



Co-production: as easy as baking a cake!

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

Funded by the Department of Health through the Common Assessment Framework demonstrator site programme

“Co-produced is a difficult word for us. If it means doing and making things together it is right that we should be involved. We should have a say about what it means to have a learning difficulty in Shropshire and what are the best things to help” (participants in the CAF project).

Some reasons for Transforming Adult Social Care (TASC) supported by co-production¹:

- It's about people living a productive and valued life
- It's about our relationships with one another
- It's about our human rights
- It's about our health and well-being
- It's about making the most effective and efficient use of scarce public resources

A new approach to care and support for all based on equality and human rights²

- Our vision and proposals will replace out moded notions of social care with a vision of care and support based on promoting life chances and well-being. A reformed approach to care and support is built around three core propositions.
- The purpose of care and support is to build the capabilities of individuals and families.
- This can only be achieved through encouraging and facilitating co-production.
- And to achieve our ambitions we need to do far more to identify and communicate the cost benefits of care and support to society as a whole, to counter this notion of growing burden.³

¹ Speech by Baroness Jane Campbell, Chair of the Disability Committee and EHRC Commissioner, at the IPPR 'Power to carers and users: transforming care services' event, 19 February 2008

² Speech by Baroness Jane Campbell to launch report: From safety net to springboard - A new approach to care and support for all based on equality and human rights 26 February 2009

³ A Vision for Adult Social Care: Capable Communities and Active Citizens – DH November 2010

Contents

Section 1	4
Introduction	
Section 2	7
Background – policy and legal considerations	
Section 3	12
Co-production – What could it mean?	
Section 4	15
Getting people involved – experiences of co-production in CAF demonstrator sites	
Section 5	22
Top Tips for involving people in co-production	
Section 6	33
Checklist (draft) of top tips for producing meaningful co-production and community involvement	
Section 7	35
Final comments	
Section 8	37
Co production resources	
Acknowledgement	38

The Putting People First team at the Department of Health (DH) asked Equal Citizen Services (ECS) to look at the role of co-production in developing and delivering excellent outcomes for everyone involved in the Common Assessment Framework for Adults (CAF) programme; namely the production of a personalised, shared solution to the use and maintenance of social care and health records.

This report is intended to share the learning and examples within the CAF programme and beyond, to people who are using public services, and to people who are providing them.

Authors: Kevin Caulfield and Wendy Gross – March 2011

Section 1

Introduction

“It must not be forgotten that personalisation is something that disabled people and their allies have been pioneering and campaigning to achieve for the last 30 years. Indeed taking personal control over one's publicly funded support began with a group of disabled people who lived in residential care in the 1970s. The blueprint for what we talk about today, was devised by the first ever recipients of an individualised budget in 1979.”⁴

Disabled and older people's organisations are an authentic voice of what needs to change locally. They hold strong values such as the social model of disability that defines disability in terms of environmental and attitudinal barriers rather than specific medical conditions. They understand how local people experience available support and services and what they need. This is because they have developed from direct experience and their voices are often seen as the most legitimate and credible voice both from the perspective of other service users and statutory agencies.⁵

The commitment to 'the equality of independent living' (Putting People First, HM Government 2007) that underpinned the launch of personalisation in public policy, is a direct reference to the values and principles of independent living as developed by disabled people.

What is the Common Assessment Framework (CAF)?

CAF is a way of sharing your assessment and care and support planning information between an individual and the people involved in their support. To do this it has to join up information across health and social care and other services. It does this by using Information Technology (IT) to share the information. People

⁴ Speech: Social care as an equality and human rights issue
Speech by Baroness Jane Campbell, Chair of the Disability Committee and EHRC Commissioner, at the IPPR 'Power to carers and users: transforming care services' event, 19 February 2008.

⁵ Practical approaches to co-production - Building effective partnerships with people using services, carers, families and citizens. Department of Health November 2011.

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

keep the same rights in respect of their information as they do currently, and are better able to keep track of it.

In this way, CAF supports personalisation. It fits well with the aim to give people more choice in and control over their care and support arrangements and to make it possible for support from different people to be organised better to suit them.

CAF demonstrator site development

The CAF programme is in its second year of three (to March 2012), although three 'phase 2' sites only began work in March 2010 (Cheshire East; Isle of Wight; and the Southampton, Portsmouth and Hampshire Consortium). Within the common objectives of the programme, each site is different in terms of partners, service areas involved, and approach: the intention of the programme being to support a variety of potential solutions to the challenges of bringing together separate information systems around the individual in such a way as to support the objectives of personalisation.

In getting the information for this report, ECS developed a set of three questionnaires, including an Easy Read version with pictures, which were aimed at:

- The CAF demonstrator site local authorities
- their partner organisations
- individuals who took part in pieces of work that were considered to be co-produced.

The questionnaires were then followed up with individual contact to some of the sites to explore some of the examples given in more detail.

This report looks at examples of good practice in action across the 12 CAF demonstrator sites. The aim of this work was to produce a useful resource as well as just information so that people can be inspired to work together even more inclusively than before.

ECS also set out to provide ideas to increase community engagement in CAF work and provide a draft top tips checklist that

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

can be adapted to suit local needs. We have highlighted some of the key messages of co-production generally throughout the report.

Whilst we have tried not to duplicate other Department of Health publications and reports on co-production we have briefly reiterated the important messages. We suggest this report is read alongside *A Vision for Adult Social Care: Capable Communities and Active Citizens* (DH November 2010), *Approaches to Co-production* (DH November 2010) and *Working Successfully with Carers* (DH, in preparation).

We have also included in section 8 a co-production resource section. They may help put your work in context and provide further ideas to help provide public services that have citizen involvement and citizen ownership.

From doing this piece of work we can see that there is sometimes a lack of understanding around the meaning of co-production and that different CAF demonstrator sites are at different stages of working co productively. We hope this publication will help to inspire and practically support CAF partnerships to further develop co-production initiatives.

Section 2

Background – policy and legal considerations

The challenges for government and public bodies to co-produce better, personalised outcomes for people in relation to active citizenship, social care and health are huge.

It is widely understood that people are living longer and that there are increasing numbers of people who are not in paid work. These people will be at risk of exclusion due to ill health and/or impairment.

“In spite of endless rounds of public service reform over the last several decades, and in spite of huge injections of public funds, there have been no significant reductions in levels of need for health and social care, for housing, policing and other public services. Inequalities have widened and there is less social mobility. Research from NESTA shows that costs related to ageing for the public sector will rise to £300 billion by 2025.”⁶

The Government’s Vision for Adult Social Care⁷

The Coalition Government has committed itself to reforming the system of social care in England and to developing co-production,⁸ to provide much more control to individuals and their carers. This vision focuses on the Government commitments to:

- break down barriers between health and social care funding to incentivise preventative action;
- extend the greater rollout of personal budgets to give people and their carers more control and purchasing power; and

⁶ Right Here Right Now – taking co production into the mainstream. NESTA July 2010

⁷ A Vision for Adult Social Care: Capable Communities and Active Citizens – DH November 2010

⁸ Practical approaches to co-production - Building effective partnerships with people using services, carers, families and citizens - DH November 2010

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

- use direct payments to carers and better community-based provision to improve access to respite care.

In *A Vision for Adult Social Care: Capable Communities and Active Citizens* the Government's values of freedom, fairness and responsibility, shifting power from central to local government, from state to citizen, from provider to people who use services are outlined. This vision sets a new agenda for adult social care in England:

We want to make services more personalised, more preventative and more focused on delivering the best outcomes for those who use them.⁹

The consultation document *Transparency in Outcomes: a framework for Adult Social Care*, published alongside this vision, proposes a new agenda for adult social care. It will be co-produced with the social care sector, voluntary and community organisations and people who use services over the coming months and years.

The government is also committed to transforming the way information is collected, analysed and used by the National Health Service (NHS) and adult social care services will be critical to achieving this information revolution.¹⁰ A process of consultation has taken place on the Information Revolution. This Government is committed to moving:

- away from information belonging to the system, to information enabling **patients and service users to be in clear control of their care**;
- away from patients and service users merely receiving care, to **patients and service users being active participants in their care**;
- away from information based on administrative and technical needs, to information which **is based on the patient or**

⁹ A Vision for Adult Social Care: Capable Communities and Active Citizens – DH November 2010

¹⁰ More information is available at http://consultations.dh.gov.uk/information-revolution/informationrevolution/consult_view

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

service user consultation and on good clinical and professional practice;

- away from top-down information collection, to a focus on **meeting the needs of individuals and local communities;**
- away from a culture in which information has been held close and recorded in forms that are difficult to compare, to one characterised by **openness, transparency and comparability;**
- away from the Government being the main provider of information about the quality of services to **a range of organisations being able to offer service information to a variety of audiences;** and
- in relation to digital technologies, away from an approach where we expect every organisation to use the same system, to one where we **connect and join up systems.**

CAF is essentially about people's information, their rights and ownership of it, and its use and exchange by organisations from which they get support. Therefore, it is of prime importance to its success that the following obligations are fully understood and practically applied by all organisations involved.

Local Councils 'Duty to Involve'

The duty local authorities have is to consult individuals, groups, businesses or organisations that are likely to be affected by their actions.

The Communities and Local Government statutory guidance, *Creating Strong, Safe and Prosperous Communities* (2008)¹¹ highlights key areas where authorities should consider providing opportunities for local people to be involved in co-production and co-design.

¹¹ More information at:

<http://www.communities.gov.uk/publications/localgovernment/strongsafe prosperous>

The NHS 'duty to involve'

The Local Government and Public Involvement in Health Act 2007¹² introduced a strengthened 'duty to involve' for the NHS which came into force in 2008.

Equality Act 2010

The Equality Act 2010¹³ sets out to strengthen and simplify the existing legislation around equality. The Act will have an impact on how services are delivered to service users. For example, the public sector will have a duty to have due regard to advancing equality of opportunity in relation to race, gender reassignment, age, disability, sexual orientation and religion or belief.

The Right to Control

Under changes introduced by the Welfare Reform Act 2009,¹⁴ the Right to Control is being piloted, giving disabled adults a legal right to exercise choice and control over support they receive from the state through a number of funding streams.

Recognising and rewarding everyone's contribution

Legislation introduced in 2009¹⁵ removed two significant barriers to involvement for service users who are in receipt of benefits.

The legislation only applies where the organisation is required by law to involve service users.

- Service users who are paid for involvement may now be reimbursed out-of-pocket expenses without affecting their benefits. Reimbursements of expenses such as travel costs, necessary subsistence, childcare, replacement carer,

¹² For more information see:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081089

¹³ For more information see:

http://www.equalities.gov.uk/equality_act_2010.aspx

¹⁴ For more information see:

http://www.opsi.gov.uk/si/si2010/draft/ukdsi_9780111502310_en_1

¹⁵ 1 Social Security (Miscellaneous Amendments) (No. 4) Regulations 2009, reg 1(1); 2 reg 1(2); 3 reg 1(6)

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

personal assistant etc and other expenses incurred because of involvement are now ignored.

- Service users who are involved may now decline an offer of a payment, or ask to be paid a lower amount or ask for the payment to be made to a charity, without 'notional earnings' being applied. Their benefits are unaffected.¹⁶

Contracting Law

Another area of law which potentially impacts positively on co-production initiatives is Article 19 of the EU Procurement Directive 2004/18/EC¹⁷ which is about reserving contracts for supported businesses. A 'supported business' is where over 50% of the workforce are disabled people.

¹⁶ For more information on DH Reward and Recognition policy see:
http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4126863

¹⁷ For more information see: Promoting the use of Supported Employment in Public Procurement
http://www.ogc.gov.uk/policy_and_standards_framework_supported_factories_and_businesses.asp

Section 3

Co-production – What could it mean?

There is a growing body of literature about co-production and the potential benefits and possible barriers that arise from taking the opportunity of working inclusively. Please see Section 8 – Co-production Resources for further information.

“People who most rely on public services tend to be those who are most disempowered by the current model. Transforming services by applying the key features of co-production offers the prospect of substantially improving outcomes for them.”¹⁸

However, of significant importance is the opportunity for people to determine to the greatest possible extent how their specific support requirements as an individual are met. Even if a particular solution has been co-produced, it does not mean that it should not still be responsive to personal preference.

There is no single definition of co-production. Some which have been put forward are expressed below. The concept represents a set of values and principles which have emerged over a period of time, and within the co-production umbrella we can find elements of engagement, participation, choice and control, and involvement.

In its broadest sense, co-production requires the active engagement, to the extent each individual wishes, of all parties who will be affected by a decision in that decision, which in public service terms requires that people who use those services are involved ‘from the design stage onwards’.¹⁹

The definition included in the Department of Health’s Personalisation Communications Toolkit which was fully co-produced with service users and carers, with the following wording being agreed:

¹⁸ Right Here Right Now – taking co production into the mainstream. NESTA July 2010 http://www.nesta.org.uk/publications/assets/features/co-production_right_here_right_now

¹⁹ Putting People First 2007 – see: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

“Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered.”²⁰

“Co-production is about ensuring that organisations effectively engage service users and carers from the outset, prior to any design of new systems or projects. Once systems are in place, if they do not meet the needs of service users and carers it is then very hard to change these systems. This then results in systems that are not fit for purpose.” (Rochdale CAF site).

Co-production is not the same as consultation

“Co-production asks us all to really think about how we work together.” (CAF demonstrator site).

“Although co-production has much in common with initiatives to encourage user involvement, it is not the same as consultation or the types of tokenistic participation of people who use services and their carers which do not result in meaningful power-sharing or change. Consultation exercises ask for feedback on a service and can often result in no real change for the person using the service.”

Co-production demands more active involvement and decision-making by the person using a service, and puts more emphasis on ‘relational’ rather than ‘transactional’ approaches to delivery.²¹

“Co-production entails a shift in approach for disabled people’s organisations. Many of our members are used to “speaking up” to and presenting difficulties and challenges to the local authority. The most effective solutions are solutions that come from disabled people ourselves. Where we are not only presenting challenges

²⁰ See:

[http://www.puttingpeoplefirst.org.uk/_library/Resources/Personalisation/Local milestones/Putting_People_First_Communications_Toolkit.pdf](http://www.puttingpeoplefirst.org.uk/_library/Resources/Personalisation/Local%20milestones/Putting_People_First_Communications_Toolkit.pdf)

²¹ SCIE Research briefing 31: Co-production: an emerging evidence base for adult social care transformation. By Dr Catherine Needham, Queen Mary University of London and Sarah Carr, Social Care Institute for Excellence. Published March 2009

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

but also suggestions for solutions, which we ourselves can deliver, we have found the local authority to be receptive, positive and supportive.” (Ellen Clifford Interim Director – Newham Coalition).

However, it has been argued there should be significant not tokenistic involvement of the communities that need to be included.

“When disabled people developed independent living - peer support, information, advocacy and training were at the centre of the concept. Without a collective critical mass, to guide, train and support, only the very able, white, middle-class had the personal resources to succeed. Organisations of disabled people in particular, in collaboration with all those engaged in the caring relationship, in my view, and must be the critical mass at the heart of the personalisation agenda.”²²

It is worth stating the key role for front line staff in making co-production a beneficial way of working. Senior management need to ensure staff development support fosters confidence in working co-productively.

‘Staff need more interpersonal, facilitative skills – rather than just having a rigid, delivery focus. To achieve this, staff morale is as important as client morale – in practice, the participation that they are asked to extend to clients is often not extended to them’.²³

It could be said that it is about actually working together to develop agreed solutions in a manner acceptable to all involved, rather than offering people the opportunity of contributing to solutions developed in advance or independently of the consultation.

²² Speech: Social care as an equality and human rights issue.
Speech by Baroness Jane Campbell, Chair of the Disability Committee and EHRC Commissioner, at the 'Power to carers and users: transforming care services' event, 19 February 2008

²³ Co-production by people outside paid employment
David Boyle, Sherry Clark and Sarah Burns 26 June 2006
<http://www.jrf.org.uk/publications/co-production-people-outside-paid-employment>

Section 4

Getting people involved – experiences of co-production in CAF demonstrator sites

1. Shropshire County Council (SCC)

In Shropshire considerable success has been achieved through working in partnership to co produce the CAF project with people with learning difficulties and to develop CAF solutions by “mutual consideration and understanding” (SCC).

People with learning difficulties who responded to this piece of work said “co-production is a difficult word for us. If it means doing and making things together it is right that we should be involved. We should have a say about what it means to have a learning difficulty and what are the best things to help”

The project has done different things to make the CAF work meaningful to real local people including:

- ‘Baking a Cake’ to explain the intention of CAF
- Developed a local Emergency Action Plan (EAP) which will provide view only useful information of people with a learning difficulty, with their consent, to partner agencies in an emergency situation.
- An explanation of language used in the CAF project and in the personalisation agenda. (Glossary of terms or jargon buster)
- We also employed someone with a learning difficulty to be part of the CAF team.

CAF as easy as baking a cake!

Shropshire County Council (SCC) employed someone with a learning difficulty as a CAF Project Support worker. They work 8 hours a week supported by a job coach.

“I first found out about what CAF meant at a workshop at the day service that I attend, where we baked a cake. I heard about this job. I wanted this job to help increase my confidence and

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

independence. I was interested in working with everyone in the CAF project and being able to share my point of view too.”

The Baking a Cake event “was an opportunity for the CAF team to introduce themselves to people we wanted to work with and to help people understand what the CAF project is all about.

The CAF team worked very closely with a wide range of people on the day with the intention of building a team. The day was led by the input of people with learning difficulties and involved a lot of participation and exercises to encourage everyone to learn something. Hats were used to introduce the team. The idea behind this was to give people a different way of remembering who the CAF team are and help us explain the job roles. For example, the CAF Communications and Development Officer wore a bicycle helmet to show how her role is to map the CAF journey, the highs and the lows.

To help people understand that CAF is about being able to share useful, agreed and correct information in the right way, chefs ‘Dumpling Dan’ and ‘Casserole Keith’ were invited to bake a cake. However, they did not work together and ignored the recipe – the result was that they made two terrible cakes!

Next, everyone, including people who might benefit from CAF and the chefs, were involved in making a second cake. By working together and using the recipe with the right ingredients, the result was a perfect cake! People decorated their own cakes to illustrate how everyone is an individual with different needs and different ways of doing things.

For the final exercise, we gave different groups different instructions on how to build a tower. The exercise helped to illustrate how important it is to have the right information as we gave the carers a set of instructions that made it impossible for them to build their tower.

“Having a Common Assessment Framework will be good - I will only have to give my details once, instead of repeating myself time and again. Everyone will understand my needs, and I believe that my care and support requirements will be met.” (Shropshire CAF Support Worker).

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

“Without question we have learnt about CAF that it means putting your information on a computer package so that people like Police, ShropDoc (out of hour’s doctor’s service), ambulances and support can see important information, especially in emergencies. It means we can feel safer and more independent.

“CAF is difficult to understand. But it is better when we are involved in getting the message out”. “Co-production can benefit individuals who in turn benefit others” (members of Taking Part Self Advocacy Group).

The exercise highlighted that people with learning difficulties in the local community have to be able to be part of implementing change, not only by producing a glossary and being involved in developing the Emergency Action Plan work but also by building relationships with other organisations. To paraphrase the young people "Together we can." (SCC).

2. Barnsley Metropolitan Borough Council (MBC)

“Superb!” Is what one older person said about working in a co-produced way.

In Barnsley, the CAF project decided to develop a partnership co produced “citizen portal” or computer based personal information sharing solution. This set out to develop a way of communicating between individuals who might benefit from Health and Social Care Records being kept together and those who were supporting them. The “citizen portal” would also be able to support the Council’s wider work on personalisation.

Barnsley MBC as well as involving individuals worked with partners in the voluntary sector Barnsley Arena (Arena is a user and carer led organisation), Age Concern, the local Links and an Information Technology (such as computers) partner (Liquidlogic) to support the development of the “citizen portal” (where the information will be kept).

“Getting together helped Liquidlogic staff who attended the service user and carer sessions understand the requirements from real people who would eventually use the computer software. As a result this feedback will also be applied to other similar projects.”

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

For example, some people will wish to take full control of their own support, whereas others may employ a Personal Assistant to provide this role. In other cases, the coordination role may reside with a social worker or other paid professional. Wherever the coordination role sits, there is a clear need for Information and Communication Technology (such as computers) to support the role and to provide accountability.

“The opportunity which we have had to work with service users directly was invaluable. The service users were mixed both in terms of support requirements and computer literacy, which ensured that a variety of viewpoints were covered.” (Liquidlogic)

Co-production in action

“I am 89 years old and I was my wife’s main carer for over 6 years after she was diagnosed with dementia until she died in 2007. I managed my wife’s individual budget. My wife’s social worker asked me if I would be interested in doing training to be a support broker and through this I got involved and joined Barnsley Arena and Age Concern.

I only started using computers 7 years ago. I have done a lot of courses but I am still learning. I am a person who has always liked new challenges and getting involved with different things and this interested me.

Working on the CAF project has been a fantastic experience. At first, we were shown screen shots of what the computer system might look like and asked to say what was good and bad about it. The next time, we were shown a prototype and asked again what was good and bad about it. It was good to see how changes had been made that showed they had listened to what we all had said. I liked that other people were involved and I could see how it would benefit the Barnsley community.

I was also one of the testers of the system and I spent the weekend at home trying it out. This was a good experience but I got annoyed and frustrated when it didn’t do what I wanted or expected it to do. I gave my feedback about this too and I could see mine and other people’s comments had been taken into account again as the system was being developed.”

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

“The final option will have been developed in partnership with a group of key people that will hopefully make it work well. A group containing representation from Service Users, Primary Care Trust, Council and Third Sector agencies, to ensure that the requirements of everyone are adequately realised and that our input and involvement from a technical perspective is crucial to the successful development of the end product. (Liquidlogic)

“The opportunity to work in this way has enabled Barnsley MBC to better understand from the ground up the needs and requirements of service users, their carers and families. We have a genuine feeling that we were doing something that will make a difference to peoples’ lives and believe that the service users and carers engaged in the process feel they are both contributing to the community and having a degree of control about how their care is managed.” (Barnsley MBC)

3. Westminster Council

In Westminster, the project started off with an IT emphasis, initially experiencing some difficulties finding the right partners.

The Council then involved the local organisation run by disabled people in Westminster, Westminster Action Network on Disability (WAND). WAND is a local disabled people’s organisation, developed as a grass roots organisation whose main activities focussed on providing information and advocacy as well as promoting user engagement.

“The CAF board meetings were about people telling you what was happening it was very complicated to understand as much of it was about council and primary care trust technologies and technology companies updating about what version they were on etc.” (WAND).

However, we then set up a business sub group with a focus on personalisation which had fewer people on it and this was much better. I felt more confidence about saying what I feel also people were more prepared to listen to me at this meeting. Most if not all of our recommendations were given the green light. I think if I had known this I would have pushed for more changes” (WAND).

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

While many other local disabled peoples organisations have moved into service delivery either through choice or by necessity WAND felt strongly that this might lessen their main role of representing people.

As a consequence WAND supported the development of a new organisation called Coalition for Independent Living (C-I-L) which is an independent, social enterprise. It aims to equip people who have health and social care needs access the level of knowledge and expertise they need to truly self-manage and increase their independence in a supported and sustainable fashion.

The mission of the C-I-L is to work in co-production with citizens to develop independent peer brokerage options. WAND was able to find local citizens who wanted to go through the C-I-L training programme and were supported to become peer brokers. The peer brokers now work to support people to explore what possibilities are available to them.

The C-I-L mission fell in line with WAND's principles as they were seeking a new way of working that supported a peer led model.

The C-I-L had already been creating a range of computer software systems, developed by local people who would use them. The aim was to bring together peoples support planning information and to provide a central place to link them up with brokers and then to find relevant support options.

One of these options was a web-based information solution named the iPlanner. This was developed to link brokers with service providers and potentially a wider network of support and services. Brokers can indicate someone's needs via the 'portal' and providers can 'apply to do the job'. iPlanner enables brokers to have access to local goods and services.

Once an iPlanner profile has been created by a professional, the person using it receives a user name and password with which to log in to iPlanner. Once they have logged in, they are guided through a series of questions which forms the start of their support plan. The person may work with a carer, family member or local advocate if support is required needed for this stage of the process.

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

Given that there existed possibilities from the work above that was already underway for a CAF solution, “C-I-L is currently working in co-production with the Westminster CAF project to implement a citizen-led Self-Assessment tool and integrated care and support plan. Using our extensive knowledge of building iPlanner we hope to create a tool for Westminster citizens engaged in a small scale peer-brokerage pilot.” (C-I-L)

“The CAF project has not always gone the way we want because the technologies have let us down and sometimes there have been huge changes internally with the statutory services. However, during the last few months we have been working very closely to design an ideas exchange bringing together users and the professionals to discuss how we communicate and what we want from professionals and what they need from us.”

“I have also come to empathise with professionals and don't see things as their fault all the time. The 'systems' can let everyone down we have to find ways of working together and see each other as allies”.

“However, if everyone understands what co production means then we can make thing happen much faster and with confidence” (WAND).

In Westminster this will be achieved by the development of a range of integrated self-directed support software tools designed to put citizens at the centre of controlling their health and social care assessments and support plans". This work is being led by C-I-L who will be developing the software with technology partners. The software tools will be used by citizens participating within an individual budgets pilot from January-March 2010.

On working in a co-produced way outlined above Westminster Council reflected ‘We wish we'd done it sooner!’

Section 5

Top Tips for involving people in co-production

The following is a list of practical tips, suggestions and ethical questions that may help you to avoid some of the pitfalls and plan for a more inclusive and co-produced outcome to your work.

- 1. When you are starting to think about who you need to involve in a piece of work, are you responding to something that others have highlighted or are you initiating the thinking? If you are initiating the thinking you will need to decide who should be involved and how you will convince people that it is something that they want to be involved in and give their time and experience too.**

When you start out on a piece of work your first thought should be ‘who do I need to involve?’

“It is important to include a diverse group of people to ensure all service user are represented in the design for the product to work and be helpful.” (Rochdale CAF participant).

Your second thought should be ‘who else should I involve?’ and your third thought should be ‘who have I forgotten?’

“I am a transgendered woman with manic depression and psychosis, who is involved on a large basis with caring, supporting people, mental health, voluntary sectors, hate crime, LGBT and council issues. I also am on an Independent Advisory group for Warwickshire Police and am an active member of Orbit Housing Association”. (Warwickshire CAF participant).

The more people you involve the better chance you have of getting it right, but you need to balance that with practicalities and work out how you get the best information and input from people in the most effective way.

- 2. To make co-production work you need to obtain information, experiences, skills and knowledge from a**

wide range of people. Try and think beyond the people that you would normally involve and think about who might have something to say or contribute to the work that you are about to undertake. Try not to pigeonhole people into specific pieces of work.

Do not forget disabled and older people can be mothers, fathers, co-workers, doctors, engineers, they use libraries, roads, waste management services, parks etc. but often they are only asked their views or to be involved in things that are disability specific. Disabled and older people all have a wealth of experience in a whole range of activities that they are often never asked about.

“I am aged 84 years. I live down here but came from Yorkshire. I am a widow, with one daughter. I also have three grandchildren down here. At first I joined the Quality Assessment panel and from that was asked to get involved in CAF work. I am a retired Social Worker – my career was in Child Guidance in both Leeds and Newcastle, working with a large team.” (Warwickshire CAF participant).

- 3. Is your management team supportive of your work? Involving people in co-production who get support or use services should result in cultural change so it is important that your managers or Board of Directors have realised this and planned for it, particularly with other staff.**
- 4. Are other staff in your organisation ‘on side’? If not, you might need to do some staff training. Other workers can sometimes be suspicious of involving people who use services because they may feel that people will be overly negative or because they feel they have not been consulted or involved themselves.**

The ‘loss of power’ that staff have if people are determining more for themselves has an impact on staff who are motivated by the need to ‘care for vulnerable people and protect them’ and so take a parental role in their work. Many of us will have heard people when talking of working with disabled adults ‘it’s like bringing up your children really’!

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

There is also the more fundamental question of how people feel 'successful' and valued in their lives: people taking control over their own lives, and the shift from the traditional ethos of 'caring for those less fortunate' to 'supporting people to live their lives as equals' challenges basic unquestioned assumptions that people have shaped their view of the world and their place within it. The point being made here is to examine your attitudes to working with disabled and older people and challenge them when you need to.

5. Before you start the actual work decide together how you are going to work and what will make it successful and stick to it. Principles and ground rules should be agreed at the outset and revisited regularly to ensure that people are reminded.

Some suggestions from the Westminster Council's partner organisation run by disabled people WAND.

- a. Co-production should be at the centre of all future working arrangements.
- b. Citizen-led organisations named as partners in funding applications should be interviewed by those people deciding whether to award funding to ensure they are genuinely being involved as partners.
- c. There should be clear outcomes for individuals and partner organisations
- d. There should be sufficient funding to include local people
- e. There should be sufficient time before, during and after the project is over to ensure the continued involvement of participants.
- f. There should be a report from participants so we can feed into monitoring with the Department of Health. Local disabled and older people should have the funding to appoint their own independent voice (sometimes it's hard to say things if your funding comes from the council).
- g. All participants should be expected to produce something of value beyond just saying things and leaving the doing to someone else.
- h. Skills sharing and training should be included from the beginning.

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

- i. Disabled and older people and their organisations should be able to walk away feeling like something has been achieved and that their contribution has been valued.

“As yet I have not been told of the end result nor had any feedback, which I would like.” (CAF demonstrator site participant).

Keep people informed even if not much is happening.

6. Are you clear about language? Be sure about how you communicate with people and that you are clear about what might offend. The use of appropriate language is important.

Understanding why some words are ok and other not is crucial. You might not see the relevance but often words reflect a historical context that you might not be aware of but would have significant meaning for someone else in the struggle for equality.

Words that have become part of our daily language have often come from beginnings and will often reflect a time and place when things were different and discrimination was acceptable and commonplace. The connection for some individuals with those words can be painful and disempowering.

7. What could stop people being involved – are there some key areas of activity that would mean it would be difficult or impossible for people to be involved. If you do not know then do not forget to talk to local community groups to offer support and advice.

“We had less success during the user acceptance testing phase. We requested that this was done independently at home by our service users and carers as this would be the environment in which they would be using the portal however we received a poor response. On reflection our approach could have been delivered differently and in a more supportive and facilitated environment.” (Barnsley CAF site).

If something does not work, change it!

8. What other resources and skills might you need, there is a good chance that you will need more than your enthusiasm and time.

Co-production can be a way for providers to recognise and support the people who use services and carers, by acknowledging the importance of their input, valuing, supporting and harnessing the power of existing informal support networks and creating better ways for people to shape services. This can be achieved by offering something in return, not necessarily money.

“People should also be paid for their input in a range of ways, reasonably and promptly and clear systems should be in place and up front for them from the beginning.” (Warwickshire County Council CAF demonstrator site)

Don't forget money! Common expenses include people's travel expenses, hospitality (including lunch, teas and coffees), training, childcare facilities/costs, venue hire and publication costs. However, for significant pieces of work you will need to think about offering people payment for their expertise. This may be problematic for some people who are on benefits, so again talk to your local community third sector groups for advice and support on how you might do this.

An amount as small as £5 out of someone's weekly budget may be the thing that stops them attending an event simply because they just cannot afford it and cannot afford to wait two weeks for it to be paid back to them particularly if they are on benefits or managing on a low income. However, that person's experience may be invaluable; by not finding a way through the bureaucracy to pay people on the day you will lose out on interesting insightful people who will add a lot of worth and credibility to your work.

Meetings might be one way of doing it but do not forget co-production is not a one-way street. Co-production is about mutual gain and shared activity and therefore you will need to think about what you have to offer that will help everyone to benefit. Asking people to come along to a meeting and offering them a sandwich and some travel expenses may get you what you want but what do the participants really get in return?

Example of mutual benefit

A small amount of money invested by a Local Authority (LA) in an assertiveness course for Asian women may provide them with a resource that they can tap into for future planning of services. The local disabled or older people's organisation in the community may run the course; the LA develops a better relationship with locally user controlled organisations and better links with the local Asian community.

The Asian community builds a relationship with the organisation and the Asian women get free training, get a chance to meet new people, improve their feelings of self esteem and have a greater understanding of what other support/ services might be happening in their community.

The Asian women who have been on the course are much more likely to be willing to be involved in helping the ULO or the LA due to their increased confidence, improved relationships and new found friends.

If you ask someone along to a meeting and offer to pay their expenses, it is not good enough that they do not have those expenses reimbursed on the day.

All this provided for a relatively small investment initially in the course at the beginning.

9. Taking account of people's access needs is crucial and often only the bare minimum is accounted for. Some stumble at the first fence by not even providing information in a format that people need in order to be able to understand.

You may need to start producing and presenting information in a different way, making sure that your language is appropriate, that you are being culturally sensitive in your approach and delivery. Make sure you have the ability to provide what people need to take part.²⁴

²⁴ For more information see 'Delivering inclusive communications' Your guide – HM Government Office of Disability Issues www.odi.gov.uk

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

“At the first programme board meeting I felt able to speak up for an inclusive perspective on the programme as some of the office workers’ presentations seemed to show they lacked understanding or experience of wider experiences of people needs. Particularly some of the points I’d raised on accessibility, language and financial and ethnic considerations were welcomed.” (Rochdale CAF site).

Making information accessible for disabled people is now a specific requirement of the Equality Act.²⁵

Disabled people need to be able to understand the information they are sent by people like their council or their bank so that they know what to do. This is a reasonable adjustment.

10. Think about your venue.

Is it reasonably central? Does it have good transport link and/or parking? Is it accessible to all disabled people? Is it welcoming? Is it culturally comfortable? Are the staff welcoming and does it look as if you could relax in it?

Accessible venues not only need to have ramped access and accessible toilets, they also need to be culturally and faith sensitive. Not everyone will be comfortable in a church hall or a local working men’s club meeting room. Neutral venues that are bright, airy and smart, that show you value the people that are attending.

Find out what people need and give plenty of time to arrange to have support in place. It is no good arranging an event and then thinking about the provision of a sign language interpreter or palantypist (speech to screen text typist) 3 days before; you are very unlikely to find one at that short notice.

Make sure information is available in large print and circulated early enough so that a person with a visual impairment who uses a reader has time to have it read to them.

²⁵ See: <http://www.equalities.gov.uk/pdf/GEO%20-%20Equality%20Act%20easy%20read%20ROYAL%20ASSENT%20PRINT%20VERSION.pdf>

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

It is recommended that you book everything you might need when you book the event and cancel what you do not need. Agree cancellation charges with providers beforehand so you do not end up paying out for something you ultimately did not need.

The most important thing to remember is that no one should be left out because of something that they need to enable them to participate. Not only is it potentially illegal, but more importantly you are missing out on a whole range of views and experiences that are vital to your work.

Often people with learning difficulties are treated differently and/or separately. There is usually no need for this you just need to make sure that what you are doing meets everyone's needs. You would not exclude wheelchair users by holding the event in a venue that was not wheelchair accessible and then offer them a different event for example. But often it seems OK to segregate people with learning difficulties.

The perception may be that it is easier to do it this way but what you do not get is the sharing of experiences and the mutual support when you arrange an event that is accessible for everyone. It is not hard it just might take a bit more planning, time and good quality effective facilitation to include everyone. There is a solution for every access need you just need to involve people to find it.²⁶

11. Being honest and trustworthy – It is really important to be clear at the outset about what is open for discussion and how decisions about where to go next will be made. Be clear about what is non negotiable and what is practical and possible.

12. Develop support for your work – nurture and develop key relationships that can help you 'make things happen'

²⁶ For more information see:

<http://www.shapingourlives.org.uk/accessibleevents.html>

<http://www.scie.org.uk/publications/misc/accessguidelinesevents.pdf>

<http://www.breakthroughuk.co.uk/OneStopCMS/Core/CrawlerResourceServer.aspx?resource=1F7062DE-99A7-4CDE-9B66-CA96FADD0ED5&mode=link&guid=98dc93a5f2ca4eb4a59c42fbae47cea9>

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

Co-production is not just about the 'Noah's Ark' approach, taking a couple of people from each 'relevant' or "hard to reach" community and bringing them all together in a room to talk about a particular issue. It is about offering something in return for something you need, and getting the most appropriate people for the piece of work in question. There are so many ways that you can do this, you are only restricted by your imagination (and sometimes budgets of course!), however there is a lot that you can do with very little if you are all mutually gaining.

"On a personal level, I can now travel independently, I have increased my knowledge of the project, and I have learnt new skills including binding, shredding, filing, using email and spreadsheets and using a camera." (Shropshire CAF project support worker).

"Make sure you have a specific customer consultant lead, from outside the authority, who is commissioned to do work on customer engagement activities. Otherwise it is difficult to co-ordinate especially across agencies, and slow to get things done. Also customers need the space of an independent space for this so they are free from their 'customer' role to input." (Warwickshire County Council).

"Working in a co-produced way is the underlying premise of CAF. It is important that in times of economic crisis that organisations' continue to undertake co-production in a meaningful way and not just pay lip-service to the need to consult on a wider basis. (Rochdale CAF demonstrator site).

Your community groups are a vital resource to the success of co-production as they understand what their community needs are and what works and what does not. Treat them well and they will support you in return.

If you are not sure what to do and how to communicate with people find local organisations that can help you, faith groups, disabled peoples organisations, community groups are all used to communicating with their users and will have a wealth of information and resources that will help.

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

You may have to pay for their assistance but it is better to get it right the first time than have to do it all over again. Better value for everyone.

The most important thing is to be varied in your approach. There are often some 'minority' groups of people who are seen to be more difficult to engage with than others. The reluctance to engage can often be about trust or time, or 'what is in it for me/ us?' or that the expectation is that they are always expected to come to you not the other way round. It could also be a lack of cultural understanding.

In these situations, it is very easy to give up and say 'we tried but nobody turned up' or 'we sent out the questionnaire but nobody replied'. What you should be saying is, 'why didn't anyone turn up?' 'What did we do wrong?' 'Who can I talk to find out how to do this better?'

This does not necessarily mean having boxes of leaflets in 20 different languages but more about knowing where to go to obtain a translation quickly and efficiently. It is about knowing the questions to ask to get the best out of people and understanding what types of support people might need and knowing where to get them.

- 13. Sustainability and moving on – supporting people you involve in work to move on from the work is important to think about. It can be unhelpful in the longer term for the work and the individual if service users 'get stuck' and are not supported to use their skills elsewhere in terms of their own development and that of their community. Renewal of staff involvement is essential too; work must be strategic to ensure that when a supportive and enthusiastic member of staff leaves the work continues.**

"Through the CAF project other joint working has evolved. For example Taking Part a Self Advocacy Group has been advising ShropDoc the out of hours GP service on how to communicate over the phone with people with learning disabilities. This has led to ShropDoc producing cards to give to individuals with clear instructions on how they can be contacted". (Shropshire CAF demonstrator site).

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

It is not difficult to involve people but there are no short cuts, it just takes time and planning and the involvement of the right support organisations that can help you get it right first time.

Section 6

Checklist (draft) of top tips for producing meaningful co-production and community involvement

Questions	Yes/No	What do we need to do now?	By which date?
<p>1. Have I thought about who to involve?</p> <p>Have I thought about who else should I involve?' and finally</p> <p>Have I forgotten anyone?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>		
<p>2. Have you obtained information, experiences, skills and knowledge from a wide range of people to make co-production work?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>		
<p>3. Is your management team supportive of your work?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>		
<p>4. Are other staff in your organisation 'on side'?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>		
<p>5. Have you decided how you are going to work together and written it down and/or communicated it?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>		
<p>6. Are you clear about the language/information you will use?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>		

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

7. Is there something that could stop people being involved?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
8. Are there other resources and skills might you need?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
9. Have you taken account of people access needs?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
10. Have you thought about your venue?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
11. Are you being clear what you are offering people?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
12. Are you developing support for your work – nurture and develop key external relationships that can help you make things happen?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
13. Are you supporting people you involve in your work to think about taking up new opportunities?	Yes <input type="checkbox"/> No <input type="checkbox"/>		

Section 7

Final comments

Over the last 30 years, the disability rights and service user movements have promoted the idea of people who need support and use services as active participants with a contribution to make rather than passive dependents with needs. This has directly resulted in innovations such as direct payments that can lead to the provision of individually tailor made support that really meets individual people's needs.

It is evident that the CAF demonstrator sites have undertaken a great deal of work in collaboration with local communities to support such a change in perspective. This has resulted collectively in lots of learning by each site.

Some more general points highlighted by the CAF demonstrator sites during this work were:

- take the time to explain what you are doing
- take time to build relationships based on trust and confidence
- you will more easily involve a diverse group of people if you make everyone feel welcome
- check out regularly that all your partners feel you are all working together co productively and it's not just you that believes that.
- do not confuse consultation with involvement and co-production
- do not make assumptions about what disabled and older people can offer
- your work can have wider benefits i.e. providing employment and building people's confidence and self esteem
- you can really achieve high satisfaction rates for everyone involved
- co-production does not have to be a one off piece of work

Co-production is not a 'magic fix':

"It does not dispense with the need for promoting equality, enforcing standards or improving delivery. However, it offers a

Sharing good practice of co-production in delivering the Common Assessment Framework for Adults (CAF) programme

different way to think about the relationship between the state, service providers and in this case disabled and older people.”²⁷

However the principles and practice of co-production have the potential to create greater social cohesion.

Co-production work should not lose sight of its role in promoting social justice and should:

“aim to achieve a fair distribution of outcomes, paying particular attention to the narrowing of unjust inequalities (such as between people from different social class backgrounds, or of different gender, ethnicity or sexuality).”²⁸

The challenge for us all is making the slogan ‘nothing about us without us’ a reality. Co-production with disabled and older people can be achieved by developing strong partnerships, supported by good communication and practice that achieves jointly agreed outcomes.

²⁷ Co production - an emerging evidence base for adult social care transformation - March 2009

Dr Catherine Needham, Queen Mary University of London and Sarah Carr, Social Care Institute for Excellence

²⁸ SCIE Research briefing 31: Co-production: an emerging evidence base for adult social care transformation

By Dr Catherine Needham, Queen Mary University of London and Sarah Carr, Social Care Institute for Excellence. Published March 2009

Section 8

Co production resources

- Co-production and self-care: new approaches to managing community care services for older people - Wilson, Gail (1994). [online]. London: LSE Research Online. Available at: <http://eprints.lse.ac.uk/archive/00001029>. Available in LSE Research Online: April 2007
- Co-production, social capital and service effectiveness, Jude Cummins and Clive Miller, October 2007 www.commissioningsupport.org.uk/idoc.ashx?docid...b38c
- Making government better Co-production in Public Services a new partnership with Citizens - March 2009 Cabinet Office
- Personalisation - don't just do it - co-produce it and live it! - A guide to co-production with older people – National Development Team for Inclusion.
- Right Here Right Now Taking Co-production into the mainstream – discussion paper. July 2010 http://www.nesta.org.uk/publications/assets/features/co-production_right_here_right_now
- SCIE Briefing Co-production: an emerging evidence base for adult care social transformation. March 2009 <http://www.scie.org.uk/publications/briefings/briefing31/index.asp>
- The Challenge of Co-production -How equal partnerships between professionals and the public are crucial to improving public services -David Boyle and Michael Harris- December 2009 http://www.nesta.org.uk/publications/assets/features/the_challenge_of_co-production

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Equal Citizen Services is a network of disabled people and allies who work to promote real involvement and equal citizenship of all disabled people.