



## AGENDA SELECT COMMITTEE - DEMENTIA

Tuesday, 29 March 2011, at 1.30 pm

Ask for: **Christine Singh/Sue Frampton**

**Medway Room, Sessions House, County Hall, Maidstone**

Telephone **01622 694334/694993**

*Tea/Coffee will be available 15 minutes before the start of the meeting*

### **Membership**

Mrs T Dean (Chairman), Mrs A D Allen, Mr D L Brazier, Mr A R Chell, Mr L Christie (co-tee), Mr J D Kirby, Mr S Manion, Mr K H Pugh Mr A Sandhu, MBE

### **UNRESTRICTED ITEMS**

*(During these items the meeting is likely to be open to the public)*

1.30 - 2.15 Interview with **Michael O'Dell**, Carer's Watch ( 1 - 32)  
pm

2.15 - 3.00 Interview with **Simon Bannister**, Neighbourhood Development  
pm Co-ordinator, Ashford Borough Council, and Chairman of Ashford  
and Shepway Dementia Working Group ( 33 - 58)

3.15 - 4.15 Interview with a panel of contributors addressing issues around  
pm Equalities: ( 59 - 68)

**Simon Bannister**, Ashford Borough Council

**Shaminder Bedi, MBE** - Guru Nanak & Milan Day Centres

**Christine Locke**, Diversity House

**Roger Newman**, East Kent Independent Dementia Support  
(EKIDS)

**Viniti Seabrooke**, Alzheimer's and Dementia Support Services  
(ADSS)

**Rock Sturt**, Alzheimer's and Dementia Support Services (ADSS)

### **EXEMPT ITEMS**

*(At the time of preparing the agenda there were no exempt items. During any such items which may arise the meeting is likely NOT to be open to the public)*

***At the end of the public session, Members of the Committee should remain in the meeting room for 20 minutes for summing up***

Peter Sass  
Head of Democratic Services and Local Leadership  
(01622) 694002

**Monday, 21 March 2011**



## **Dementia Select Committee – Hearing 29<sup>th</sup> March 2011**

### **Michael O'Dell – 2Find Me (1.30)**

#### **Biography**

Michael has 34 years experience in industry including engineering and project management, which included large investment programmes at several sites in the UK. For the past two years he has worked as a consultant covering project and health and safety management. In 2010 he visited Australia where a relative was involved in the development of the watch for a family member. The product went into production and Michael at that time realised it had great potential for the UK market.

Michael will make a presentation to the committee, demonstrate the Carer's Watch and answer questions including those outlined below.

#### **Themes & Questions**

1. Could you please introduce yourself and your organisation and tell us how you came to be involved with the product you have come to demonstrate – the Carer's Watch.
2. Could you please demonstrate how the device can be used and its various features and functions?
3. Have any trials of the Carer's Watch been undertaken in Australia or the UK and if so what feedback have you had from those trials?
4. Do you have any case studies involving use of the watch to assist a person with dementia/their carer?
5. In what ways is it envisaged the cost of these devices may be met by a person with dementia or a carer?
6. Could you please summarise for us what in your view are the advantages of this type of device in meeting the specific needs of carers/people with dementia in order to help with behaviours such as wandering or otherwise maintaining safety.

This page is intentionally left blank

# 2find-me Carers Watch

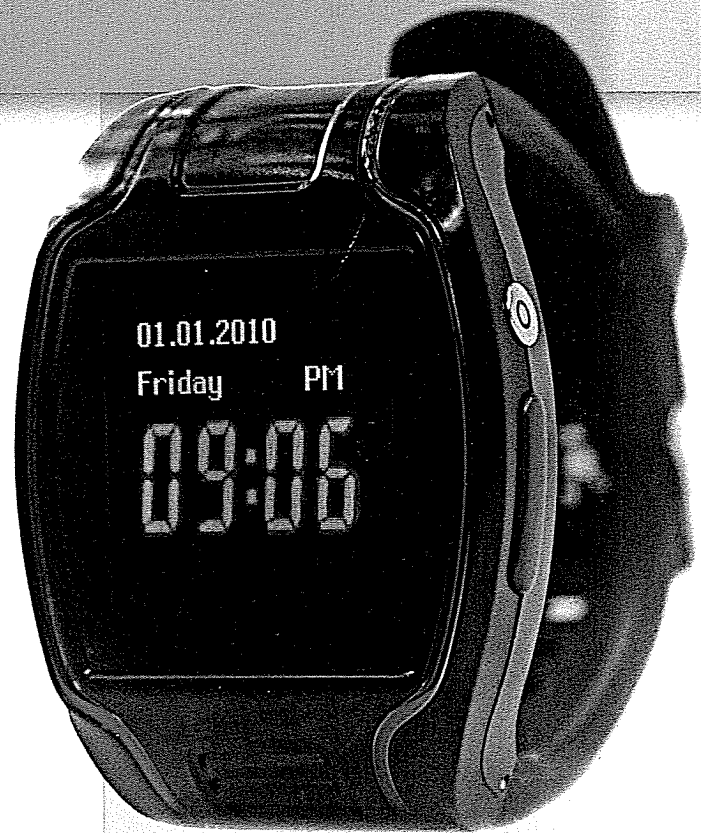
**A revolution is here in personal safety**

**The 2Find-Me Carers Watch  
security for people who care**

The Carers Watch is the world's first personal mobile emergency alert system in the form of a watch.

The Carers Watch is different from any other product. It can be changed as your needs change. The Carers Watch was designed by someone who has both the carers and wearers needs in mind. The Carers Watch can assist individuals who want to keep their independence or those who care for people who are vulnerable in our communities.

A personal safety system that is not limited to your home!



## **About the Carers Watch**

Until now, personal emergency alarms have been large and normally limited to working around the home. The Carers Watch will work anywhere there is mobile phone coverage.

Tracking units are large and too uncomfortable to wear for many with a medical condition. The Carers Watch is lightweight and can be worn the same as an everyday watch, and also has an optional feature whereby the watch strap can be changed to a lockable strap to prevent removal by the wearer. It can also be adapted to be worn as a brooch or pendant making the Carers Watch suitable for all needs.



**The 2Find-Me Carers Watch - creates a powerful tool for  
your peace of mind and for the safety of those you care for.**

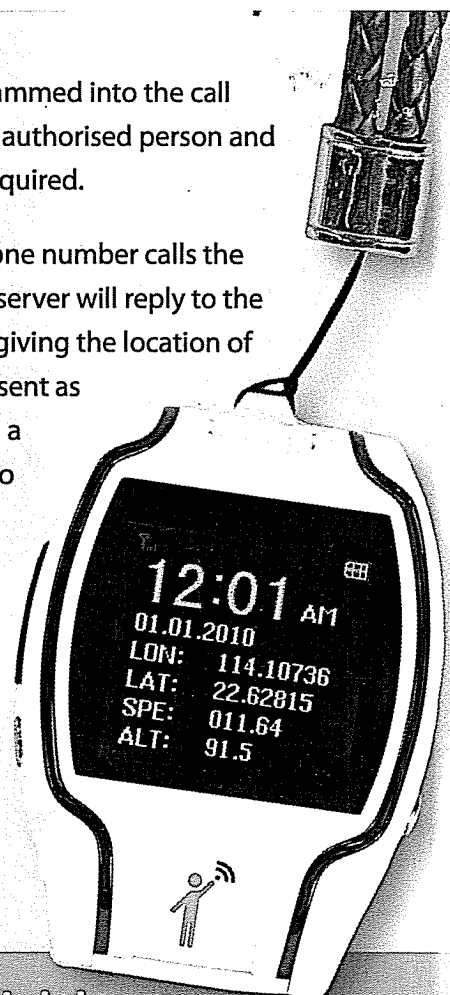
The Carers Watch is a wrist watch that not only tells the time, but also incorporates the capabilities of a mobile phone and a panic alert. The Carers Watch can receive incoming calls, from any land line or mobile phone and has a Global Positioning System that can "talk" to any authorised mobile phone and the internet.

The Carers Watch has two call out buttons (A and B) and one red panic button. The panic button transmits the wearer's location and alerts the authorised contacts of a potential emergency. The call out buttons are programmed with your choice of contact numbers. These can be a family, friend or neighbours' contact numbers, so you are assured you are speaking to someone that you are familiar with. *Please note, extra charges may be incurred if the Carers Watch is continually used to call out.*

The contact numbers programmed into the call buttons are specified by the authorised person and can be turned on or off as required.

If the authorised mobile phone number calls the Carers Watch, the 2Find-Me server will reply to the authorised number by SMS giving the location of the wearer. This SMS will be sent as a simple street address, with a link that gives a map detail to an internet enabled phone.

The Carers Watch has a battery life in excess of 24 hours in normal use, but this will be reduced if the advanced features are activated. The Carers Watch also comes with a charger and a spare battery.



## The Carers Watch has additional advanced features:

### Auto Answer

The Carers Watch can be programmed to auto-answer in the event that the wearer is unable to answer themselves.

### A Safe Zone (an invisible electronic fence)

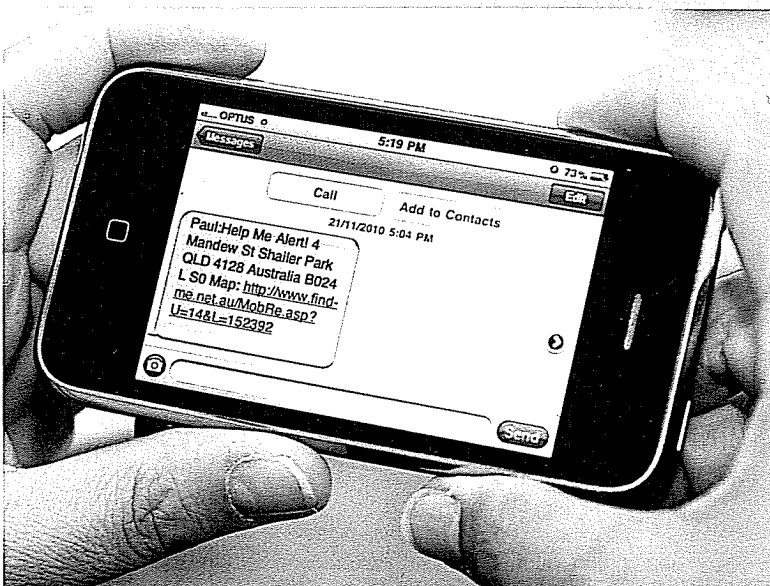
The authorised person can program a safe zone ranging from 100m to 2000m around the wearers current location. Should the wearer leave the safe zone, then an automatic alert will be generated from the 2Find-Me server to the authorised person's mobile phone by SMS or via e-mail advising them that the wearer has left the safe zone.

### GPRS Tracking

The Carers Watch sends repeated location details to the 2Find-Me server which enables an authorised person to know where the wearer has been and the direction in which they are heading. These details are then displayed on the authorised person's secure webpage along with a map image that can be used to direct emergency services if required.

### SMS Breadcrumbs

The Carers Watch has the ability to track the wearer's position at intervals from 1 minute to 99 minutes. These details are automatically sent to the authorised persons mobile phone and webpage at a minimal cost. This feature would only be used when mobile internet coverage is not available, but there is mobile phone coverage.



**Device:** Mike new  
**Date:** 24/11/2010 9:41:18 AM  
**Address:** Biggleswade Central Bedfordshire SG18 0ED UK  
**Type:** KeepAlive  
**Speed:** 0 **Battery:** 100



## **Dementia Select Committee – Briefing Note – Telecare and Dementia**

(relevant to hearings on 29<sup>th</sup> March, 5<sup>th</sup> and 8<sup>th</sup> April)

It is envisaged that Telecare will be one of the ways in which people will be better able to balance caring responsibilities with their own work responsibilities. The intended dual benefits are that businesses and the wider economy can continue to benefit by retaining skilled and experienced workers for longer while, at the same time, technology is used to enhance the safety and security of the home environment for the cared for person.

The Department of Health has funded a two year trial of both Telecare (which is particularly relevant to the review topic of dementia) and its companion programme Telehealth, involving 6000 participants including 470 carers. The outcomes are currently being evaluated, with a report expected later this year. Kent has taken part in the Whole System Demonstrator (WSD) programme and Members will be informed about its progress by Hazel Price at an interview on 8<sup>th</sup> April.

Ethical issues that may arise from the use of Telecare to augment the provision of social care services have been the topic of much debate and the most crucial issues are those concerning autonomy, mental capacity and consent balanced by the need, and indeed duty, to safeguard and protect people who are vulnerable.<sup>1</sup> These issues are of particular relevance when such methods are used to safeguard people with dementia.

Other technological safeguards such as the use of cameras to 'keep an eye on' a person in order to protect them and alert a carer to any difficulties and other products such as the Carer's Watch being demonstrated today are further solutions which may be favoured by carers in their attempts to keep a loved one safe, particularly when he or she is prone to wandering, a behaviour which may be exhibited by a person with dementia (in some cases) at any stage of illness.

Wandering referred to in connection with dementia is not to be confused with 'going out for a walk' in the usual sense as it may place the person concerned in harms way if they are unable to reach home safely, or for example are inappropriately dressed. These issues were the topic of a lecture attended on behalf of the Select Committee at the Dementia Services Development Centre (DSDC), Canterbury Christ Church University.

Feedback notes from the lecture at DSDC are being emailed to members of the Select Committee separately – these are relevant to hearings on 29<sup>th</sup> March (Mr. O'Dell) and to a panel discussion on 5<sup>th</sup> April on the theme of crisis/emergency (prevention and response) when Mr Ivatt, a volunteer with Kent Search and Rescue, who contributed to the lecture, will be taking part.

---

<sup>1</sup> Social Care Institute for Excellence (2010) Ethical issues on the use of telecare <http://tinyurl.com/telecare-ethicalissues>

This page is intentionally left blank

# Whole Systems Demonstrators

## An Overview of Telecare and Telehealth



# The WSD Programme

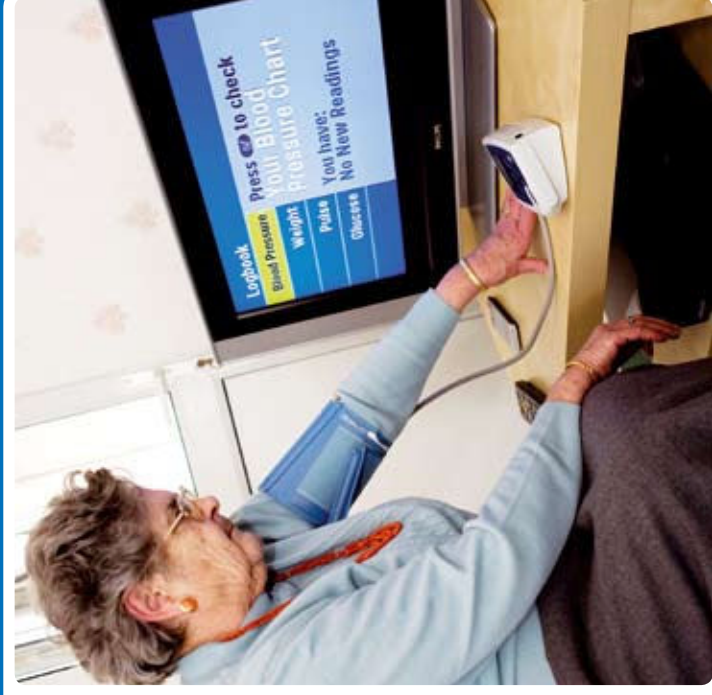
## The WSD Programme

The Whole System Demonstrator (WSD) programme is a two year research project funded by the Department of Health to find out how technology can help people manage their own health while maintaining their independence.

## The WSD Trial

Currently there is a lack of robust evidence around the effectiveness of Telecare and Telehealth technologies but the WSD programme should help to close this evidence gap.

The WSD programme is believed to be the largest randomised control trial of Telecare and Telehealth in the world to date. Thousands of members of the public will be involved in the programme with individuals being recruited at three sites (Cornwall, Kent and Newham).



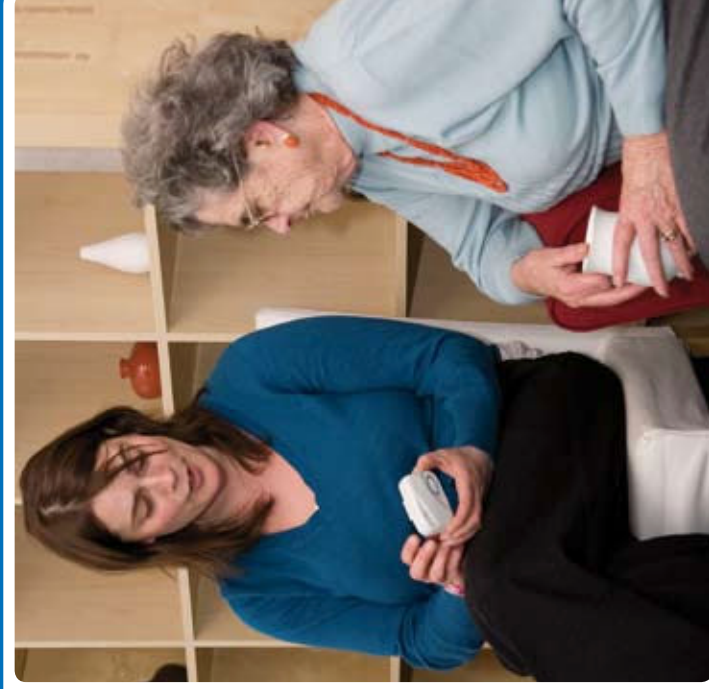
# The WSD Programme

## Telecare

This service is aimed at vulnerable people who need the support of Social Care or Health Services to keep living on their own. For example those with physical disabilities, the frail and elderly or those suffering from dementia or epilepsy.

## Telehealth

This service is aimed at helping people manage their long term health conditions in their own home. (Conditions include - diabetes, heart failure and/ or chronic obstructive pulmonary disease).



# The WSD Programme

## The Purpose of the Trial

The results of the WSD trial will help us to understand to what extent the integration between Health and Social Care when supported by these technologies can:

- promote people's long term health and independence
- improve quality of life for people and their carers
- improve the working lives of health and social care professionals
- provide an evidence base for more cost effective and clinically effective ways of managing long term conditions.



# What is Telecare?

## Telecare Technology

Telecare uses a combination of alarms, sensors and other equipment to help people live independently. This is done by monitoring activity changes over time and will raise a call for help in emergency situations, such as a fall, a fire or a flood.

Telecare is not intended to replace human contact but is designed to support carers and people living alone. For instance, a bed occupancy sensor can be used to monitor when a person gets out of bed at night and if they do not return within a certain period, an alarm would be raised as they may have fallen. The bed sensor can be combined with an automatic light sensor so that when the person gets out of bed the light turns on and allows them to immediately see where they are going.



# What is Telehealth?

## Telehealth Technology

Telehealth uses equipment to monitor people's health in their own home. So for example equipment can be used to monitor vital signs such as blood pressure, blood oxygen levels or weight. These measures are then automatically transmitted to a clinician who can observe health status without the patient leaving home. The clinician monitors daily readings to look for trends that could indicate deterioration in condition. Readings that are out of the range expected are flagged to the clinician using a traffic light system.

Telehealth solutions offer a way of delivering tailored care for patients with long term conditions, which helps improve quality of life and prevent avoidable hospital admissions.

By using Telehealth equipment individuals can take the same measurements that a nurse or GP would

take at a surgery thereby avoiding frequent visits to the surgery. Measurements are automatically sent through the telephone line and the nurse or GP will be able to read those measurements from their desk at the surgery to monitor the user's progress.



6

What is Telehealth?

# Eligibility and Trial Design

## Trial Design

The WSD Programme is a randomised control trial. This means that participants are randomly allocated to either a control or intervention group. The unit of randomisation is the GP practice. In other words the GP practice that an individual belongs to will determine whether they are allocated to the control or intervention group and have the equipment installed now or in 12 months time.

The GP practices that are part of the trial have been randomly split by the evaluation team into 4 groups which are matched to provide a balanced mix of practice sizes, disease prevalence and demographics.

## Intervention Group

Half the people on the trial will be in the intervention group and have either the Telecare or Telehealth

equipment installed depending on their health or social care needs.

## Control Group

As with all trials there needs to be a control group for the Whole System Demonstrators. This means that some people will receive usual care for 12 months. We have made a commitment to provide appropriate Telecare and Telehealth to those in the control group after 12 months.

## Eligibility

To be eligible to take part in the trial individuals must meet the relevant Telecare or Telehealth eligibility criteria which have been agreed across all 3 sites (see pages 8 and 9 for more detail).

7

# Telecare Eligibility Criteria

Those individuals aged 18 and over with social care needs who meet one of the following criteria are eligible to participate in the WSD Telecare trial:

- 1.** Currently in receipt of (or considered to have a need for) night sitting.
- 2.** Receiving 7 or more hours per week of home care or 3.5 or more hours per week of home care plus a meals service (defined by individual not household).
- 3.** Receiving one or more days per week of day care.
- 4.** Have had a fall or who are considered at high risk of falling.
- 5.** Have a live-in, or nearby informal carer, who are facing difficulties carrying their current burden of responsibilities.
- 6.** Carer call-out.
- 7.** Cognitive impairment/confusion.



# Telehealth Eligibility Criteria

Those individuals aged 18 and over who meet the following criteria are eligible to participate in the WSD Telehealth trial:

- Diagnosed with one or more of the following long term conditions:
  - a.** Heart failure - diagnosis confirmed by echocardiogram or by a specialist assessment
  - b.** Type 1 or 2 diabetes - with HbA1C of 7.5 or greater in the previous 15 months
  - c.** Chronic Obstructive Pulmonary Disease (COPD) - diagnosis confirmed by spirometry and FEV1 is less than 70% of predicted normal and FEV1/FVC ratio is less than 70%

Note: additional co morbidities may be present and these individuals will still be eligible.

- In addition, we identify people who meet the eligibility criteria above and have had least one

of the unplanned following events in the last 12 months in relation to their long term condition:

- a.** Unplanned hospital admission
- b.** Intermediate care/ Rapid response service use
- c.** Treatment following call out of Ambulance services
- d.** Accident & Emergency visit



# Telecare Products - General



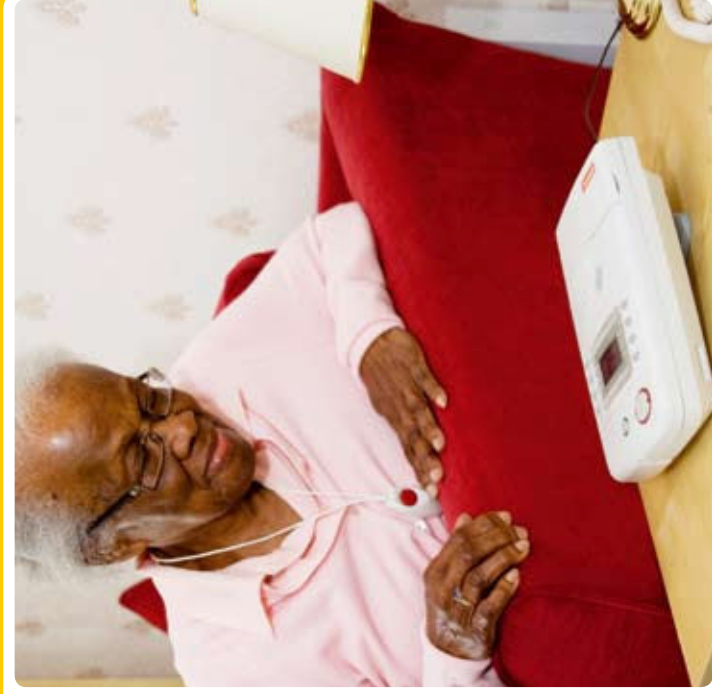
## Telecare Home Unit

- Recordable Reminders
- Speaker connected to Call Centre
- Linked to sensors



## Big Button Telephone

- Large buttons and white numbering
- Hearing aid compatibility
- Visual call indicator
- Earpiece volume control



10

# Telecare Products - Personal



## Personal Alarm

- Panic button
- Activates Telecare home unit



## Epilepsy Sensor

- Bed sensor
- Tonic Clonic seizures
- Monitors heart rate
- Monitors breathing patterns



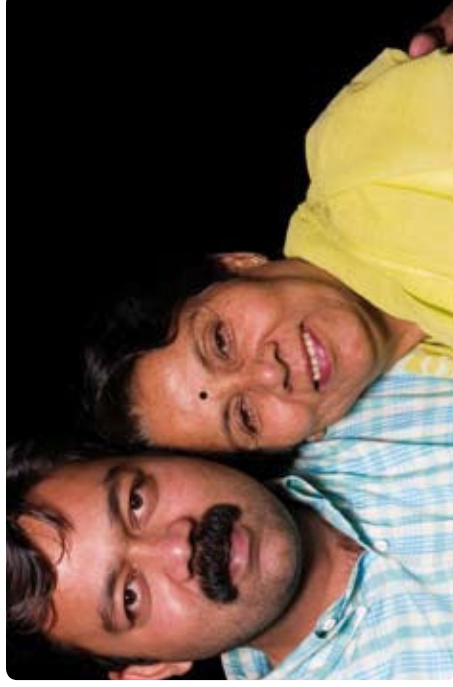
## Enuresis Sensor

- Detects bed moisture
- Alarm prompts action to be taken
- Eliminates need for constant physical checks



## Fall Detector

- Portable
- Detects serious falls
- Ideal if wearer is unable to rise



# Telecare Products - Environmental



## Temperature Extremes Sensor

- Battery operated
- Used in kitchen
- Monitors high and low temperature extremes



## Carbon Monoxide (CO) Detector

- Battery operated
- Audible warning
- Linked to Call Centre



## Flood Detector

- Battery operated
- Used in kitchen or bathroom
- 1st Alert – Audible
- 2nd Alert – Call Centre



## Gas Detector

- Battery operated
- Can be linked to gas shut-off supply if leak detected

# Telecare Products - Additional



## **Buddi System**

Buddi is a discreet GPS personal tracking system which can give carers complete peace of mind. It has the ability to locate a wearer 24/7 365 days a year. It also contains an emergency panic button which can be triggered by the wearer.



## **Key Safe**

A very secure safe to store keys in a heavy duty, weatherproof container which uses a code for easy access by carers or emergency services.



# Telecare Carer Support

The Telecare service aims to be beneficial to the service users, but it also ultimately gives full-time and part-time carers reassurance, peace-of-mind and respite in the care of their family or clients if they have to leave them alone i.e. to go shopping, return to their own homes, or go to work.

Every time the Telecare system raises an alert carers will be notified immediately via their own mobile or land-line telephone.



14

# Telecare Carer Support

**There are a number of Telecare products that are suited to carers:**



## **DDA Pager**

Carers can carry this during the day time, even if they are out in the garden, and be alerted immediately should any of the Telecare units be activated.



## **Fast PIR**

This movement sensor is useful to monitor activity/inactivity when the carer is absent. For instance if a service user suffers from diabetes, a PIR could alert a carer if the patient has not gone into the kitchen for something to eat when they should have.



## **Pillow Alert Solution**

This unit can be placed under the carer's pillow so that at night, if any of the alerts are activated around the house it will vibrate to wake the carer.



## **Medication Dispenser**

This dispenser enables the carer to be absent when patients are due to take their medication as it automatically sends a reminder and dispenses the appropriate dosage only.

# Telehealth Products - Monitors

Telehealth monitors are the equivalent of the Telecare home unit (see page 10). They store vital signs data, provide instructions and also display results in a user friendly manner. The more sophisticated also allow educational videos and questionnaires to be shared with an individual in their home. The content of these is tailored to their care package and the stage of their condition.

Telehealth needs to provide a flexible solution to meet the requirements of remote health monitoring as patients' needs change.

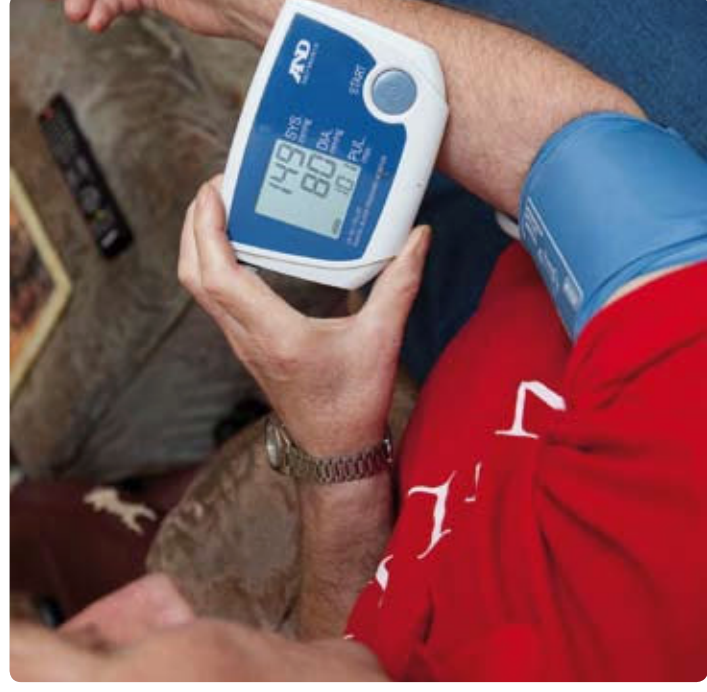
The monitors work with peripherals such as blood pressure monitors and scales (see page 18). Telehealth systems use a phone line and/or broadband at no additional cost to the user.



# Telehealth Products - Peripherals

There are a variety of peripherals available which are linked to the Telehealth monitor (see page 18). Some of these are wireless and can work via Bluetooth. In other instances readings may be taken remotely and then the peripheral can be connected to the monitor to allow the data to be transmitted.

Tailored packages of peripherals and associated educational content are available for different long term conditions and can vary depending on the severity of that condition. For example there are different packages for individuals with the early onset of COPD and for individuals with severe COPD. Packages are also available for people with multiple long term conditions.

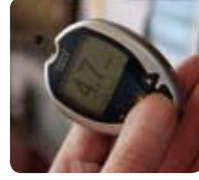


# Telehealth Products - Peripherals



## Blood pressure monitor

A cuff for the arm which can be used to check blood pressure.



## Blood glucometer

Used to measure an individual's blood sugar level.



## Pulse oximeter

Clips onto the individual's finger to measure blood oxygen levels and/or heart rate.



## Spirometer

Used to measure the volume of air inhaled and exhaled by the lungs.

## Weighing scales



Used to monitor an individual's weight as rapid weight change can indicate increased risk.

# Common Myths

## Common Telecare and Telehealth Myths

There are number of common myths about Telecare and Telehealth:

### **It is an emergency service**

Telecare and Telehealth products are used to support individuals with longer term and complex health and social care needs. The technology enables individuals to live more independently, however it is not a replacement for emergency services which users are advised to make use of in critical situations.

### **It's like Big Brother**

Service users and carers are made fully aware of what sensors are being fitted. They can also raise any concerns with their care co-ordination manager. In most



19

Common Myths

# Common Myths

cases the devices are unobtrusive and only activate when a potential adverse incident has occurred.

## **It leads to greater isolation**

Telecare and Telehealth enables individuals to live independently at home and can help improve the user and carer's quality of life. Support is still available from NHS and Social Care staff who will intervene when required. Many users and carers find that the technology reduces their anxiety and gives them the confidence to live fuller lives.

## **It creates a greater workload for staff**

Staff will need training to be able to use these technologies, however, in the long term it should enable them to better manage caseloads and work more efficiently. As a result, it is expected that the

proportion of time staff spend on planned, rather than unplanned reactive care, will increase.

## **It leads to redundancies**

Telecare and Telehealth technologies are not intended to replace care professionals. The vision for the Whole System Demonstrator Programme is principally to establish person-centred integrated health and social care, with advanced Telecare and Telehealth technologies acting as an additional mechanism to support and complement the care package within a home-setting. The demographics of an aging population will necessitate us providing our workforce with tools such as Telecare and Telehealth to help them cope with increased workloads.

# Case Studies



## Telecare Quotes

“Living on my own it’s nice to know I can call for help if I feel ill during the night or fall.”

“The alarm system allows me a lot more freedom and peace of mind.”

“My family are pleased with Telecare. If I was to fall or needed help anytime they would be contacted straight away.”

“It means that I don’t have to go into a care home which I don’t want to do. I want to stay in my own home as long as possible.”

# Case Studies



## Telehealth Quotes

“I feel much more confident knowing that someone is keeping an eye on my health every day. I think it's great.”

“Since I started using Telehealth I've been able to manage my condition better.”

“It changes the whole concept of my life. I can get on with my daily activities... and am totally independent.”

“I was worried that it would be a problem but Telehealth has actually created a routine and fits into my day really well.”

“Now if my condition changes I can speak to someone quickly and they have a record and can see what has changed - they know what to do to sort it out.”

# WSD Outputs & Further Information

## WSD Outputs and Further Information

### WSD Outputs

The WSD Programme was launched in May 2008 and will run for over two years with all participants being recruited by Summer 2009 and results being published in late 2010.

The evaluation work is already underway but it is currently too early to provide any results from the trial. The results of the WSD evaluation will provide an evidence base for future care and technology models and may potentially influence future DH policies leading to wide scale investment in Telecare and Telehealth.



### Further Information

- Further information about the WSD Programme can be found on the Department of Health website: [www.dh.gov.uk/en/healthcare/longtermconditions/wholesystemdemonstrators](http://www.dh.gov.uk/en/healthcare/longtermconditions/wholesystemdemonstrators)
- The WSD Action Network (WSDAN) has been established to disseminate the lessons learned on the three sites and will become a source for the collected worldwide evidence on the effectiveness of Telehealth and Telecare. In addition, another 12 organisations and partnerships that bid to be part of the WSD Programme, but did not become one of the three sites, are involved in helping to generate best practice data for the benefit of all.
- For more information and to register with the WSDAN visit the website at: [www.wsdactionnetwork.org](http://www.wsdactionnetwork.org)

This page is intentionally left blank

## DEMENTIA SELECT COMMITTEE

### Feedback from Dementia Services Development Centre talk on the topic of 'Wandering' – 15<sup>th</sup> November 4-5.30pm - Matt Hinds-Aldrich, Dave Ivatt and Kevin Harris

1. Sue Frampton attended along with Mr Steve Manion.
2. A presentation/talk was given by three members of Kent Search and Rescue (KSAR) which is a voluntary organisation that started in East Kent more than 10 years ago and now operates Kent-wide, funded by donations and small grants.
3. The organisation takes an average of 35 calls per year for missing persons in Kent including children, though the proportion of calls for dementia patients is increasing.
4. Due to their workload, the Police do not prioritise missing persons unless classed as vulnerable (practice varies between Police Forces) but Kent Police notify KSAR who 'mobilise' their volunteers immediately. (In 2009 UK Police spent £350 million on missing persons and data from Sussex for 2006/7 indicates a £5 million spend or £1,000 per missing person. KSAR have no Kent data.)
5. It is estimated that between 15 and 60% of dementia patients 'wander' and the distinction was drawn between 'going for a walk' and 'going for a walk and not knowing where you are'.
6. The 'problem' can be communication with a carer, i.e. the carer does not know where the person with dementia is and their worries and concerns about them are uppermost.
7. There are other issues around wandering such as: the level of activity a person has access to and needing to escape from some form of abuse.
8. The issues of stigma and prejudice associated with dementia were raised. For example, carers who report a person with dementia as missing often will not mention dementia at first, for fear of being thought inadequate carers, or, if the person lives alone, of the person being put in residential care. A second example was used of the sometimes less than sympathetic view that (often younger) police officers have of elderly wanderers.
9. KSAR has in the past been reactive but they are trying to be more proactive – going out and giving talks, helping to improve awareness, and they are running a campaign called Safe and Sound (leaflet attached).
10. There are various types of assistive technology, which were not necessarily advocated by KSAR, which could include low-tech options like locks and chains (which themselves could pose a fire or other hazard), alarmed panic bars, behavioural solutions like moving a persons coat and shoes away from

the door (though this does not always work!) or hanging a curtain to obscure the door (which could again pose a hazard or cause confusion in the situation of a fire). There are also pressure sensitive mats to alert carers of a person moving around/out of the house, and these can be linked to Telecare. Door alarms can sound a warning or be linked to text messages to carers. Radio Frequency Identification can be used (such as GPS and 'electronic tags', though wrist-watches and other types of 'device' can be used. Older people's mobile phones are currently being trialled in Kent & Medway and medical jewellery is being trialled in Torbay.

11. There are ethical concerns and some of these measures are considered to be a breach of a person's human rights. They are no substitute for quality care and attention.
12. Statistics show that there is an 8 month lag between first reports of a person wandering, and their being placed in a care home.
13. KSAR consider that the 'way forward' is a more joined-up approach to dementia care with better communication between all the involved organisations.
14. KSAR's Safe and Sound Campaign recommends simple measures (which make a big difference when a person goes missing) including taking a regular head-and-shoulders photo of the cared-for person and keeping a filled in Life History Questionnaire (Penny – Director of the Dementia Services Development Centre, suggested this could be kept in a small container in a fridge in case it is ever needed). These simple measures can save precious time and allow searchers to get out immediately in the event a person goes missing, particularly as speed is of the essence and the likelihood of a person dying is much reduced if they are located in the first 24 hours.
15. KSAR feed statistics (on missing persons) to various, including international databases. ISRID (online) contains data on search and rescue and this has a section on dementia.
16. KSAR, by talking to carers and using 'essential information' are often able to target the places where people who wander are likely to be. Once a person is found, a 'return interview' is carried out and it was stressed that this was often better carried out by a person not seen to be 'in authority'.
17. This talk was part of a series being held at Christ Church University, Dementia Services Development Centre.

## **Dementia Select Committee – Hearing 29<sup>th</sup> March 2011**

### **Simon Bannister (individual interview 2.15 and Panel 3.15)**

#### **Biography**

Simon is Neighbourhood Development Coordinator within the Cultural Services section of Ashford Borough Council. Over the last three years he has been in the very unusual position of straddling public and voluntary sector dementia services. He is Chairman of the Ashford and Shepway Dementia Working Group and in this role has gained a great deal of experience on maximising the role of the voluntary sector. He believes fervently that if we are going to improve services for people with dementia we need to improve the integration of services; increase the role of the voluntary sector to co-design services; mobilise volunteers and communities; facilitate people to establish and run self help groups and mentoring schemes; work with carers, and reduce the stigma sufferers face.

#### **Themes & Questions**

1. Please can you introduce yourself and tell us something of your interest in and current work associated with dementia?
2. Could you please tell us about the Ashford and Shepway Dementia Working Group – what are its aims and objectives and how does the work of this group feed into or have the opportunity to influence other work on dementia in Kent?
3. Could you please elaborate on your statement regarding the integration of services – in your view, how well integrated are services now and what actions should we be taking to ensure that services in the future are co-designed to be person (or family) centred and supportive?
4. Current funding pressures mean that many Voluntary Sector organisations on which people have come to depend are themselves facing uncertain futures while trying to continue providing services and support – given that many have arisen to address unmet need in local areas, how can these local roles and services be protected as future services are commissioned?
5. Can you comment, from your own experience, on how the voluntary sector is or could be more involved in the work of local GP practices in order to contribute to advice and support for people with dementia and their families?
6. In addition to national campaigns to raise awareness about dementia, what in your view can be done locally to both inform, and mobilise communities in order both to reduce stigma (among all age groups) and forge supportive community networks?
7. Carers for people with dementia face multiple challenges – some are reluctant to accept help, under the misconception that this in any way signifies a failure to cope; some are unable to access support for themselves as the person they support does not accept their own situation and is unable to empathise with that of their carer– what advice would you offer to people in this position and what type of interventions or services could help to address these difficult situations?

This page is intentionally left blank

# RIGHT HERE, RIGHT NOW

Taking co-production  
into the mainstream

**David Boyle, Anna Coote,  
Chris Sherwood and Julia Slay**



# EXECUTIVE SUMMARY

People's needs are better met when they are involved in an equal and reciprocal relationship with professionals and others, working together to get things done. This is the underlying principle of co-production – a transformational approach to delivering services – whose time has now come.

For over a year, nef and NESTA have been working together to grow a network of co-production practitioners. We are building a substantial body of knowledge about co-production that offers a powerful critique of the current model of public service delivery and a key to transforming it.

The conventional delivery model does not address underlying problems that lead many to rely on public services and thus carries the seeds of its own demise. These include a tendency to disempower people who are supposed to benefit from services, to create waste by failing to recognise service users' own strengths and assets, and to engender a culture of dependency that stimulates demand. Co-production has the potential to transform public services so that they are better positioned to address these problems and to meet urgent challenges such as public spending cuts, an ageing society, the increasing numbers of those with long-term health conditions and rising public expectations for personalised high quality services.

This is an important time for those of us who have been trying to shape a new conversation along these lines, arguing that the key to reforming public services is to encourage users to design and deliver services in equal partnership with professionals.

The government wants to put more power into the hands of families, groups, networks and local enterprises, to realise its vision of a 'Big Society'. Co-production is central to realising that vision because it offers an effective way of combining the public resources allocated to services with the assets of those who are intended to benefit from them. It promises a new kind of public sector based on relationships rather than departmental

structures. By transforming the way public services are understood and conceptualised, designed and delivered, it promises more resources, better outcomes, reduction of unnecessary waste and diminishing need.

We have a unique opportunity to rethink and reshape the relationship between citizens and the state. If we get it right, then co-production will help rebuild public services as equal and reciprocal partnerships between professionals and the people they serve. If we get it wrong then we may see the post-war welfare state dismantled without sustainable alternatives, while citizens – especially those who are poor and powerless – are left to fend for themselves.

This document is the last of three reports from nef and NESTA. The first report, *The Challenge of Co-production*, published in December 2009, explained what co-production is and why it offers the possibility of more effective and efficient public services. It offered the following definition of co-production:

*“Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.”*

The second report, *Public Services Inside Out*, published in April, described a co-production framework comprising the following key characteristics:

- Recognising people as assets.
- Building on people's existing capabilities.
- Promoting mutuality and reciprocity.
- Developing peer support networks.

- Breaking down barriers between professionals and recipients.
- Facilitating rather than delivering.

Now is the right time to move co-production out of the margins and into the mainstream. This report provides the basis for a better understanding of how to make this happen. We have identified four barriers to mainstreaming, which this report looks to address:

- Commissioning co-production activity.
- Generating evidence of value.
- Taking successful co-production approaches to scale.
- Developing professionals' skills.

Our work has shown that co-production is developing strongly on the periphery of public services, especially in social care and supported housing. It offers transformative solutions not only for these sectors, but also for a range of complex relational services including healthcare, criminal justice, education and welfare to work. Yet the structural and cultural features – and the in-built bias of the incumbent delivery model make it difficult to take it into the mainstream.

This report offers recommendations for the direction of travel, based on what we have learnt so far. They focus on three themes:

- **Changing the way services are managed and delivered:** here we consider how to make it everybody's business by building the key features of co-production into services. We make recommendations about the necessary systems, structures, incentives and workforce skills to mainstream co-production.
- **Changing the way services are commissioned:** we recommend building co-production into the commissioning framework, giving priority to prevention, encouraging flexibility and collaborative working and finally measuring what matters.
- **Opening up new opportunities for co-production:** we want to see prototypes launched in new sectors to test how co-production could be mainstreamed. We also call for the introduction of a 'Co-production Guarantee' to facilitate wider adoption and scaling.

This series of reports does not provide all the answers that we need. NESTA and nef will be embarking on further work to consider how to move co-production into the mainstream. This work will combine practical experiments with policy and research to look at how this can be done. This is the right time to take co-production in to the mainstream so that it becomes the default model for public services.

# CONTENTS

<b>Part 1:</b> The challenge	<b>6</b>
<b>Part 2:</b> New directions	<b>8</b>
<b>Part 3:</b> What co-production means	<b>9</b>
<b>Part 4:</b> Moving co-production into the mainstream	<b>12</b>
<b>Part 5:</b> Recommendations	<b>15</b>
<b>Part 6:</b> The future	<b>20</b>
<b>Endnotes</b>	<b>21</b>

## PART 1: THE CHALLENGE

**C**o-production is an idea whose time has come. The idea, put simply, is that people's needs are better met when they are involved in an equal and reciprocal relationship with professionals and others, working together to get things done. It's a key to transforming public services so that they are more able to meet today's urgent challenges.

The most immediate challenge is the new government's commitment to reducing the current £155 billion deficit by making deep cuts in public spending. Efficiency drives and salami slicing are unlikely to deliver 'more for less'. Instead, there is a danger that the cumulative effects will add to the very social and economic pressures that give rise to demand for more benefits and services. We need to find new ways to improve quality and constrain costs – and here innovation has a critical role to play.

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.<sup>1</sup> The 'have-nots' still find it hard to improve their social and economic circumstances, while the 'haves' accumulate and consolidate their advantages.

These pressures are exacerbated by several factors:

- *Demographic changes.* As people live longer and the post-war baby-boomers come up for retirement, there are rising numbers who are not in paid employment and who run higher risks of chronic ill-health and disability. Research from NESTA shows that costs related to ageing for the public sector will rise to £300 billion by 2025.<sup>2</sup>
- *Changing expectations.* Public attitudes to public services have changed dramatically

over the lifetime of the welfare state – from pride and gratitude in the early years, through decades of routine but not uncritical acceptance, towards an increasingly consumerist stance, with individuals wanting to choose and receive high-quality 'personalised' services.

- *New demands.* Problems associated with patterns of inequality, such as obesity, substance abuse, chronic disease and social conflict, are giving rise to new and intensified claims on public services. New studies suggest that cuts in public expenditure, without the drive for innovation for which this report argues, will hit the poor hardest and widen inequalities, creating a vicious cycle that continues to drive up demand.<sup>3</sup>

While it is impossible to calculate how far existing services have stopped things getting a great deal worse, the current model has tended to disempower people, to induce a dependency culture and to create unnecessary waste in the system because services have been shaped with only minimal recognition of users' assets as well as their needs. For all these reasons, it has not built a healthier, happier, fairer or more secure population, or a more creative or dynamic human economy – let alone a society that is more self-sustaining and less dependent for its well-being on interventions by the state.

The reasons for this are multiple and complex, and have been well explored elsewhere.<sup>4</sup> They include: a bias towards top-down solutions, generating a 'them and us' culture where professionals do things to or for 'vulnerable' and 'needy' individuals; a preference for tackling the immediate problem, not the whole person; a blindness towards the assets and strengths of those on the receiving end of services, and a tendency to see the effects of poverty and inequality as a problem belonging to poor people, to be fixed by their becoming more 'resilient', rather than as a problem for society as a whole, in

need of systemic change.

The lack of progress has also been attributed to: services organised in separate silos with too little sharing of planning and investment; a reluctance to focus on measures that prevent needs arising in the first place; endless chopping and changing in the direction of public sector reform; over-dependence on short-term actions and 'quick wins', a bean-counting approach to assessments of success or failure; an aversion to risks inherent in radical innovation, and an implicit denial of vital links between economic and social systems.

One strong theme running through these problems is at the heart of our interest in co-production. It is the dysfunctional relationship between the state and the people who are supposed to benefit from state-funded services. This has three dimensions. First, there is the perceived and actual distance between 'providers' and 'users', with different meanings, status and values attached to each category – and a strongly implied inequality of worth. Accordingly, providers are supposed to have power, knowledge, skills, and capability to act effectively, while users are assumed to have little or none of the above. Next, there is the often lamentable waste of human capacity by services that are neither designed nor delivered in ways that tap into the abundant and priceless resources that 'users' have at their disposal – both as individuals and as members of groups and networks. Thirdly, and most importantly, the main effect of putting distance between 'providers' and 'users' and neglecting human capacity is to make people weaker rather than stronger, more isolated and divided from each other, more dependent rather than more resourceful, and more at risk of ill-being and distress. This is the very reverse of what we all need our welfare system to achieve: a strong and cohesive society where human resources and inventiveness flourish and grow, where inequalities dwindle and well-being for all steadily improves.

## PART 2: NEW DIRECTIONS

**T**here is broad agreement that we need to transform our welfare system to make it fit for the 21<sup>st</sup> century.<sup>5</sup> This involves fundamentally shifting the purpose and shape of state-funded activities so that they build rather than waste human capacity, while making sure they are economically sustainable in an ice-cold fiscal climate.

The government says it is committed to building a 'Big Society', by getting more people working together to run their own affairs locally. It aims to put more power and responsibility into the hands of families, groups, networks, neighbourhoods and locally based communities, and to generate more community organisers, neighbourhood groups, volunteers, mutuels, co-operatives, charities, social enterprises and small businesses: the idea is that all of these will take more action at a local level, with more freedom to do things the way they want.

There is much that is promising in the vision of a 'Big Society'. When people are given the chance and treated as if they are capable, they tend to find they know what is best for them, and can work out how to fix any problems they have and realise their dreams. Bringing local knowledge based on everyday experience to bear on planning and decision-making usually leads to better results. Evidence shows that when people feel they have control over what happens to them and can take action on their own behalf their physical and mental well-being improves.<sup>6</sup> When individuals and groups get together in their neighbourhoods, get to know each other, work together and help each other, there are usually lasting benefits for everyone involved: networks and groups grow stronger, so that people who belong to them tend to feel less isolated, more secure, more powerful and happier.

This kind of localism also serves the well-established principle of subsidiarity: that matters should be handled by the smallest, lowest or least centralised competent authority. In addition, it may help to constrain costs. Increasing the

volume of unpaid citizen action is certainly intended to help cut public spending. Getting people at local level to take more responsibility and do more to help themselves and their neighbours may become an alternative to action taken by publicly-funded organisations.

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 (outlined below) offers the prospect of substantially improving outcomes for them.

The vision has yet to be tested in practice. It carries some risks that may make it harder to achieve the good intention of getting better results for less money. One is that people who are currently poor and powerless may be less able to benefit from greater opportunities to do things to help themselves and others locally. If we are to make the best of the 'Big Society', all the changes that are put in place to implement its ambitions will need to be shaped and measured by the principles of sustainable social justice – the fair and equitable distribution of social, environmental and economic resources between people, places and generations. Within that framework, co-production should become the standard way of getting things done or – put another way – the 'default model' of public service delivery.

Co-production is central to delivering the 'Big Society' vision because it offers a way of integrating the public resources that are earmarked for services with the private assets of those who are intended to benefit from services. There is far more to be gained from this approach than from current practice that separates 'users' from 'providers', or from a retrenchment of the state that leaves citizens themselves to fill the gap.

## PART 3:

# WHAT CO-PRODUCTION MEANS

*“Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.”*

This is our working definition. It describes a particular way of getting things done, where the people who are currently described as ‘providers’ and ‘users’ work together, pooling different kinds of knowledge and skill. By changing the way we think about and act upon ‘needs’ and ‘services’, this approach promises more resources, better outcomes and a diminishing volume of need. It is as relevant to third sector bodies as to government institutions and public authorities. Applied across the board and properly supported, it can help to realise the best ambitions of the ‘Big Society’.

In this context, co-production is broadly about equal partnership and transformation, and specifically about changing the way public services are conceptualised, designed and delivered. At the same time, we know it is important not to define co-production so tightly that it inhibits innovation and creativity. So we have homed in on a set of defining characteristics. Co-production can be achieved through a myriad of activities, processes and tools, but it is normally possible to recognise co-production because it exhibits most or all of these features:

- **Recognising people as assets:** transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services.
- **Building on people’s existing capabilities:** altering the delivery model of public services from a deficit approach to one that provides opportunities to recognise and grow people’s capabilities and actively support them to put these to use with individuals and communities.

- **Mutuality and reciprocity:** offering people a range of incentives to engage, which enable us to work in reciprocal relationships with professionals and with each other, where there are mutual responsibilities and expectations.
- **Peer support networks:** engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change.
- **Blurring distinctions:** blurring the distinction between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.
- **Facilitating rather than delivering:** enabling public service agencies to become catalysts and facilitators of change rather than central providers of services themselves.

These defining features are what give co-production its transformative approach. It moves far beyond ‘citizen engagement’ or service user involvement in governance. It changes people from being ‘voices’ to being agents in the design and delivery of public services. The radically different nature of co-production is often best illustrated through examples that show just how different it is, and how it generates better outcomes and lower costs. We have documented a definition and a range of examples and analysis of co-production in *The Challenge of Co-production* and *Public Services Inside Out*. Further examples are provided below:

### Local Area Co-ordination, Australia

Local Area Co-ordination (LAC) is a model developed in Australia that puts people at the centre of things. It employs a local area co-ordinator linked to between 50 and 60 individuals with disabilities. Instead of starting with the question ‘what do you need?’ – which

focuses thinking on specialist services – the co-ordinator asks ‘what kind of life do you want to live?’ The answers to this question are more often about friendships, a job, living independently: things that we value universally. Co-ordinators work with each individual to identify existing local networks and resources, such as a church group, library or local timebank, and introduces them to other people, integrating them into existing local networks rather than allocating them to a specialist group according to their condition. Funding and support is devolved to individuals and attention is paid to maintaining existing support networks, such as the family, friends and neighbours. The result has been a complete shift away from residential care or ‘drop in’ centres. Evaluations of the LAC service in Australia have demonstrated a 30 per cent reduction in costs as part of a move towards a preventative service with much lower levels of acute interventions and much higher levels of participation and enthusiasm from the people who use the service.<sup>7,8</sup>

### **Holy Cross Centre Trust (HCCT)**

Holy Cross Centre Trust is a pioneering service delivering mental health day services on behalf of Camden Council. Through a range of programs and activities they build on the skills and capabilities of their members, facilitate peer support between members, and focus on extending their social networks, and confidence to work and get involved in the local community. Time-banking is used at Holy Cross as an innovative way of encouraging and rewarding contributions from both staff (who spend at least 10 per cent of their time each week in the time-bank) and members. The time-bank has helped to blur the boundaries between staff and members, and has helped to make HCCT’s services more about facilitation than providing, with staff and members having equal roles in ‘delivering’ the services and moving towards the outcomes they want to achieve.

### **Skillnet**

Skillnet is a Community Interest Company

based in Kent. It was co-founded by Jo Kidd, her husband, and a group of people with learning difficulties. Their aim is to support people so that they can make independent choices about their lives, working together with staff to develop projects and support networks that build on people’s interests, skills and capabilities. Their programmes and projects are directed by the individuals they support. One project, Risky Business, is an arts and drama group held every Friday morning in Sittingbourne. There are three members of staff, including one who has a learning disability (some 30 per cent of Skillnet’s employees have disabilities themselves), and around 12 group members who attend every week. Everyone at Risky Business is eager and excited about developing their skills, looking for paid employment in a ‘normal’ job, living independently, socialising with one another and being able to be seen as people, not service users, clients or residents. Skillnet actively supports these wishes, yet still faces an uphill battle with other organisations and local authorities who are concerned about risks to ‘vulnerable people’ and ‘crossing professional boundaries’.

### **Nurse Family Partnerships**

Nurse Family Partnerships have demonstrated significant savings across a range of services, and inspiring improvements in outcomes. They were initially rolled out in the United States as a preventative programme, pairing up nurses with first-time mothers in low income, high-risk groups. The nurses develop a strong relationship with the mothers, providing support and coaching on a range of issues, from feeding, nutrition and literacy to sexual health, employment and safety. The approach often includes peer support and building on the mother’s individual skills and capabilities. The outcomes achieved include improved prenatal health, fewer incidents of child abuse, improved self sufficiency and increased economic activity, higher rates of literacy, lower rates of obesity, and fewer interactions with the criminal justice system. The US programme has seen a decrease in child arrests by 59 per cent, a 48 per cent reduction in child abuse and neglect, and a 67 per cent reduction of behavioural difficulties at age six.<sup>9</sup>

Financially, each \$1 invested in the programme provides savings of between \$2.50 and \$5.70 in preventative costs across criminal justice, education, welfare and health. Once the costs of the programme are covered, the benefits per child are estimated at \$17,180. The preventative cost savings associated with the parents include a 20 per cent reduction in months on welfare and an 83 per cent increase in employment for the mother by the child's fourth birthday.

services that relieve the pressure on more costly acute and specialist interventions.

In summary, this is what co-production can offer to a welfare system in acute crisis: by transforming the way public services are understood and conceptualised, designed and delivered, it promises more resources, better outcomes and a diminishing volume of need. That's why now is the right time to move co-production out of the margins and into the mainstream.

#### Positive effects of co-production:

- Co-production taps into priceless human resources – all the knowledge, time and skills, all the loving, caring and reciprocal relationships – that are present in everyone's everyday lives. These human assets make up a much bigger pool of shared resources than can be provided through taxation, for meeting needs that people can't meet on their own: so there is abundance instead of scarcity.
- By bringing people out of service silos and isolation, and by encouraging individuals to join forces and make common cause with each other, co-production helps to break down barriers between different kinds of people and build stronger networks and groups.
- It also helps to build up everyone's capacity, including 'providers' and 'users', both individually and in groups, to help themselves and each other, so that the resource base can keep on growing.
- It brings into play the direct wisdom and experience that people have about what they need, how their needs can be met and what they can do with and for others. When these are combined with professional expertise, there are likely to be better outcomes.
- It minimises waste by developing solutions with users rather than doing things 'to' and 'for' them. For all these reasons, co-production helps to improve well-being and prevent needs arising, so that moving it into the mainstream would mean that the inflation in demand for public services that has prevailed since the 1940s can begin to subside.
- In addition, it can often reduce the costs of a service by shifting the focus towards person-led, community-involved, preventative

## PART 4: MOVING CO-PRODUCTION INTO THE MAINSTREAM

**M**oving co-production into the mainstream really can – if handled with care – provide a new model of public service delivery, which can achieve better outcomes and save money. It can break through the stultifying ‘doing-to’ culture of mainstream public services that saps power and confidence from the people they are trying to help and leaves the ‘providers’ under increasing pressure to deal with a growing volume of demand. It can replace this negative effect with a range of positive, mutually reinforcing effects. That means identifying and addressing the main challenges and creating the necessary conditions for taking co-production to scale.

### The main challenges

For over a year, NESTA and nef have grown and supported a network of co-production practitioners – alongside an advisory group of co-production thought-leaders and policymakers – who have helped us to identify the key barriers to taking co-production forward. We have identified four main challenges, where further work is needed to open the way for co-production to move into the mainstream. These are explored in more detail in our earlier publication, *Public Services Inside Out*, and are briefly summarised below.

- **Commissioning co-production activity**

Co-production can be awkward for funders and commissioners, who tend to look for specific objectives and pre-determined outputs generated from a narrow range of anticipated activities and measured by a limited set of indicators.<sup>10</sup> Co-production looks much messier than this, often encompassing a broad range of activities that continue to evolve as relationships develop between professionals and people using services. The indicators of success are found in broader outcomes and longer-term changes that

often fall across multiple funding streams and are not always easy to measure with current methods (see below). Failure to encompass what is new and innovative will hold back the development of co-production. NESTA and nef will be working with commissioners to find ways of opening up to new ideas and becoming less risk averse, focusing their efforts on outcomes rather than just outputs.

- **Generating evidence of value**

Co-produced services can incur costs in one service area and yet produce benefits in many others, which can act as a disincentive to commissioners. Their effects are often long-term and complex, making them relatively difficult to assess and measure. There are many important examples of co-production that have been evaluated, demonstrating multiple benefits, including prevention of harm and cost efficiencies. Most are drawn from other countries, notably the United States. NESTA and nef will be working together to develop an evaluation framework and a range of tools for more comprehensive evidence gathering, reviewing and building on existing approaches to develop an appropriate model. This should be able to capture the immediate and longer-term, direct and indirect, costs and benefits of co-production, which can then be related – critically – to conventional systems for evaluating public services. We will also work to find ways for services to capture the value delivered by co-production within existing measurement and accounting systems, even where benefits accrue to a different service.

- **Taking successful co-production to scale**

Taking co-production into the mainstream is made much harder because of the in-built bias in public services to the incumbent delivery model. The work of NESTA and nef over the past year has shown that co-production is a promising new and emerging field of practice.

It is developing strongly on the periphery of public services and is slowly seeping into mainstream services because of pioneers such as Sam Hopley at Holy Cross Centre Trust. This model can be challenging for practitioners because of the lack of detailed guidance and diverse interpretations of the term 'co-production'. The aim is to get smarter at drawing down and sharing lessons from individual projects, to find ways of replicating the key features of co-production, and to improve the conditions for scaling. NESTA and nef are working with our practitioners' network and with policymakers and commissioners to take this forward.

- **Developing professional skills**

Co-production practitioners require a particular mix of skills. These include being able to see and harness the assets that people have, to make room for people to develop for themselves, and to use a wide variety of methods for working with people rather than processing them. They suggest a significant shift away from a culture of 'caring for' to a culture of enabling and facilitating, but the skill-set must also be able to change systems and operate on a large scale. And, while professional expertise is vital, it can never replace the knowledge that comes from personal experience. Real change comes from combining both these sources of knowledge. NESTA and nef will be working with partner organisations to build the skills that will be necessary, both for the transition into the mainstream and for making co-production work as the default model of service delivery.

People who are already disempowered and disadvantaged have most to gain from co-production. The experience of the practitioners within our network has shown that this approach can help to strengthen relationships between individuals, families, neighbours and communities. Government, nationally and locally, can play a vital role in ensuring that those who are the poorest and most marginalised can participate on an equal footing with everyone else. This is important because failing to tackle inequalities will undermine all attempts to build a flourishing economy and society, and all efforts to bring spending on public services under control.

Co-production is not an alternative to public service but a way of transforming it and making it effective, affordable and sustainable. To make sure that effective support is provided for all and for the long term, there will need to be profound

changes in the way that people who work in public services – at all levels – understand their roles and carry them out. At the heart of the co-production idea is a new kind of partnership between public service workers and those who are intended to benefit. That partnership is equal and reciprocal. It combines and strengthens different kinds of knowledge and skill. It aims to build capacity for people to help themselves and each other. That goes for public service workers too: building their capacity to get better outcomes even while service budgets are shrinking. The ultimate goal is to improve well-being for all.

In the right conditions, co-production can become a way of breaking down social divisions, creating new connections between different groups and improving the resourcefulness and well-being for all, especially those who are less well-off and more in need. It can become a creative and dynamic alternative to salami-slicing services and leaving 'communities' to fend for themselves. As the government moves to realise its vision of the 'Big Society', using co-production as a central mechanism for shaping relationships, making decisions and getting things done, can help to bring out the strengths of this idea, fill in the gaps and give it lasting coherence.

### Where is the greatest potential?

NESTA and nef are working with a network of frontline practitioners who are already involved in co-production. This has enabled us to identify areas with immediate potential for this kind of change. These are:

- Adult social care and elderly care.
- Healthcare.
- Mental health services.
- Supported housing.
- Criminal Justice and community policing.
- Education, early years, youth services, childcare and families.
- Welfare to work.
- Regeneration.

These services are all highly relational, and involve frequent contact between people and professionals. In order to achieve their desired outcomes they all need to harness and build the capacity, skills and abilities of the people who are 'users'. Any sustainable outcome depends on the nature of the relationship between 'users' and professionals, and the extent to which they co-produce both the strategies for meeting challenges that face individuals, and the processes by which those strategies are realised. Some areas of public sector activity seem to be less suited to co-production. Obvious examples are emergency healthcare and acute interventions such as surgery. Beyond that, any area where the public sector meets individuals, networks or local groups has scope to shift the relationship towards one of equal partnership.

What is clear from our work to date on co-production is that there can be no exact guidance, toolkits or 'how-to' manuals for co-production. The examples we have observed are highly relational and have been designed to account for many local factors. What is clear from these examples, however, is that there is a robust framework for co-production based on the six key features that we have described in this publication and in our earlier work. This framework offers the opportunity for local adaptation by practitioners and citizens who can design ways of working that reflect these features, and so drive a cycle of innovation.

## PART 5: RECOMMENDATIONS

**H**ere, we offer suggestions for the direction of travel, based on what we have learned so far. Our aim is to transform public services by moving co-production into the mainstream. We want these recommendations to help achieve systemic change through further practical experimentation and a wide-ranging dialogue about how to establish co-production as the standard way of getting things done. Our recommendations fall under three main themes:

- Changing the way services are managed and delivered.
- Changing the way services are commissioned.
- Opening up new opportunities.

### Changing the way services are managed and delivered

#### 1. Build the key features of co-production into existing services

As a first step, public service managers can consider the key features of co-production, set out on page 5, and begin to build them into existing services. You don't have to call what you are doing 'co-production', but you can start by encouraging staff to recognise that service 'users' have assets not just problems, and to think about what they can contribute. Other possibilities include:

- Developing peer and support networks for groups of service 'users'.
- Asset mapping to identify resources at neighbourhood level, where spare capacity can be harnessed and opened up to other people and organisations to be linked up to each other.

- More extensive use of tools that facilitate self-help and mutual aid, linked into the local community in order to achieve maximum benefit. One example is time-banking.

#### 2. Change the systems and structures that underpin public services

For co-production to become the default model of service delivery, it will not be enough to change existing policies and procedures by adding in the words 'co-production' and 'co-design'. The underlying systems and structures must change. This will involve, for example:

- Re-evaluating who is involved in the delivery of public services, and working with those who use services to carve out a new role for them.
- Amending policies and processes to take account of the enhanced role of user/participants; these must be flexible enough for organisations to co-create projects with them as equal partners. This will almost certainly require a review of how risks are understood and managed.
- Build on initiatives such as Total Place and consider how the services cross over in practice, supporting different groups of people, and how they can become more holistic.
- Change the way co-production is measured to enable the value to be captured in measurement and accounting systems even where it crosses service silos.
- Stop doing what isn't needed, reducing unnecessary waste.
- A systematic study of the barriers to co-production that occur in different sectors and at different stages of development, a thorough analysis of how far each one is

justified, and a good understanding of they can be lowered or removed altogether.

### 3. Make it everybody's business

Avoid the danger of establishing a new cohort of 'Co-production Officers' and 'Co-production Champions' and instead get everyone involved, so that they all feel they own the idea and resources are focused on developing co-production, not on creating new posts or rearranging internal structures. We want to develop a new kind of public service professional (see below) but if the idea is to be mainstreamed, it must happen everywhere, not just in corners reserved for 'co-production' experiments. Throughout the system, lessons from co-production can be shared by role models, mentors or 'experts by experience', who learned how to do it through active participation. Initiatives such as participatory budgeting could also be expanded into mainstream services.

### 4. Shift the role of frontline staff

Co-production requires a major shift in the way professionals and other frontline staff work and are organised. The aim is to enable them to become partners, mentors, facilitators and catalysts, not just 'fixers' of problems and guardians of resources. This will not end their traditional role – people still need direct professional help as well – but it will represent a whole new direction for staff and services. It implies:

- New criteria and methods for recruiting frontline staff, for example, to seek out those who instinctively respect others, who are good at forming equal relationships, and who have a talent for motivating people.
- Radical changes to the way frontline staff are trained, so that they learn about the values and skills of co-production. This training should be integral to core in-service curricula and professional qualifications as well as training for new entrants such as nurses and teachers.
- Radical changes to incentives for frontline staff and new criteria for performance management.
- More power and autonomy devolved to the frontline.

- Frontline roles restructured to give staff time to make reciprocal relationships work well (for example, staff working in Nurse-Family partnerships deal with 25 families at a time).
- Recognition for those who put co-production values and skills into practice, with special accreditation not only for staff but for their lay partners in co-production.

### 5. Get the best out of 'personalised' services

Personalisation is a good idea in theory, but in practice, especially where it applies to elderly or disabled people holding individual budgets, it can make service 'users' worse off, with fewer choices, than before.<sup>8</sup> The pioneering charity In Control has been experimenting with projects to link up local recipients of personal budgets into networks of broader mutual support. This kind of adaptation enables personal budget holders to co-produce the services they need, making their resources go further by pooling them (including budgets) with others and getting better results all round.<sup>11</sup>

### 6. Put the right incentives in place

Co-production is all about reciprocity – giving something, and getting something back. To encourage people to participate, some co-production programmes have reserved part of their resources to reward people for taking part, perhaps most obviously in the time-banking model pioneered in the South Wales Valleys.<sup>12</sup> This kind of pay-back could become a normal component of many more services as they move towards co-production. Rewards should probably not, normally at least, be financial – they are a mark of thanks not a motivator. Possible examples include:

- Working with private and public sector organisations to offer, for example, discounted matinee performance tickets at the cinema or free off-peak swimming at local pools.
- The development and roll out of community dividends so that when communities are involved in co-producing services that result in lower costs, a proportion of the savings go back into the community so they can decide where it would be best spent.
- Incentives will need to include

encouragement for organisations to invest more widely in prevention. We therefore need to explore the feasibility of new financial instruments that can draw forward the potential savings from co-production projects, and to invest this money to make the savings possible. Social impact bonds may be one way forward, but there are other approaches which would also provide investors with a return, perhaps based on social versions of the Energy Savings Companies (ESCOs) which invest in future energy saving or the KIVA model that connects individual investors with social innovators.<sup>13</sup>

## Changing the way services are commissioned

### 7. Build co-production into the commissioning framework

When services are commissioned, bidders need to be asked to explain how they will build in the essential features of co-production, how beneficiaries will be helping to deliver services, how their bid will build mutual support and how it will prevent problems in the future. Bids will be assigned accordingly with these commitments embedded in service contracts so that these can be assessed along similar lines. Services should be commissioned and managed around their outcomes rather than outputs.

The **London Borough of Camden** has already been experimenting with this approach, asking bidders for a contract to provide mental health day care services to set out explicitly what role they would envisage for service users, how they would identify and mobilise service users' strengths, and how they would measure and reward the contribution of service users, carers, family, peer group, neighbours and the wider community.

The experiment has been part of a wider attempt to shift commissioning from narrow deliverables to broader outcomes in Camden. Treasury commissioning rules positively encourage commissioners to look at outcomes more broadly, and this can include co-production.

### 8. Give priority to prevention

Higher priority must be given, for reasons discussed above, to commissioning services and other activities that help to prevent needs arising or intensifying. Ultimately, this is what commissioning for outcomes should be all about: finding ways, as far as possible, to keep people free from harm and living healthy, satisfying and self-sufficient lives, instead of fixing things when they go wrong. In many respects, co-production is a preventative measure. If prevention becomes a guiding principle for commissioners, against which their performance will be judged, it will add to the incentives to co-produce services.

### 9. Encourage flexibility and collaborative working

When service 'users' are engaged in co-producing what they need to live well, get well and stay well, they do so as whole people, not as sites of multiple disconnected problems. So in developing co-production within public services, there is a strong bias against departmental silos, separate budgets and rigid procedures. Co-production can broaden and deepen the range of possible activities, and begin to stitch them together locally – but this can only happen where service commissioners as well as local managers and public service budgets are sufficiently flexible. People's problems are no respecters of departmental boundaries and are better tackled together.

Services must do more to combine their respective resources and work closely with the individuals and/or groups concerned to co-produce single outcomes and solutions, generated through that partnership. A big hurdle in the way of making co-production mainstream is that the benefits of investment in co-production don't always fall in the same budget. They tend to accrue to a range of different public service budgets locally. More flexibility is badly needed to encourage managers to invest in co-production. This can be done through:

- Identifying areas where services cross over and support the same people in different areas: pooling resources and budgets in these areas and replacing the multiple contact points with a single point of support – a person who can support and co-produce a 'whole life' solution with people.

- Develop a framework which can capture the savings accrued across different service provisions and begin to use this in informing budget decisions.
- Invest in programmes, such as Nurse Family Partnerships, which have preventative effects across a wide range of services.

More flexibility, collaborative working and pooling of budgets will not only help to develop co-production, but also help to reduce costs by minimising duplication, streamlining management and delivery systems and reducing demands over the medium and long term.

## 10. Measure what matters

The way public services are currently measured by narrow output targets within an increasingly risk-averse culture has limited opportunities for co-production. Co-production needs its own, more appropriate, measures of success.

The way services are evaluated should be reformed to take better account of innovation and broader outcome measures. Indicators of success should be generated through co-production partnerships and based on the outcomes that ‘users’ want to achieve. This may be a more labour-intensive approach, but the evidence is that – by being more effective – it will in fact save money.

In addition, service organisations should be able to measure easily, and for themselves, how and how far they are engaging their beneficiaries as equal partners in the delivery of services. This requires:

- Developing and applying co-production audits to services to help professionals and other participants identify where they are already working in partnership, and where they can further shift towards co-production.
- Including wellbeing, and environmental and social outcomes, in evaluation frameworks (this ties into our recommendations on commissioning services) so that the true benefits and costs are accounted for.
- Make sure that the effects of reciprocity (such as hours exchanged) and network-building are embedded in the evaluation frameworks

for all services where they may add value.

## Opening up more opportunities

### 11. Launch more prototypes in new sectors

Co-production has been tested most extensively in the fields of social care and housing. But there is also plenty of experience in the UK and elsewhere to suggest that it can also work well in other sectors such as education, criminal justice, youth services and healthcare. What is urgently required is a programme to develop and test prototypes in a wide range of areas. There is a fast-growing interest among local authorities, primary care trusts and other public service organisations who want to improve outcomes and constrain costs, and see this as way of achieving both objectives. Part of this prototyping activity should focus on learning how to replicate and scale co-production more effectively, as well as developing a better understanding of the conditions that would enable this to happen. NESTA and nef are working to encourage more prototypes, to learn from them and spread knowledge and practice across the country.

### 12. Embed co-production as the ‘default’ model through a ‘Co-production Guarantee’

If we want co-production to become the ‘default’ model of service delivery, the time should come when it is formally acknowledged and established as such. Until now, people who want to introduce co-production often find they have a battle on their hands to argue the case for doing things differently. When the idea is more widely understood, when commissioners begin to promote co-production as a matter of course, and when it has been tried and tested by a wider range of practitioners, the onus should shift so that people who don’t want to co-produce are the ones who have to argue their case. We propose examining the feasibility of a Co-production Guarantee, which sets out the government’s commitment to this approach and clearly states where it can appropriately be applied. This guarantee would grant official sanction to services to use co-production and embed it in their own operations. Its purpose would be to encourage regulators and local authorities to allow co-production to take place on a much

wider scale. It would provide an official stamp of approval, with reasonable safeguards, and so help to establish co-production as the standard way of getting things done. This would give substance to the Prime Minister's description of his programme for government as "an invitation to the whole nation: we'll give you the power, so you can take control".<sup>14</sup> The Guarantee could be invoked when people who want to co-produce find that their efforts are unreasonably thwarted. Providers and budget-holders who resist efforts by others to introduce co-production would be called upon to justify their objections.

## PART 6: THE FUTURE

In spite of recent efforts to introduce ‘choice’ and ‘personalisation’, the dominant post-war model of public service delivery has prevailed: a top-down, ‘doing-to’ culture with an undifferentiated approach, a narrow kind of efficiency and too little value attached to human interaction. Co-produced services assume a quite different model: it is human, local and diverse. And it must remain so if it is to continue to be effective.

What co-production means in practice is a huge and unprecedented mobilisation of unpaid participation by public service users, their families and their neighbours. It means a massive increase, not so much in volunteering – because it will be outside the conventional volunteering infrastructure – but of mutual support and activity organised through the public sector, so that every school, surgery, hospital or housing estate becomes, as part of its fundamental purpose, a hub of increasing local action. It is about building human resources and minimising waste. In practice, co-production is an answer to the question of how to mobilise civil society: using the public services infrastructure. But this will only happen if co-production ceases to be a matter for marginal experimentation and becomes the standard way of getting things done.

To reach that point effectively, we have to be able to imagine in some detail what public services will look like afterwards, when the main job of the public sector is not just to provide help and support to people who need it, but to engage people directly in deciding how they want to lead their lives and to embed them in mutual networks for continuing and reciprocal support.

This does not mean an end to state services. Quite the reverse, as they have a crucial role to play in making sure that opportunities to co-produce are genuinely sustainable and available to all. But it means an end to the language of ‘services’, and a re-organisation of public resources and professional skills as nodes of multiple networks and social catalysts, able to reach out into the

surrounding neighbourhood with a specific objective of preventing needs arising wherever possible. It means more effective meshing of different kinds of service, which will make them much more personal and local. It will also release resources for intense professional attention where that is necessary, and at a much earlier stage.

This is a new kind of public sector, with complex relationships rather than complex metrics at its heart. It is one that will require substantial training and, in the future, more investment and development to bring services together. It will require different kinds of skills, different kinds of buildings and different kinds of systems. Investment will be justified because of the revolution in efficiency that it will bring about. The basic resources are already in place. They are largely overlooked, underestimated and untapped: the multitude of clients, patients and ‘users’ of public services, and their families and neighbours, and all the human assets and relationships they have at their disposal. As we enter a period when public resources seem to be increasingly scarce, it is time to acknowledge that these are both priceless and abundant.

# ENDNOTES

1. Marmot, M. (2010) 'Fair Society, Healthier Lives: the Marmot Review Final Report.' London: Department of Health.
2. Harris, M. (2009) 'Preparing for Ageing.' London: NESTA.
3. Stuckler, D., Basu, S. and McKee, M. (2010) Budget crises, health and social welfare programmes. 'British Medical Journal.' 340:c3311. Available at: [http://www.bmj.com/cgi/content/full/340/jun24\\_1/c3311](http://www.bmj.com/cgi/content/full/340/jun24_1/c3311); also Asthana, A. (2010) George Osborne's budget cuts will hit Britain's poorest families six times harder than the richest. In 'The Observer.' 27 June 2010. Available at: <http://www.guardian.co.uk/uk/2010/jun/27/osborne-budget-cuts-hit-poorest>
4. One example is the recent series of publications from the 2020 Public Services Trust looking at the need to transform the future of Public Services. <http://www.2020publicservicestrust.org/publications/>
5. One example is the recent series of publications from the 2020 Public Services Trust looking at the need to transform the future of Public Services. See <http://www.2020publicservicestrust.org/publications/>
6. Review of the evidence on volunteering impact, in Swinson, J.L. (2006) Focusing on the health benefits of volunteering as a recruitment strategy. 'International Journal of Volunteer Administration.' Vol. 24, No 2, October; for evidence on time-banks and well-being, see Harris, T. and Craig, T. (2004) 'Evaluation of the Rushey Green Time Bank: Final Report to the King's Fund.' London: Socio-medical Research Group, St Thomas' Hospital.
7. See The Value for Money Review of LAC in Australia. Available at: [http://www.disability.wa.gov.au/dscwr/\\_assets/main/report/documents/pdf/final\\_report\\_lac\\_review1\\_\(id\\_369\\_ver\\_1.0.2\).pdf](http://www.disability.wa.gov.au/dscwr/_assets/main/report/documents/pdf/final_report_lac_review1_(id_369_ver_1.0.2).pdf)
8. See for example the evidence on Local Area Co-ordination: Government of Western Australia (2003), Review of the Local Area Co-ordination Program, Perth.
9. See <http://www.nursefamilypartnership.org>
10. Neitzert, E. and Ryan-Collins, J. (2009) 'A Better Return.' London, Cabinet Office.
11. Boyle, D. (2008) Assets that can't be bought. 'The Guardian.' 16 July.
12. See [www.timebankingwales.org.uk](http://www.timebankingwales.org.uk)
13. For the KIVA model, see: <http://www.kiva.org/>
14. David Cameron, launch of the Conservative Election Manifesto, 13 April 2010.

## **THE LAB AND CO-PRODUCTION**

Our public services face unprecedented challenges, made more urgent by the impact of the current economic crisis. Traditional approaches to public services reform are unlikely to provide the answers we need.

NESTA is applying its expertise to find innovative ways of delivering our public services. More effective solutions at cheaper cost will only come through ingenuity. Our Public Services Lab is trialing some of the most innovative solutions and bringing them to scale across the country's public services.

Co-production is a new vision for public services which offers a better way to respond to the challenges we face – based on recognising the resources that citizens already have and delivering services alongside their users, their families and their neighbours in partnership with the public. Early evidence suggests that it is an effective way to deliver better outcomes, often for less money.

This paper is the third publication from a major project between the Lab and nef (the new economics foundation) to increase the understanding of co-production and how it can be applied to public services. We have established a network of pioneering frontline workers from across the UK who are using co-production to engage citizens and improve services, and will use these insights and evidence to promote a more positive environment for co-production in our public services and in policymaking.

### **nef (the new economics foundation)**

nef is an independent think-and-do tank that inspires and demonstrates real economic well-being. We aim to improve quality of life by promoting innovative solutions that challenge mainstream thinking on economic, environmental and social issues. We work in partnership and put people and the planet first.

**[www.neweconomics.org](http://www.neweconomics.org)**





**NESTA**

1 Plough Place London EC4A 1DE  
research@nesta.org.uk

[www.nesta.org.uk](http://www.nesta.org.uk)

Published: July 2010



## **Dementia Select Committee – Hearing 29<sup>th</sup> March 2011**

### **Panel (Equalities theme):**

Simon Bannister, Ashford Borough Council  
Shaminder Bedi, KASS - Guru Nanak & Milan Day Centres  
Christine Locke, Diversity House,  
Roger Newman, East Kent Independent Dementia Support (EKIDS)  
Viniti Seabrooke, Alzheimer's and Dementia Support Services (ADSS)  
Rock Sturt, Alzheimer's and Dementia Support Services (ADSS)

### **Biographies**

#### **Simon Bannister**

Simon is Neighbourhood Development Coordinator within the Cultural Services section of Ashford Borough Council. Over the last three years he has been in the very unusual position of straddling public and voluntary sector dementia services. He is Chairman of the Ashford and Shepway Dementia Working Group and in this role has gained a great deal of experience on maximising the role of the voluntary sector.

He believes fervently that if we are going to improve services for people with dementia we need to improve the integration of services; increase the role of the voluntary sector to co-design services; mobilise volunteers and communities; facilitate people to establish and run self help groups and mentoring schemes; work with carers, and reduce the stigma sufferers face.

#### **Shaminder Bedi, MBE**

Shammi works for Kent Adult Social Services and manages 2 Day Centres for Asian older people - Guru Nanak Day Centre, Gravesend and Milan Day Centre, Dartford. His other voluntary involvements include being a former chair of Gravesham Police Community Liaison Group; he is a member of the Asian Welfare Society; supports a local carers association and helped formed the Gravesend International Club. Shammi received an MBE in 2005.

#### **Christine Locke**

Christine Locke is the Founder and Project Lead of Diversity House based in Sittingbourne, Kent which opened in March 2007.

Christine holds degrees in Modern languages, Addictive Behaviour, Community Cohesion Management and Community Care Practice. She is currently studying for a Masters MSc in Public Health. She is passionate about equality and diversity and works with many local organisations and minority groups to raise awareness amongst various groups. She strives to promote diversity and community cohesion especially within our local area.

## **Roger Newman, MBE**

Roger Newman is a 69 year old retired teacher from Margate. As a result of caring for his partner, David, who had dementia, he co-founded the LGBT Support Group of the Alzheimer's Society.

He is heavily involved locally with supporting carers of those with dementia and is a co-founder of 'East Kent Independent Dementia Support' (EKIDS).

He contributed to the books 'Telling Tales about Dementia' and 'Changing Minds' and is the subject of the film 'Roger's Story' made by SCIE. He writes and speaks on the subject of the needs of older LGBT's and represents that issue on two committees of AgeUK. In 2007 he was awarded the MBE for charitable services.

## **Dr. Viniti Seabrooke**

Viniti is Project Manager for a 5 year Early Intervention Project at the Alzheimer's & Dementia Support Services (ADSS) in North West Kent. She has been working with ADSS since 2002 and began by researching the dementia-related needs of the Black and Minority Ethnic (BME) communities. Since then she has focused on raising awareness of dementia among the BME communities and developing multicultural services to meet these needs.

In 2007 Viniti led a pilot collaborative project with colleagues in Health, Social Services, GP practices and the University of Kent, to raise awareness of the need for the early diagnosis of dementia among BME patients. Alongside her current role, she continues to oversee the development of services for BME communities in N.W Kent. Viniti has worked in mental health and dementia since 1997 and is now committed to ensuring that dementia services are responsive to the needs of individuals, including those from the BME communities.

Born in India and educated in the UK, she graduated in pharmacology from London University in 1976 and gained her doctorate from the University of Aberdeen in 1983. In the early stages of her career she worked as a medical research scientist in various fields, including cardiovascular and central nervous system pharmacology.

## **Rock Sturt**

Rock works for Alzheimer's & Dementia Support Services as the BME Service Development Officer in Dartford, Gravesham and Swanley.

Rock's remit includes making presentations on dementia awareness and he is ADSS' main contact for referrals. His aim is to enable people from BME communities to access relevant services and also to signpost carers to finances and facilities that may be available to support them.

Another part of his role consists of networking with other statutory and voluntary agencies in order to develop multicultural services and improve BME uptake of dementia services.

He has a consultative role in West Kent and recently has been tasked with promoting the 24 hour Kent and Medway Dementia helpline.

## **Panel - Themes & Questions**

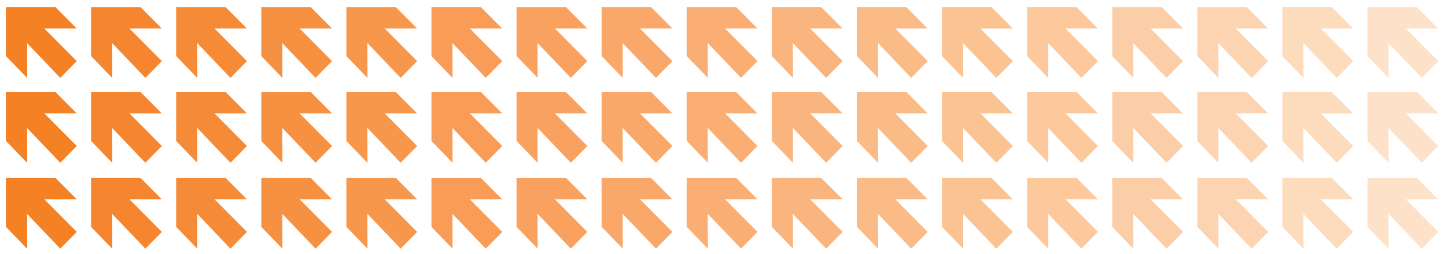
1. How well are the cultural needs of ethnic minorities understood and provided for within the range of services and support for people with dementia and their carers? What cultural and social difficulties arise when helping people with dementia from different communities?
2. How should Health and Social Care Services be finding out about the particular needs of people with dementia and carers from different communities?
3. Are any particular groups of people less likely to obtain an early diagnosis of dementia, what are the reasons for this and what is being, or should be done to address this?
4. What are the issues affecting people with learning difficulties that go on to develop a dementia?
5. Where and how, in your view, should people be able to access information about dementia, and caring for a person with dementia – how can any imbalance of information provision across the County be addressed and how can equal access to information that is sensitive to cultural, sexual or other differences be assured?
6. What groups of people might suffer additional stigma for cultural/other reasons and how could this be addressed?
7. What can be learnt from diverse communities elsewhere about the care and support of people with dementia and their carers?

This page is intentionally left blank



# EQUALITY ACT 2010: WHAT DO I NEED TO KNOW AS A CARER?





## Foreword

The Equality Act 2010 replaces the existing anti-discrimination laws with a single Act. It simplifies the law, removing inconsistencies and making it easier for people to understand and comply with. It also strengthens the law in important ways to help tackle discrimination and inequality.

This quick-start guide is intended to help carers understand how the new law coming into effect in October 2010 can help them. Carers are people who care, unpaid, for others who are elderly or disabled.

## Introduction

The Equality Act 2010 is a new law aimed at stopping discrimination and helping to encourage equality. It could help you if you care for someone who is elderly or disabled; this quick-start guide uses the word 'carer' to mean a person with these sorts of responsibilities.

Most of the Equality Act will start to apply in October 2010. The Government is looking at how the rest of the Act can be implemented in the best way for business. It will make an announcement about this at a later stage.

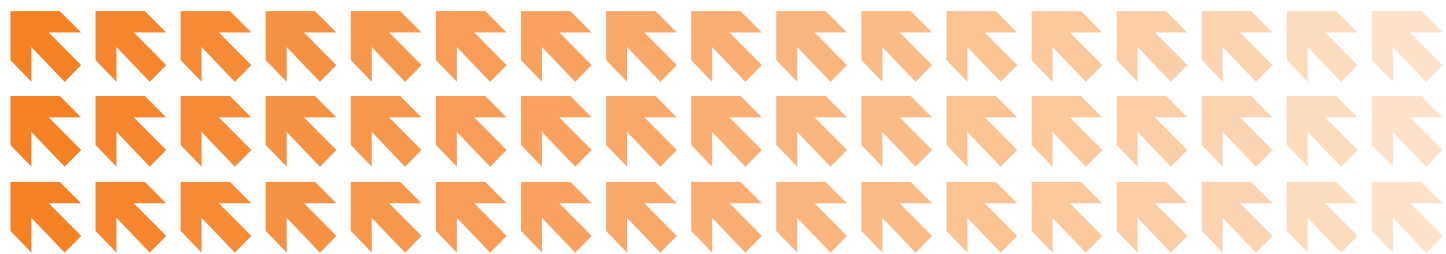
**Get advice about the dates when the new law comes into effect from your local Citizens Advice Bureau, or look on the Citizens Advice website at: [www.adviceguide.org.uk](http://www.adviceguide.org.uk).**

This quick-start guide tells you about some of the most important things in the Equality Act, but it doesn't cover all your rights as a carer. Get advice if you're a carer and you think you're being treated unfairly or if your needs aren't being met, even if we don't cover your situation in this guide.

**Get advice about your rights as a carer from your local Citizens Advice Bureau, or look on the Citizens Advice website at: [www.adviceguide.org.uk](http://www.adviceguide.org.uk).**

**You can also visit the Carers UK website at: [www.carersuk.org](http://www.carersuk.org).**

This quick-start guide covers people in England, Wales and Scotland.



## How the new law could help you if you're a carer

If you're looking after someone who is elderly or disabled, the law will protect you against direct discrimination or harassment because of your caring responsibilities. This is because you're counted as being 'associated' with someone who is protected by the law because of their age or disability. You're already protected from discrimination and harassment if they happen at work, but the new law will also protect you, if you are caring for a disabled person:

- when you shop for goods
- when you ask for services
- when you get services
- when you use facilities like public transport.

If you're caring for an elderly person, the new law will only protect you at work until more new parts of the law come into effect later.

### Direct discrimination

This is where you're treated less favourably than someone else because you're caring for an elderly or disabled person. At work this could include your employer:

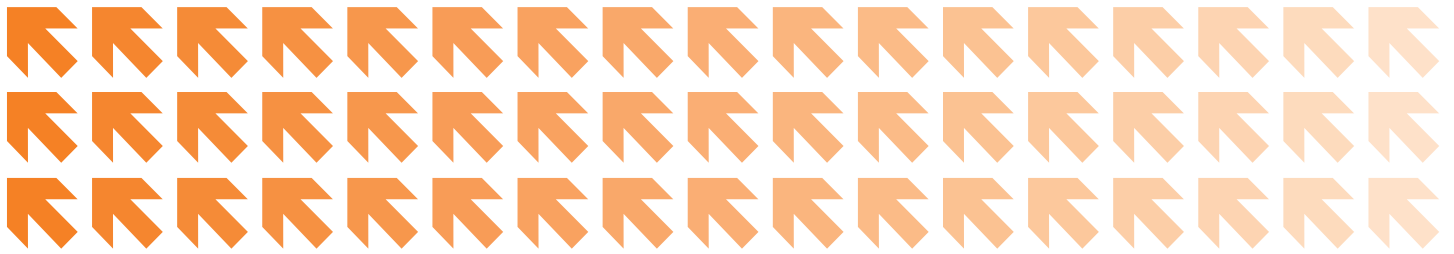
- refusing to offer you a job because of your caring responsibilities
- treating you less favourably because of your caring responsibilities.

You are also protected outside work from direct discrimination, which could include:

- discouraging you from using a service because you care for someone who is disabled
- making it impossible for you to use a facility because you look after someone who is disabled
- providing you with a worse service than someone else who isn't caring for a disabled person.

### Example

Ms Battle applies for a job which involves a lot of travelling. She has the best skills and experience but the company knows that Ms Battle cares for her son who is disabled. The company makes an assumption that she cannot manage because she has a disabled son and so it doesn't offer her the job. This is direct discrimination because Ms Battle is associated with a disabled person. It's against the law to refuse to offer her the job for that reason.



## Harassment

The new law will protect you from harassment because you're looking after an elderly or disabled person. Harassment is unwanted behaviour related to, say, disability or age. It hurts your pride or creates an intimidating, degrading or offensive environment for you. It might be deliberate but it doesn't have to be. Someone could be harassing you even if they don't mean to or don't realise they are doing so.

It's already against the law to harass you at work but it will also be against the law to harass you when you buy goods or get services if you are caring for a disabled person. If you're caring for an elderly person, the new law will only protect you at work until more new parts of the law come into effect later.

### Example

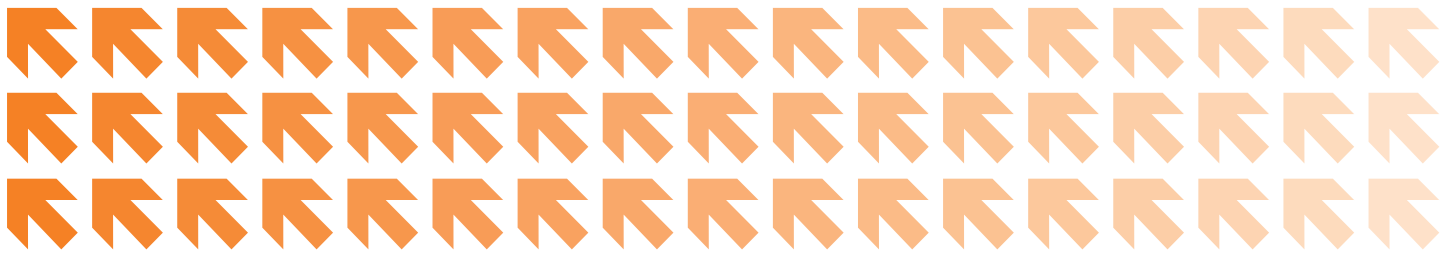
You're a carer for your disabled husband, who is a wheelchair user. When you're trying to buy something in a shop, the shop assistant makes rude remarks about wheelchair users to her colleague, which you find offensive and upsetting. You may have a claim of harassment related to disability, even though you are not disabled.

## Victimisation

If you complain about direct discrimination or harassment, the law will protect you if you are treated unfavourably because of your complaint. You have to believe that your complaint is true for this to apply.

## Exceptions

If you were disabled yourself, you'd have the right to have reasonable changes made so you could use services and facilities or go to work. This doesn't apply to people associated with disabled people so it won't apply to you as a carer. However, as a carer you already have the right to ask for flexible working hours so that you can fit in your caring responsibilities with your work.



## Taking action about discrimination

### Employment tribunals

If you're experiencing discrimination at work and you can't sort out the problem with your employer, you can take your case to an employment tribunal. If you win your case, you might get compensation and the tribunal could recommend that your employer stops discriminating against you. If you've been sacked because of your caring responsibilities, the tribunal could recommend that your employer allows you back to work.

Be careful not to miss the deadlines for taking your case to the employment tribunal.

**Get advice about the deadlines from your local Citizens Advice Bureau, or look on the Citizens Advice website at: [www.adviceguide.org.uk](http://www.adviceguide.org.uk).**

Employment tribunals have been given extra powers under the new law. They will be able to make recommendations in discrimination cases that make things fairer for other workers, as well as for the person who has made the claim.

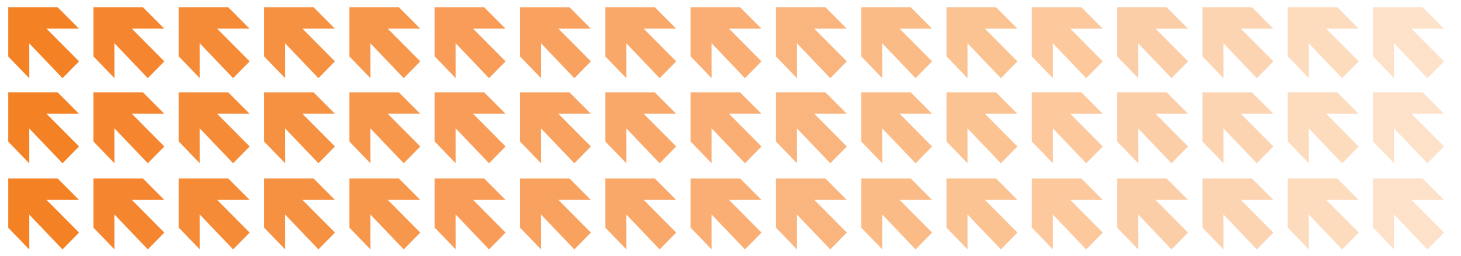
### County court claims in England and Wales and sheriff court claims in Scotland

If you've been discriminated against when buying goods or getting services, you might be able to bring a claim in the county court in England or Wales or in the sheriff court in Scotland.

An expert in discrimination might help the judge to hear the case and you might get legal aid. If you win your case, you could get compensation and whoever discriminated against you could be ordered to stop doing so.

Be careful not to miss the legal deadlines to bring a claim.

**Get advice about the deadlines and about legal aid from your local Citizens Advice Bureau, or look on the Citizens Advice website at: [www.adviceguide.org.uk](http://www.adviceguide.org.uk).**



## Find out more

### Other new leaflets

*Equality Act 2010: What do I need to know?*  
*A summary guide to your rights*

### Other information

Age UK: [www.ageuk.org.uk](http://www.ageuk.org.uk)

Carers UK: [www.carersuk.org](http://www.carersuk.org)

Directgov: [www.direct.gov.uk](http://www.direct.gov.uk)

Disability organisations – there are many local and national organisations that could help you. If you go to the Directgov website, you can find useful contact details. Go to: [www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/DG\\_10037826](http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/DG_10037826)

Equality and Human Rights Commission:  
[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

Government Equalities Office:  
[www.equalities.gov.uk](http://www.equalities.gov.uk)

You can also visit your local Citizens Advice Bureau.