in cooperation with the communities in which they live in, whilst ensuring their health and wellbeing. Build on the expertise and assets of community members so as to avoid one-size-fits-all approaches to involvement. **Ensure diversity** and the inclusion of groups that may be marginalised for ethnic or other reasons. The life goals of persons with dementia should be the starting point for the design of all health and social care interventions that relate to specific care needs.

3. Perceptions and the framing of dementia

Raise awareness about what is needed to increase the wellbeing, resources and potential of people with any cognitive impairment and their family carers, thereby contributing to a **change in perceptions of such people** in society and in the health and care systems.

A **society-wide change in mind-set and appropriate care provision** will improve the quality of life of people with dementia and their families, reciprocally enabling them to become more visible and actively-participating members of society, whilst also reducing the stigma and fear of the disease. **Frame**¹⁴ dementia actively and positively, especially in the media, to change the negative image of dementia among the public.

14 I'm still the same person, Patrick De Rynck 2012 <https://efid.info/resource/i-am-still-the-same-person/>



4. Alliances & synergies

Build partnerships, networks and collaboration among various stakeholders and organisations to enable the **co-production of wellbeing**.

Integrate the crucial role played by health and social care organisations and dementia-specialist organisations in the development of inclusive communities. **Create synergies** between civil society organisations, health and social care services and carers (both family carers and professionals).

5. Prevention & diagnosis

Invest in prevention and health promotion, while **reducing health inequalities**.

Ensure early screening for dementia for everyone, including in remote areas, followed by timely diagnosis and prompt referral for services. Advise those living with dementia of the possibilities of advance care planning¹⁵ and enable family carers to navigate easily between, and engage with, care and support services.

¹⁵ Rights, autonomy & dignity of people with dementia, ALCOVE, 2013 https://webgate.ec.europa.eu/chafea_pdb/assets/files/pdb/20102201/20102201_d7-01_en_ps.pdf#page=87&zoom=100,109,613



6. Coordinated strategies

Promote the adoption and implementation of **dementia strategies** in every country in Europe in collaboration with the community and all stakeholders at local, regional and national levels. **Ensure** adequate **support and strategies** for dementia-friendly initiatives and for social and health care interventions at home, in nursing homes, hospitals and community-based services etc... National governments, NGOs and other organisations should **secure resources** for inclusive community development.

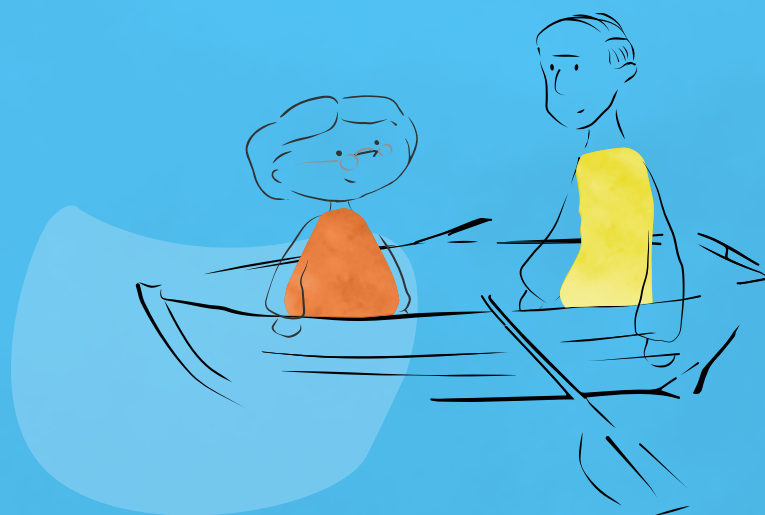
7. Evaluate and adapt

Collaborate to evaluate the impact and outcomes of projects (which actively involve people with dementia), enable joint learning and ultimately **adapt** policies, services and activities. Develop evaluation criteria together with all actors in a participatory way, involving them from the beginning to the end of the process.¹⁶

¹⁶ EFID Toolkit for Planning, Reflection and Learning, 2020 <https://efid.info/resource/download-the-toolkit/>

People with dementia are individuals,
with their own stories, experiences,
preferences, needs...

Dementia is like a box of chocolates,
said Agnes, with different flavours.
When creating services for people with
dementia “one size does not fit all”.



Acknowledgements

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2010–2020

A road well-travelled

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