

PRESENT in East Dunbartonshire:

# Co-production with people living with dementia



## 1. What PRESENT aims to achieve

The idea is simple—giving people living with dementia a stronger PRESENCE in local communities and public services and enabling them to make a contribution to other people’s lives. It therefore means moving from needs assessments to capability assessments.

This implies a new type of collaboration between people living with dementia and public services, based on co-production approaches and values.

*“Co-production is about professionals and citizens making better use of each other’s assets, resources and contributions to achieve better outcomes or improved efficiency.”*

Source: Governance International



## 2. Why use co-production with people living with dementia?

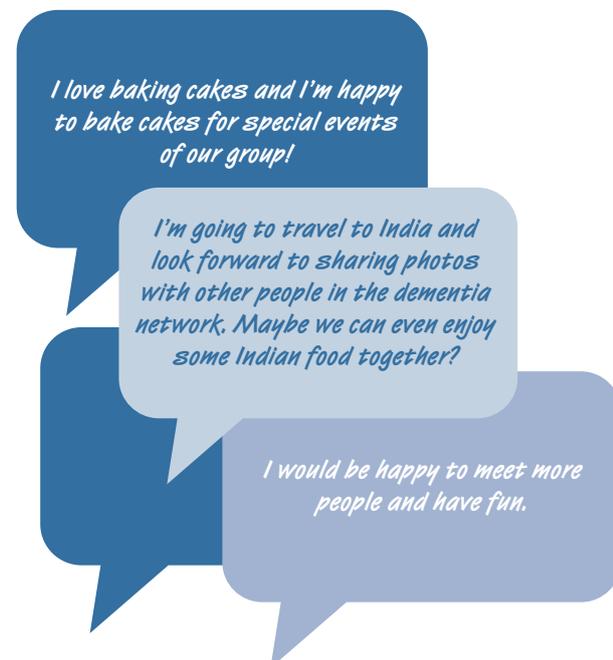
When people are diagnosed with dementia they often experience ‘prescribed disengagement’—this is how Kate Swaffer, a person with young onset dementia in Australia, describes the way many professionals and members of the local communities assume that people with dementia will ‘fade away’ from the public gaze in her recent blog.

*„People who have dementia are citizens, members of society with the same human rights as other citizens. However, they often find themselves waiting on others to include them. Exclusion, stigma and isolation are common experiences.“*

Adapted from Christie, J. 2007 Ethics, evaluation and dementia pgs 197-213. In: Innes and McCabe (eds) Evaluation in Dementia Care. London: Jessica Kingsley.

Therefore, it is time to ask people with dementia—and also their carers and families—some new questions. In particular, we believe it is important to add capability assessments to needs assessments. This involves questions such as “What makes you smile?” or “What would you like to do with others?” or “What’s the stuff you know which could help others?” Working out, with people living with dementia, what they can contribute to improving their own outcomes, and those of others, will open up a new quality of life for them.

So, that’s what we did with people living with dementia and their carers in East Dunbartonshire. And here is what they said when we asked them these questions:



Of course, it takes courage to ask these questions—the answers may suggest the need for big changes to services. Such boldness requires a culture change in statutory services, third sector organisations and local communities.

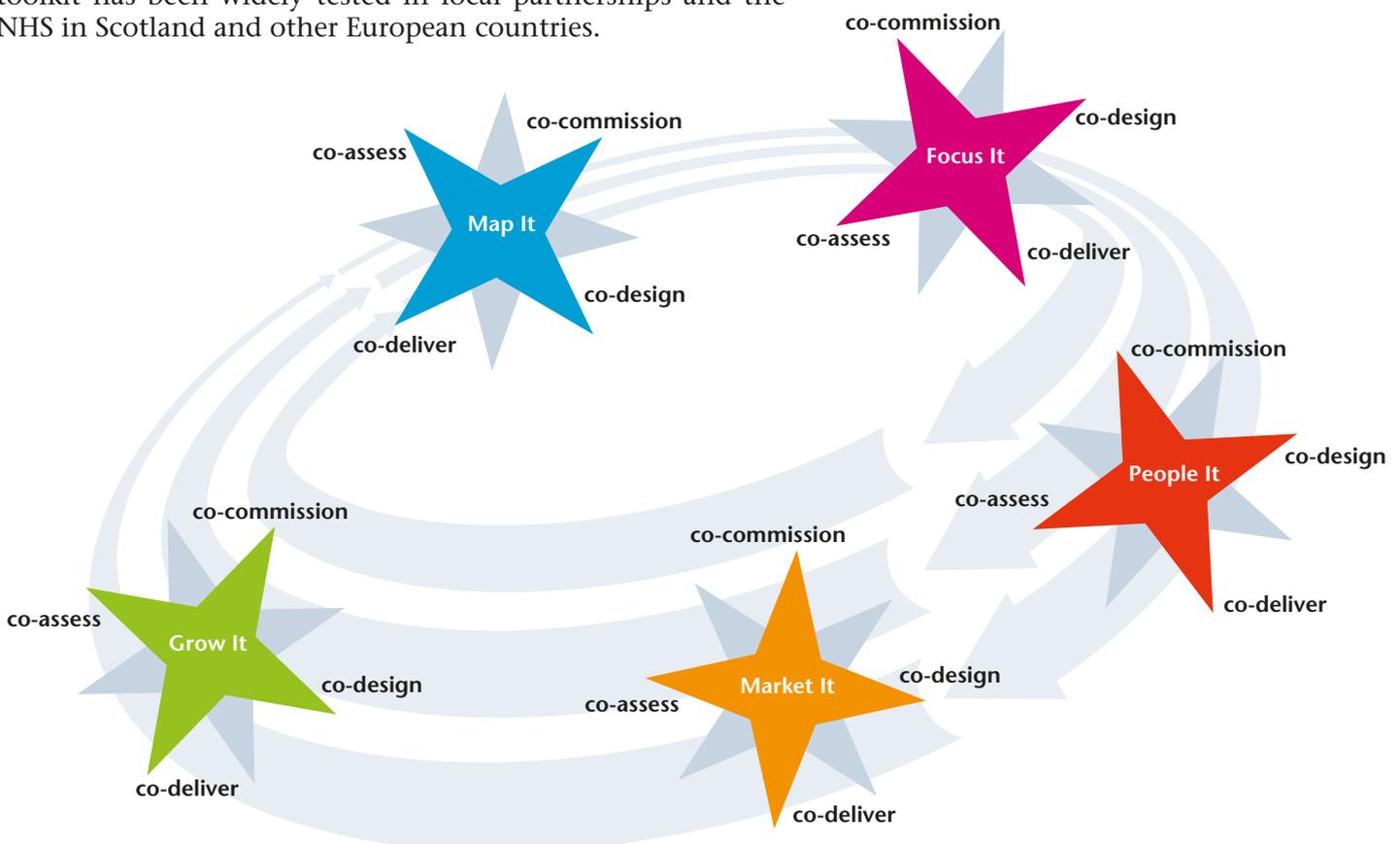
Furthermore, this new vision of people with dementia and their carers as ‘active co-producers’ of personal and social outcomes requires a ‘co-production infrastructure’ underlying public services, which again may involve transformation of the current service system.

The Community Asset Map which East Dunbartonshire Council has co-designed with IRISS has already provided a first stepping stone to help people living with dementia, public services and local communities to put their assets, resources and capabilities to best use. Now it is time for these community assets to be matched imaginatively with the resources of public services in an effective co-production strategy for dementia.

### 3. Moving towards ‘co-production as default’ with people living with dementia

Co-production is not so difficult, once we look carefully at what it involves. The Co-Production Journey with people living with dementia in East Dunbartonshire Council is being guided by the *Governance International Co-Production Star*. This toolkit has been widely tested in local partnerships and the NHS in Scotland and other European countries.

**Graph 1: The Governance International Co-Production Star—A Toolkit for Co-Producing Better Outcomes**



A Report of the Co-Production Training Workshops in Scotland during 2012 shows that the *Co-Production Star* is applicable to a wide range of public services and outcomes, including health and wellbeing, greener, safer, cleaner as well as specific groups such as young people, elderly people and disabled people.

The *Co-Production Star* highlights four different ways of involving citizens and communities in public services. The Four Co's include:

**Co-commissioning public services**—shifting the focus from services that councils think people need to outcomes that local people themselves believe to be priorities, e.g. through using the methodology TALKING POINTS.

**Co-designing public services**—using the customer journey approach to look at how the service process can be improved from the service user's point of view. The *Governance International* co-design case study of the new Dementia Portal of Warwickshire County Council and Solihull MBC with people living with dementia show the valuable contribution that 'experts by experience' can make.

**Co-delivering public services**—the prize-winning project EDUCATE in Stockport trains up people with dementia as peer trainers for awareness-raising activities and in sessions for a wide range of professional groups.

**Co-assessing public services**—training citizens to carry out service inspections and scrutiny, often through the use of social media or online ratings. The *Governance International* case study of people with learning disabilities working as peer assessors of social care in Warwickshire County Council shows that 'community evaluators' can see many things that professional inspectors do not notice.

Of course, each of the Four Co's involves changing what we do now. The *Co-Production Star* sets out a five-step model for making co-production central to public services, local communities and individuals

### Step 1: 'Map it!'

We typically find in our training and coaching that co-production is already happening in every organisation and community—but only here and there, in pockets. This means that it's really important for councillors, staff, local communities and people who use services to map the way in which they collaborate with each other, so that they can build on what works to avoid re-inventing the wheel. Our *Co-Production Explorer* supports the creative process of identifying new scenarios and working out how to make this new vision real by building on existing practices of co-production.

### Step 2: 'Focus it!'

After mapping what is happening and what needs to happen, public services, local communities and the individuals living with dementia need to prioritise their efforts to take co-production further so that resource investments are based on evidence. Our *Co-Production Priority Matrix* is a simple technique to prioritise co-production activities—distinguishing priority projects to be taken on, and those to be dropped or put on the back burner. 'Quick wins' (high impact, low effort initiatives) are self-evidently the optimal starting point—establishing success, to catalyse further co-production.



### Step 3: 'People it!'

Here we need to ask: How can we involve the right people from local communities and from public, private and third sector organisations to contribute to improved public services and outcomes? The *Governance International Community Asset Survey* helps identify what local communities are already doing and how they want to get more involved. The *See What You Can Do-Toolkit* which *Governance International* piloted with Walsall MBC, supports service users and carers to identify interesting activities that could help others and to find matching partners to enrich their own social lives and make the most of their own capabilities. Having identified these key people who want to help make co-production really work, it is important to bring them together in 'Co-Production Labs', so that they can join in designing action plans to take their priorities forward.

### Step 4: 'Market it!'

Having reached this stage, we have to make it simple and worthwhile for people to contribute and to collaborate with others. This stage is often missing from current co-production approaches. Incentives and nudges are really crucial to encouraging behaviour change. There are lots of different kinds of incentives: *psychological incentives*, which reinforce an individual's 'feel good factor' with appreciation or other informal rewards; or more formal mechanisms like '*recognition awards*', which can include prizes or vouchers from local business.

Another way of encouraging individuals and groups to put co-production principles into practice is to agree a *Co-Production Charter* that outlines explicitly the principles and values of co-production and what each stakeholder pledges to contribute. These can provide an effective framework to show people what responsibilities they are committing to—and what the local council or third sector provider is committing to provide by way of support to those who co-produce with it.

### Step 5: 'Grow it!'

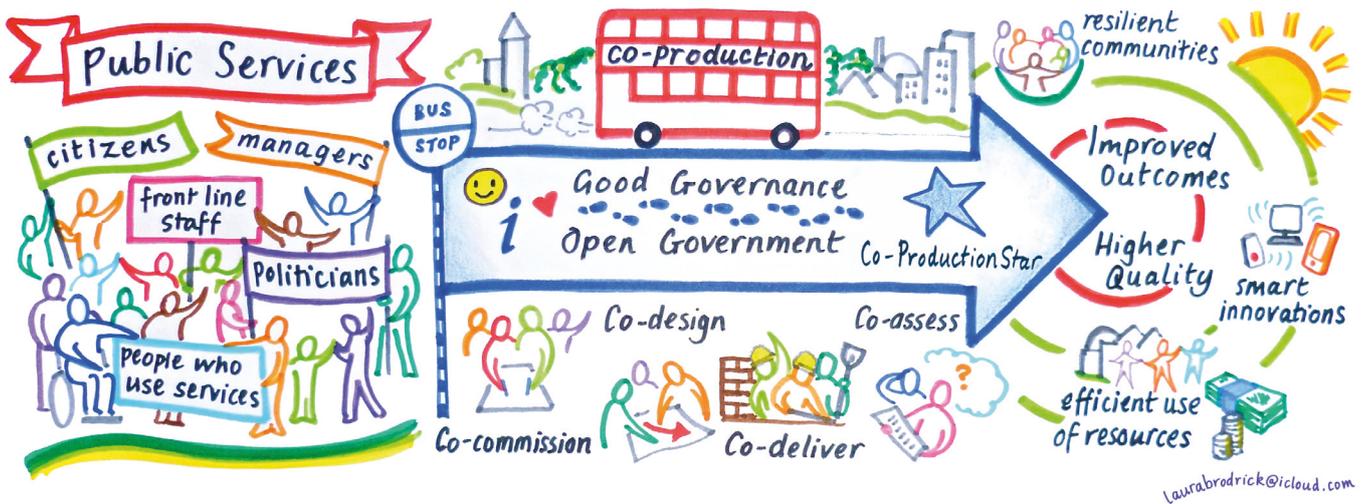
Once the co-production ball is rolling, the momentum for culture change needs to be kept up and even increased. This involves highlighting the impact of co-production and celebrating success by showcasing 'champions' and or delivering road shows at neighbourhood level.

At the same time, system-wide change needs to support co-production. This will involve a range of mechanisms to connect local communities. In particular, outcome-based commissioning is likely to highlight co-production as central to more enabling ways of working with local communities in the commissioning process of statutory agencies.



## 4. The Co-Production Journey of the PRESENT Project

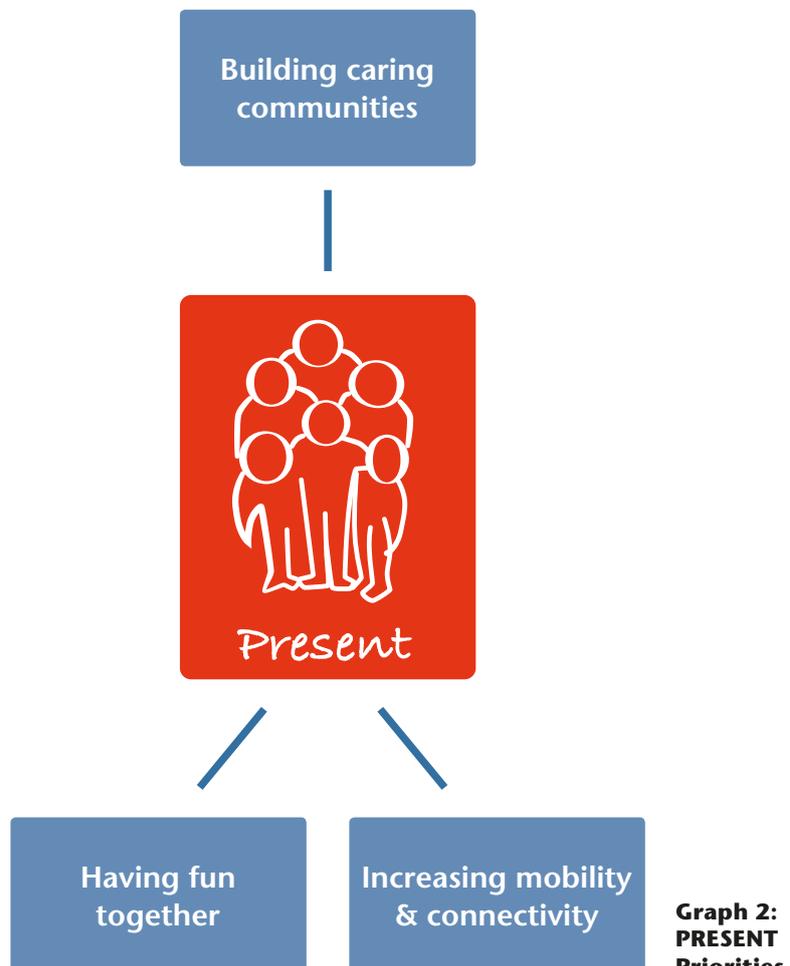
The project PRESENT with East Dunbartonshire Council and the Joint Improvement Team breaks new ground in applying the *Co-Production Star* to work towards **co-production as default** in the context of the dementia challenge.



Following an extensive mapping of co-production initiatives (Step 1 of the *Co-Production Star*) and the prioritisation of the identified initiatives (Step 2 of the *Co-Production Star*) three issues emerged as key priorities for people living with dementia and service providers working in the public, third and private sectors in East Dunbartonshire:

1. Building caring communities
2. Having fun together
3. Increasing mobility & connectivity

Each of these priorities implies specific co-production initiatives and requires development of an 'infrastructure' to scale up co-production. Moreover, the priorities clearly are strongly interlinked, so they need to be tackled together.



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## *Mini-case studies of the role of faith groups in co-production*

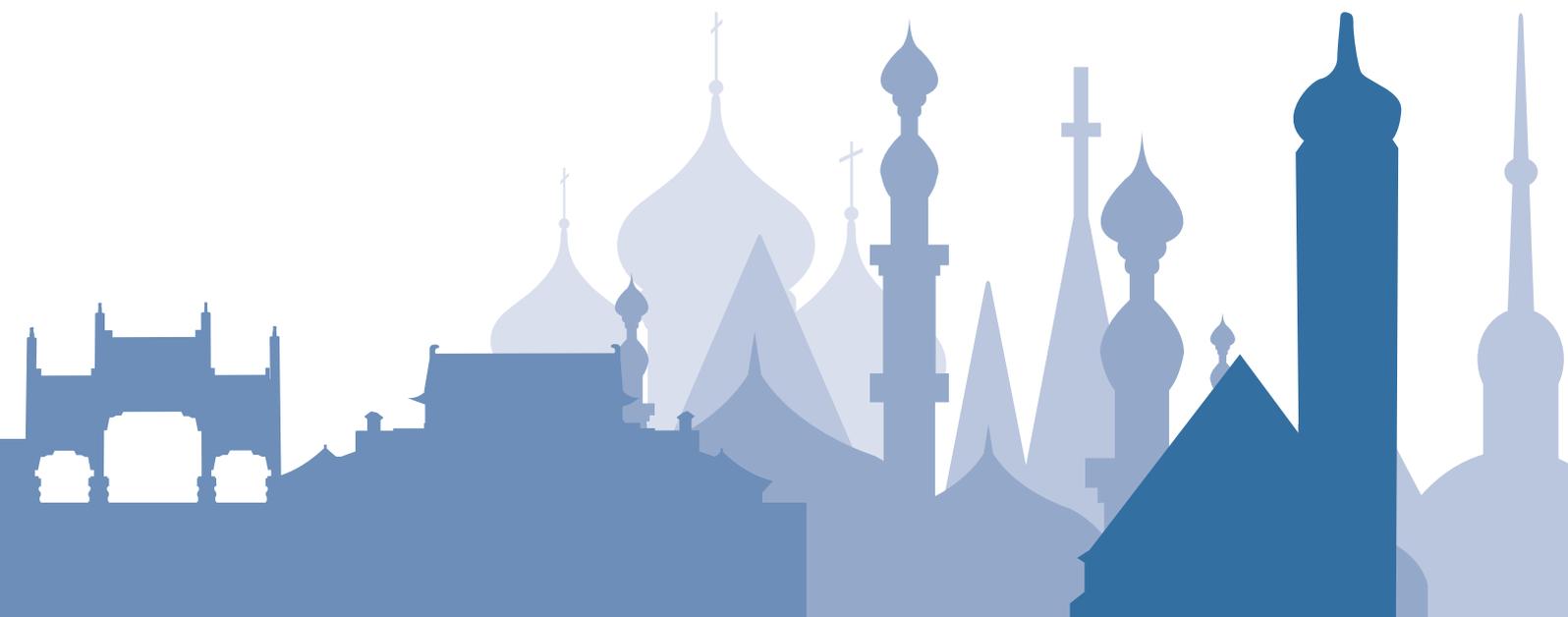
For example, faith groups may draw on their links with the local community and use available community rooms in churches to promote the creative activities of community groups in supporting people living with dementia. For example, at the end of Mass, Caroline Brown, a local carer and member of National Dementia Carers Action Network (NDCAN) often invites members of the congregation to visit the Alzheimer Scotland Memory Bus, which offers information and advice about coping with the illness.

Another example of good practice is the coordination role played by the Morningside United Church in Edinburgh. The Church noticed last year that nearly all groups regularly hiring the church premises were music groups or alternative health/exercise groups. The Church liaised with them to create an information leaflet of all that goes on, with up-dates two or three times a year. This is now distributed to the two local GP practices, the Pastoral Foundation and around the local community.

Contact person: Jenny Williams  
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## 4. What the Co-Production Cafes were about

The next step (Step 3) of the Co-Production Star (PEOPLE IT) is about getting co-producers on board who have the energy, expertise and experience to turn the priorities identified in Step 2 into action. This involves stakeholder mapping to ensure that organisations and people with a high-level of interest and influence are signed up to the three priorities.

Three informal Co-Production Cafes were organised in March 2014 in order to explore the level of interest in the community for getting involved. These half-day workshops provided participants with a recap of what had happened at previous workshops, invited them to draft initial action plans and encouraged them to sign up to making the action plans real.

The participants of the Co-Production Cafes included staff from public, third and private sector organisations, people with dementia and their carers. It was clear that PRESENT had already attracted the interest of a wide range of services such as the police and was no longer considered to be just 'the responsibility' of social care. Consequently, PRESENT is now also contributing to the integration agenda and enables the involved co-producers to see issues related to dementia from an 'outcomes' perspective and not just through the lens of 'their' service. In particular, the third sector has had a strong presence in the Co-Production Cafes. Moreover, the media have had a valuable involvement, in the shape of East Dunbartonshire Radio.

Third sector organisations have been quick to understand the potential benefits from asset-based approaches, working closely with their clients and the wider community to build on their strengths. In this way, the third sector has a crucial role to play in public service co-production as an intermediary between statutory services and local communities.



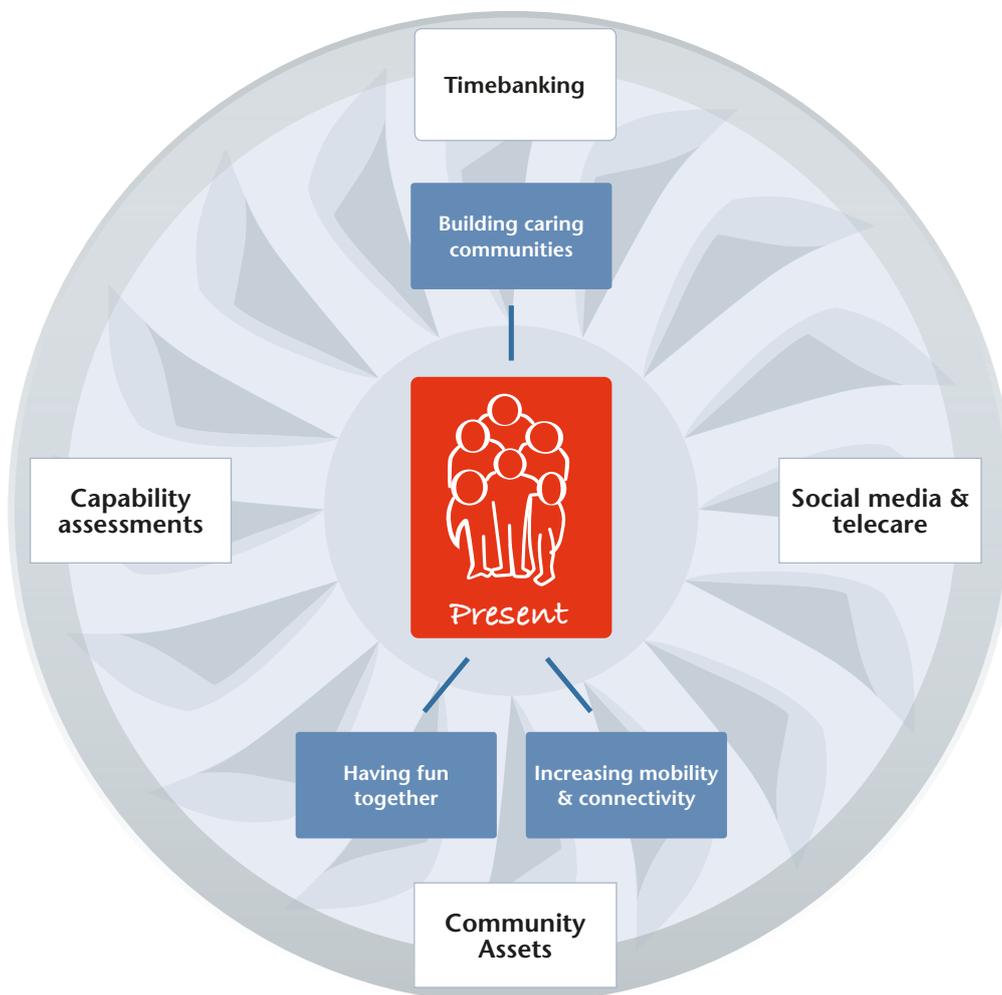
**Graph 3: Key benefits of co-production for third sector organisations**



## 5. A Co-Production Lab for 'developing an infrastructure for co-production'

Group work and plenary discussions took place in four 'Co-production Labs', held as part of the Co-production Cafes. These discussions took forward the debate on 'dementia-friendly communities' in new directions. As many participants recognised, inclusion and recognition of the contributions of people living with dementia isn't just about the experiences of those people. It requires 'inter-generational approaches', which bring together the energy, expertise and experiences of people from different age groups and walks of life. In particular, bringing in different age groups can both solve some of the mobility issues of people living with dementia and can also open up possibilities for all kinds of fun activities.

The action plans developed in group work during the Co-Production Cafes highlighted the need to develop an 'infrastructure' for transforming the identified priority areas through co-production. In particular, participants discussed the opportunities offered by time-banking; the potential of social media and telecare to connect people (not least by sign-posting them to time banking); and, last but not least, building 'capability assessments' into existing tools such as satisfaction surveys or needs assessments, so that more people could become aware of what they might do to improve their own outcomes and those of others.



**Graph 4: PRESENT in East Dunbartonshire—towards co-production as default**

## Mini-Case Study: What is a time bank?

A time bank is a “network of people, usually concentrated around a local community or neighbourhood, focusing on mutual self-help in which the ‘economy’ is based on the reciprocal exchange of time”.

Timebanking principles include:

„An hour for an hour“

Assets-based approach

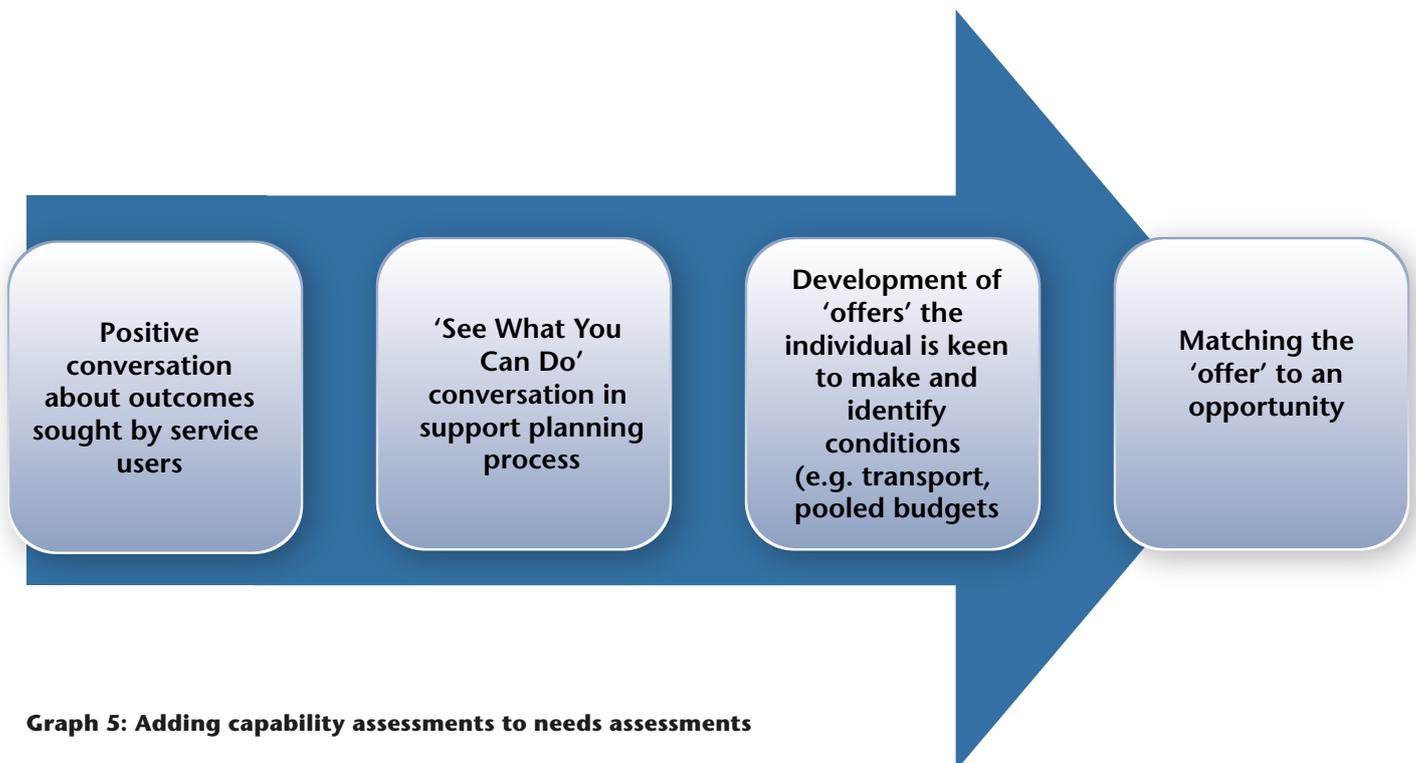
Time broker

Time credits

Intergenerational

Source: Presentation by Gerry Power, Joint Improvement Team, on 25 March 2014

A number of participants also suggested exploring with others what they are doing in the community and how/why they do it. Elke Loeffler outlined how the *Governance International* ‘See What You Can Do’-Toolkit provides brief ‘capability assessments’, which will highlight how people can contribute positively to improving their own outcomes or those of others. The toolkit can be used by social workers and other staff working with people living with dementia, e.g. in needs assessments of people using services or in satisfaction questionnaires or as part of community events such as Dementia Cafes.



**Graph 5: Adding capability assessments to needs assessments**

There was a widely shared view that social media, including Skype and tablets, as well as telecare, have a lot to offer to people living with dementia and others experiencing limited mobility. The new dementia website of East Dunbartonshire Council and third sector partners should signpost people to relevant digital communities and encourage them to experiment with new digital forms of communication.

The Co-Production Café focussing on ‘Having fun together’ also raised awareness of the online East Dunbartonshire Assets, which will allow local residents to identify existing resources in a user-friendly way. Carole Anderson gave a demonstration so that participants could understand how this works in practice.

## 6. A Co-Production Lab for ‘building caring communities’

The participants designed a number of action plans to shift resources and expectations from a focus on social care services towards caring communities. Often this involved incorporating co-production principles into existing activities or processes to make them more ‘co-productive’.

- ➔ For example, a participant suggested that Housing Associations or third sector organisations might also prepare an ‘Adult at Risk’ report and pass it to social workers when they come in contact with vulnerable adults. At present legislation only requires the Police, Fire Services and Social Work to prepare such reports. However, such reports could be valuable starting points for engaging with vulnerable adults in a ‘See What You Can Do’ conversation which would focus on identifying individual capabilities.
- ➔ Another suggestion was to develop Dementia Cafe events where service users had the opportunity “to tell their stories in order to make others aware of their situations”. The initial conversations might be led by staff trained up in the use of Talking Mats (a social enterprise whose vision is “to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them.”). Moreover, people with dementia and carers could be invited to have a conversation about their capabilities to find out what they can contribute, using the ‘See What You Can Do’-Toolkit.

A number of action plans proposed new ways in which people with dementia and carers could contribute to the training of professionals and managers from statutory, third sector and community groups, including shops and businesses. For example, stories told at DeCafes might be fed into awareness training packages through blogs, Storify, mini-case studies or video-clips (and these could be produced by young people, in order to promote inter-generational understanding).

## 7. A Co-Production Lab for 'having fun together'

The participants developed a number of action plans which could boost the creativity of people with dementia and connect them with local communities. Sylvia Rossi, Dementia Champion East Dunbartonshire Social Work, provided a brief presentation on the Care Home Music Network to demonstrate the potential of music for bringing people together as equals.

### *Mini-case study: East Dunbartonshire Care Home Music Network*

The East Dunbartonshire Care Home Music Network is an email community with members of all 11 care homes and supporters in the broader community including Ceartas, Carer's Link, three faith groups, Care Inspectorate, Health Asset mapper, Glenkirk and Woodlands Memory Clinic, Art Beat, Alzheimer Scotland, PlayList For Life and local musicians. This is an organic group with the membership growing week on week due to the overwhelming interest in this area. The group was initiated in late December 2013 in the spirit of co-production and is led by Sylvia Rossi in her role as Dementia Champion.

Driven by the principles of inclusion and quality of life for people with dementia in care homes, music is being used as a medium to bring fun, stimulation and community inclusion to local citizens often excluded in care home settings. Primarily the network is a medium to share information about what's happening locally and ensure that care home staff and residents begin to feel linked in. This gives people with dementia the opportunity to take part in purposeful activity with loved ones and the broader community on an equal footing.

Current strands include:

Alzheimer Scotland 'Mind That Song' monthly music group first event in March 2014 attended by over 50 people, including 31 residents from across 7 care homes.

Linking with local faith groups, established music groups and voluntary agencies to encourage new networks events.

Spreading information to care homes on current training opportunities e.g. Nordoff Robbins Music Therapy in Scotland training events

Passing links to care homes on all matters musical.

Supporting the work of PlayList for Life in organising a donation drive for equipment within East Dunbartonshire and in return PlayList For Life providing a training/information session to Activity Leaders from local care



homes. Opportunities exist for highlighting current and developing positive inter-generational experiences.

Providing learning opportunities for Local Activity Leaders in the care homes and stimulating improved and new practices in quality of life issues.

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- ➔ One proposed new co-production initiative involves experimentation with a new radio programme to raise awareness of dementia but also to change perceptions of people with dementia by showcasing them as active community members. This could take different forms—for example, East Dunbartonshire Radio might highlight some current contributions to the community by people living with dementia or facilitate discussion features on some of the positive activities open to people living with dementia.
- ➔ Another proposed co-production initiative aims at bringing older and young people together through football. By visiting care homes, members of the Junior Football Team will become more aware of dementia, while the care home residents will benefit from the exchange with the football team members on sports issues. The Junior Football Team may also facilitate visits of care home residents to football matches.
- ➔ The Kirkintilloch Canal Festival arouses a lot of interest in the community every year. Participants proposed to use the popularity of the upcoming Festival from 18–24 August 2014 for dementia awareness raising.
- ➔ Another action plan aims at engaging local communities and people with dementia in creative art sessions. In East Dunbartonshire therapeutic art sessions are currently provided by the social enterprise EDICT but one participant suggested joint working with the Heart for Art project of the Church of Scotland to involve faith groups as well.



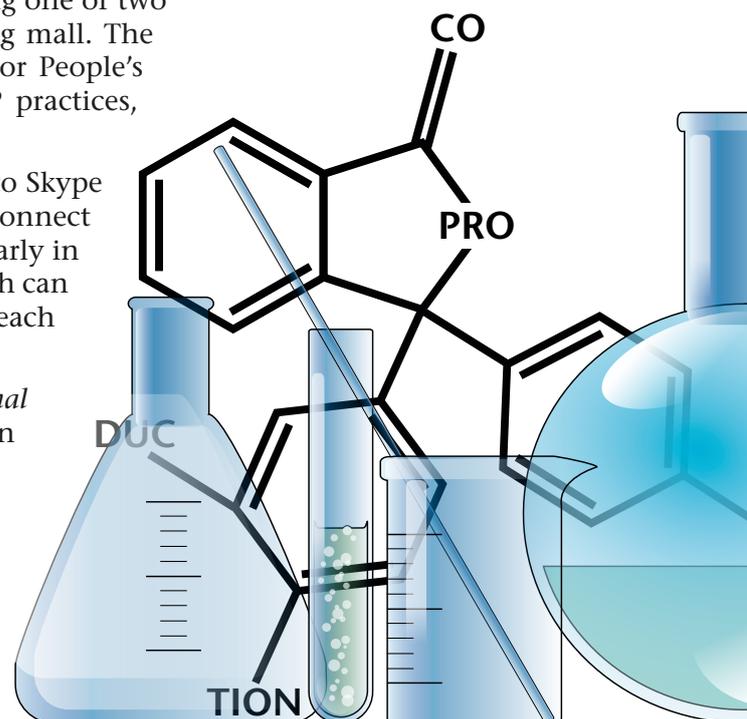
## 8. A Co-Production Lab for 'increasing mobility & connectivity between local people'

This Co-Production Lab focussed on identifying new ways of making it easier for people with dementia to move about in their local area, be it as a pedestrian, by bike or using local transport. At the same time, the participants explored virtual ways of connecting people with dementia and their carers with local communities.

- ➔ One action plan is about encouraging elderly people who may experience anxiety and lack of self-confidence to participate at events in the evening, go shopping or just go for a walk in the neighbourhood by offering a Buddy Service to people who have used Community Alarm or OPAL.
- ➔ Another project aims at transforming public spaces to respond to the needs of people with dementia and elderly people in general and at encouraging inter-generational exchange. This involves the co-design of public spaces in East Dunbartonshire with people living with dementia. This could take the form of joint walks in East Dunbartonshire to enable planners to see 'journeys' from the perspective of people living with dementia, plus planning of spaces to sit down and of open gyms/playgrounds.
- ➔ A further project aims at improving the health and wellbeing of elderly people, including people living with dementia, through an innovative cycling scheme which involves young people. This could involve younger people delivering shopping or newspapers to elderly people by bike. Furthermore, the biking scheme could also encourage elderly people who are sufficiently fit to get engaged in bike trips with their grandchildren.
- ➔ Another project aims at setting up a mini-bus service to enable people living with dementia and other groups to have a fun afternoon out together. This would involve defining one or two bespoke bus routes to a garden centre or shopping mall. The new service would be marketed through the Senior People's Forum, Ceartas, OPAL and flyers provided in GP practices, bookies, bingo halls, etc.
- ➔ A final project aims at introducing elderly people to Skype and tablets and other modern media which can connect them to their children and grandchildren, particularly in cases where their family has moved away, and which can connect elderly people who are housebound with each other.

Of course, as one participant of a *Governance International* Co-Production Workshop once observed after finishing an action plan: The most important step is 'JUST DO IT'!

The PRESENT project team will now support these four Co-Production Labs to help them to realise their action plans and to identify a lead and co-lead to drive the work of each Co-production Lab. The project manager will agree milestones and deliverables with each Co-Production Lab to ensure some 'quick wins'.

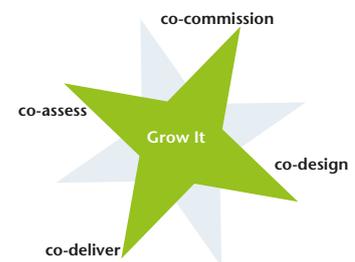


## 9. Next steps: Market and grow co-production beyond PRESENT

**Step 4 (MARKET IT)** is about getting the buy-in of a wider group of people into the activities developed by the Co-production Labs. This will involve identifying incentives for each stakeholder to contribute to making the new co-production approaches real. It will also involve identifying at an early stage risks and barriers which could demotivate stakeholders or even put an end to their engagement. *Governance International* suggests the value of a meeting of all Co-Production Labs before the summer break to take stock of progress made and to agree on a Co-Production Charter which sets out the ‘values and principles of co-production’ with those involved.

**Step 5 (GROW IT)** aims at scaling up the new co-production approaches across East Dunbartonshire Council, its local partners as well as in Scotland and Europe. This will involve the dissemination of local case studies, stories and personal experiences through a wide range of mechanisms.

At the same time, it will be important to agree on the design of the evaluation framework in order to underpin the new co-production approaches with evidence and to feed-back learning to all project partners. The results of the evaluation are to be fed back to all participants of the evaluation in a workshop before the end of 2014.



## 10. Contact the Project Team

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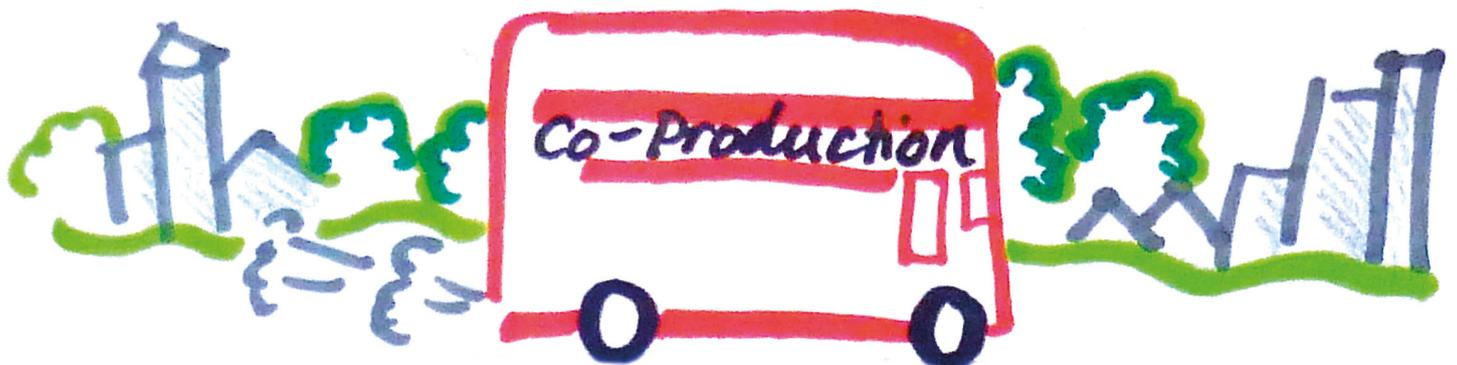
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## 11. Interested in using the Governance International Co-Production Star in your local area?

Our Co-Production Toolkit provides your organisation, local communities and people who use services with skills, tools and resources to improve personal and social outcomes.

*Governance International* supports your co-production journey with advice, coaching, training and peer reviews. Our Good Practice Hub provides you with 40 innovative case studies from all over the world. Our UK and international network gives you access to peer support with hands-on advice.

### Our recent clients and partners include:

Argyll and Bute Council  
Bertelsmann Foundation, Germany  
East Dunbartonshire Council  
Glasgow Council for the Voluntary Sector  
Hertfordshire CCG  
Joint Improvement Team in Scotland  
London Borough of Lambeth  
Midlothian Council  
Organisation for Economic Co-operation and Development (OECD), Paris  
Police Scotland  
Scottish Borders Social Enterprise Chamber  
Stockport MBC  
Surrey County Council  
Swedish Local Government Association  
Walsall MBC

### Editorial

This report has been prepared by *Governance International* in co-production with East Dunbartonshire Council, their local Dementia Network and the Joint Improvement Team.

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