Delivering Integrated Care – The Service User and Carer View

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Making Integrated Care Happen...
...a Carer Perspective

Laura Collins - East Belfast ICP Carer Representative
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Time-frame
“I spend as little as possible. I only buy reduced food where I can. I had been saving for a house since I was 18, so all that money has been used up by caring. I have no life. I only spend what I must and it depresses me to live like this.”
“We have no savings left, no private pension or life insurance.

We are older and feel the cold but are frightened to put the heating on and my wife and I are in bad health.”
In the next year, half (50%) of carers expect their quality of life to get worse, while only 5% think it will get better.

52% of all carers responding to our survey are worried about cuts to social security.

55% are worried about cuts to care and support services.

60% of working carers are worried about their ability to remain in work.

76% are concerned about the impact of caring on their health.

54% are worried about their finances.

State of Caring 2015

Carers UK carries out an annual survey of carers to build a picture of the state of caring in the UK. This year over 4,500 people shared their views and experiences on what life is like for carers in 2015.¹
Personal and Public Involvement (PPI) is the active and effective involvement of service users, carers and the public in Health and Social Care (HSC) services.

People have a right to be involved in and consulted on decisions that affect their health and social care. We know that when people are meaningfully involved in decision making about their health and social wellbeing, or listened to when they complain or raise concerns, this leads to improved quality and safety.

PPI is a statutory duty for HSC organisations. It is a two-way process and not solely to be used when we want to hear the views of service users and carers on something which we bring to them for their consideration.

“Play schemes and youth clubs have all closed. Respite care has been reduced. This has had a huge impact on my daughter’s ability to socialise and I am simply tired all the time now.”
"At present I am recovering from a cancer operation and still have to care for my husband as he won’t go into respite care."
"I have had a stroke and my own care needs have changed. I am now disabled but I still get no support."
NICON 2015 Conference Key Messages

We know what to do – let’s get on with it!

We have the right Vision
- The 2015 election briefing captures how we need to move forward
- We have a compelling vision set out in TYC – akin to neighbouring nations
- Over 45 organisations have come together to create one voice to Call for Action
- We have begun the journey – but need to pick up the pace, engaging fully with the public and staff

Invest in people
- We need to fully prioritize better workforce planning to meet modern demands
- Everyone has a role to lead and do develop a more open culture
- Patients and service users must be fully involved

Invest in new conversations and innovations
- Greater level of collaboration and partnership
  - Eg Integrated care partnerships, GP Federations, fully engaged allied health professionals
  - Role of third sector and business
- A whole system approach increasingly important to co-design and co-produce
- Change happens at the edge – invest in key areas of innovation

Focus on key enablers
- Embrace technology
- Stable financial framework and investment in transitional funding
- Focusing on the right thing to do – will improve the money and outcomes

Build on exiting progress
- There is groundbreaking work happening every single day
  - We need to support and build on this
  - Need to use evidence – accept that there will be mistakes

Leadership
- To create something new always takes bold courageous leadership

There is a big debate required with the public
- We must engage more fully with the public
  - Politicians follow the public voice
  - Support society make informed choices about how we best provide care for future generations

**"I have no life of my own – people expect me to be the carer forever. Which I probably will be because the person I care for is my brother, and he is entitled to a life as well."

- Male carer in his late sixties"**
Caring into later life
The growing pressure on older carers

I'M A CARER
I LOOK AFTER MY MUM WHO IS 92
AND HAS DEMENTIA
I'M A PENSIONER
BUT I DON'T GET A FULL PENSION.
I DON'T GET CARER'S ALLOWANCE BECAUSE
I'M A PENSIONER.
THE GOVERNMENT THINKS THIS IS FAIR!
"I have to do everything in the home – washing, cleaning, preparing meals, shopping, looking after my wife… it is very hard work. I am fortunate that in spite of having suffered a heart attack, which destroyed half the muscles in my heart, I can still manage to cope."

- Male carer in his early eighties**
Impact is the broader or longer-term effects of a project’s or organisation’s outputs, outcomes and activities.

Why is it important to measure impact?

So that we can:
- know what has changed and what works about an intervention or funding programme
- know the extent and intensity of the change
- benchmark and make comparisons
- learn and make improvements
- test assumptions
- provide evidence of value for money which can increase sustainability
- detect any unintended impacts
People Powered
Health & Wellbeing
Shifting the balance of power
IHI’s Strategy to Improve Health and Health Care Worldwide

Transforming health care will require:
- Reliable systems for providing safe, harm-free, evidence-based care
- Patients and families empowered to be genuine partners in their care
- New models for high-quality, high-value care
- Building improvement capability at all levels
- Improving health, improving care, and lowering per capita cost (Triple Aim)

Accelerate the pace of improvement in health care

AND

Innovate and partner with organizations and communities to improve health

Creating a culture of health will require:
- Health care systems optimized for “health” and “care”
- Bridges between health care, community, and public health
- Healthy communities initiatives
- Creating enabling conditions
- Peer-to-peer supports
- New mindsets

Supporting our customers wherever they are on the journey

Working in five Focus Areas

Leveraging IHI’s Core Strengths

Innovating new models and methods

Convening globally to harvest, share, and spread learning

Partnering with others to accelerate the pace and scale of improvement

Driving measurable results worldwide within health care and across communities

October 2014
The Scale-up Framework

Best Practice exists

New Scale-up Idea

Set-up → Build Scalable Unit → Test Scale-Up → Go to Full-Scale

Phases of Scale-up

Adoption Mechanisms

Support Systems

Leadership, communication, social networks, culture of urgency and persistence

Learning systems, data systems, infrastructure for scale-up, human capacity for scale-up, capability for scale-up, sustainability
“Caring can be such a lonely existence... There is so much people don’t understand. I think people tend to think that when someone has dementia they only lose their memory, but the impact is much, much greater. You really lose a person. When you grow older one of the huge joys is to share memories. We can no longer do this. We can no longer share the joys of our grandchildren.
- Caryl, 74, cares for her husband who has dementia”**
“The single biggest reason companies fail is that they overinvest in what is, as opposed to what might be.”

Gary Hamel