

Special Report 15



'in Control' – a focus on the individual.



www.careknowledge.com

info@careknowledge.com

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**OLM-Pavilion Ltd
The Old Tannery, Hensington Road, Woodstock, Oxon OX20 1LJ.
Tel : 020 8973 1100**

'In Control' – a Focus on the Individual

In this CareKnowledge Special Report, the fourth in an ongoing series on personalisation, 'in Control' offers a more personal account of why self-directed support matters.

Introduction

CareKnowledge has provided several special reports outlining key aspects of the personalisation agenda. These have described the background to the policy, its core elements and the key challenges for the future.

One of the strongest influences on current developments has undoubtedly been by 'in Control', a charity that has been championing concepts of self-directed support for the past few years.

Our previous special reports have included some detail on 'in Control's' work, but in this report, alongside a short reminder of its key methods, 'in Control' offers a more personal account of why self-directed support matters. In that section of the special report, Alex McNeil makes an impassioned case for the impact that self-directed support has on the lives and aspirations of the service users involved, and more widely, on local communities.

The approach adopted by 'in Control' is only one of a range of influences on developing wider policies. Alongside central initiatives, work to identify and implement local solutions to the requirements of the Putting People First Concordat and the associated Transforming Social Care Grant is now underway across all English authorities.

A key tenet of wider policies is that national development should be driven by locally identified priorities – and locally agreed systems. It seems likely that localities will adopt service elements based on the 'in Control' methodology, but will also pick up inspiration elsewhere. The next few years should therefore see a rich diversity of specific, local solutions that will hopefully also have an impact on national developments.

One of the most important questions that will be addressed during the next few years is that extent to which relatively small scale projects such as 'in Control' can be 'sized up' to a much broader geographical and service user base. For example, it's clear that several authorities are already grappling with dilemmas about the universal – and more specialist – elements of new systems. It will also be interesting to see how achievable 'whole system' change is, where authorities decide on a radical, overall shift to truly self-directed support arrangements.

Another key development during the next few years will be a re-definition of the staff roles necessary to make a much more user-driven service work. Here, a wide range of commentators have drawn attention to the fact that self-directed support cannot mean 'do it yourself'.

Individuals in any system will still need support, advice and good quality information to help them make choices and then to help them manage on-going arrangements. The level and type of support required will vary enormously. So, although self-directed support

clearly implies changed roles for social workers and other LA staff, it doesn't necessarily point to an overall reduction in the level of staffing resource required.

CareKnowledge recognises that 'in Control' is one voice among many. This special report simply provides an insight into the organisation's thinking and adds to the developing range of materials we provide to enable CareKnowledge readers to make their own critical judgements about the best way forward.

Why self-directed support matters

A brief history

This section of the special report is based on a transcript of a speech given by Alex McNeil, of in Control, at the Pavilion Independent Living conference held in London, on 21ST May 2008. The speech doesn't deal with the processes or technology of self-directed support, but argues in a direct way for the core, person-based values of the approach.

"The seeds for the development of 'in Control' were sown in 2002, when a small group of people from a wide variety of interests began to explore how concepts of self-directed support could be brought fully into the mainstream. 'In Control' is the name of the charity whose job it is to promote self-directed support as the best model for the welfare state to adopt.

As with most good ideas, the people involved in 2002 were fully aware that they were standing on the shoulders of giants – the shoulders of people in the independent living movement, the shoulders of people in the inclusion movement, and the shoulders of the many individuals who have never identified with a movement – but simply knew there must be a better way.

Knowing who came before was critical to the development of the model of self-directed support. In particular, the path had been cleared by those families and individuals who didn't wait for their "common sense" approach to be christened self-directed support, but who strode into their own review meetings and worked tirelessly to become the first few people in the country to begin to use the system differently.

The central role of people who use services

Just as it's important to recognise the role of those people in developing the idea in the first place – it's now more important than ever to recognise the ongoing, pivotal role they have in the process of transformation that providers, local authorities and increasingly PCTs are facing.

Where we see transformation and better lives, some families and individuals see only service cuts and closures; or older people see only that self-directed support means they must manage and administer their own direct payment. Many of these people have fought long and hard for the inflexible services they now receive – and when compared to what their life was like before, they will fight to keep it and resist change.

Some people are using their individual budgets to continue to buy their existing services – not always because these are best, but because no one they trust has helped them to see beyond what they've got – and into what could be possible.

When you take a step back and think about the complexities and red tape in the old system, it doesn't take long to realise that it would never have been designed that way by the people whose lives it was supposed to make better. As transformation teams across the country sit down to re-design the system in their local areas, it is common sense to do that with local people – with those who use, and may need to use services, and with local communities.

Checks and balances

To be effective, transformation plans will need to build in the checks and balances necessary to make sure that the changes are making the right sorts of differences in the right sorts of places.

And there is a risk that authorities will get caught up in the cycle of consultation that might tick the right box, without being meaningful. "Putting people at the heart of what we do", being "person centred" has become common parlance, without becoming common practice.

It's possible to over complicate and systemise "working with people" into a complex programme of consultation. Genuine partnership working with people requires honesty. It requires telling people that you don't always have the solution and asking them for help. It requires listening. And it requires the confidence to let go of some of the control and the willingness to support the people who will be taking back that control.

The much wider value of self-directed support

Occasionally, people comment that 'in Control' is perceived as "evangelistic" – and perhaps this is because we don't see self-directed support as just the latest trend in social care. The reason the charity relentlessly returns to measuring the impact on people's lives is the belief (backed up by research and evaluation) that when self-directed support is delivered well, in partnership with people, its impact goes way beyond an individual's life – and reaches right out into the community.

When self-directed support works, some people who would otherwise be missing from the community become visible again – at work, at the football, on the high street. Understanding the scale of the potential transformation enables us all to keep the end in mind – to see disabled and older people active and present in our communities, rather than kept at home waiting for an inflexible homecare service or leaving the pub at 9pm when the late shift finishes.

Many of us can remember how disabled children were missing from our early lives. As children growing up in the 1970s and 1980s, there were no disabled children at our schools, in our parks, or at brownies. Everyone's life was less rich because of that. There are people who should have been part of our lives and whose lives we should have had the opportunity to be part of removed from our experience. This sense that people have somehow missed out, drives the 'in Control' belief that this change is about all of us, not only those people who traditionally receive health and social care.

The national change programme

The transformation that is happening is about much more than just “the system”. It has never been ‘in Control’s’ mission purely to change a system without being able to use people-based outcome measures to clearly demonstrate that the changed system is helping people get better lives.

Innovation goes hand in hand with inspiration. It’s unthinkable to imagine any of the important innovations of the past 100 years happening without inspiration – that “vision” that the innovator keeps in mind. The inspiration behind self-directed support is the people whose lives have been transformed or simply made better.

‘In Control’ believes that the trick for change that has a real impact on people’s lives is to not let the inspiration disappear as we move from the innovation stage into the implementation stage. In the case of self-directed support, without inspiration, it could become just another system – detached from people’s lives. As we move from innovative, cutting edge pilots into more mainstream practice, inspiration is critical. And it comes from people.

A bit of inspiration supports those who are tasked with changing the systems and keeps them connected to what’s most important.

Perhaps that’s why ‘in Control’s’ most regular and frequent feedback from people when they come to an event is: “It’s so good to be reminded of what it’s really all about”.

The ‘in Control’ model: principles and processes

This section of the Special Report provides, for ease of reference, a brief reminder of the ‘in Control’ approach and methodology and was supplied in large measure, by Laura Bimpson of ‘in Control’.

‘In-Control’ was set up, in 2003, as a partnership between central and local government and some independent organisations working with disabled people. They began work with a small number of local authorities who had come to believe that the current system of social care was inadequate. In its place they developed a new system of self-directed support.

‘in Control’ identifies 7 ethical principles that underpin its version of self-directed support.

The right to independent living

- If someone has an impairment that means they need help to fulfil their role as a citizen, then they should get the help they need.

The right to an individual budget

- If someone needs on-going paid help as part of their life they should be able to decide how the money that pays for that help is used.

The right to self-determination

- If someone needs help to make decisions then decision-making should be made as close to the person as possible, reflecting the person’s own interests and preferences.

The right to accessibility

- The system of rules within which people have to work must be clear and open to maximise the ability of the disabled person to take control of their own support.

The right to flexible funding

- When someone is using their individual budget they should be free to spend their funds in the way that makes best sense to them, without unnecessary restrictions.

The self-directed support process promulgated by 'in Control' involves 7 steps:

Step 1 - Everyone is given an indicative financial allocation and they decide what level of control they wish to take over that budget.

Step 2 - People plan how they will use their budget to get the help that's best for them; if they need help to plan then family, friends, social workers or others can support them.

Step 3 - The local authority confirms the budget, checks that they are safe and makes sure that people have any appropriate representation.

Step 4 - People control their budget to the extent they want; they can manage the money themselves, have someone else manage it for them or have the local authority continue to commission their support.

Step 5 - People can use their budget flexibly: they can use statutory services, (the cost of which is taken out of the budget) or other forms of support; if they change their minds they can re-direct their budget to more appropriate forms of support.

Step 6 - People can use their budget to achieve the outcomes that are important to them in their context of their whole life and their role and contribution within the wider community.

Step 7 - The authority continues to check people are okay, shares what is being learned and can change things if people are not achieving the outcomes they need to achieve.

Conclusion

This special report has provided a concise account of one organisation's view of the key values and objectives underpinning 'personalisation'. As noted in the introduction, the material we received from 'in Control' focuses on the belief that drives its approach.

The practical application of the beliefs expressed is without doubt the real challenge for the future. In some ways, the values embedded in the 'in Control' approach have been the intended bed-rock of successive policies for a considerable period. Will we see real change this time round?

CareKnowledge will continue to feature the full range of other materials being made available, to support 'personalisation', including those critical of the particular approach adopted by 'in Control'.

The key objectives of providing better services, tailored to individual need, and controlled and managed by the individuals concerned are the benchmarks for future development –

rather than the emergence of any single model. A wide range of initiatives, both local and national, will be needed to create effective solutions.

Recent Special Reports

Adult Support and Protection : The Adult Support and Protection (Scotland) Act 2007.

CareKnowledge Special Report 14, August 2008. Provides a short single-source briefing on Part 1 of the Act and on the requirements of the associated Code of Practice.

Safeguarding Children : the third joint chief inspectors' report on arrangements to safeguard children 2008.

CareKnowledge Special Report 13, July 2008. This CareKnowledge special report provides summary and analysis of the most recent joint chief inspectors' report. It is a key publication with implications for safeguarding and with significant recommendations for government and local agencies.

High Quality Care for All - NHS Next Stage Review Final Report by Lord Darzi.

CareKnowledge Special Report 12, July 2008. This Special Report provides a brief analysis of the main contents of Lord Darzi's review.

The Government's strategy for carers - 'Carers at the heart of 21st century families and communities'.

CareKnowledge Special Report 11, June 2008. This Special Report provides a summary and analysis of the government's much heralded long-term strategy for carers. It is intended to provide quick access to the key points of the strategy and to identify some of the policy and practice questions it raises

Personalisation – the challenges.

CareKnowledge Special Report 10, May 2008. This is the third in a series of Special Reports looking at personalisation and what it will mean for social care and adults in need of support. Moving to a personalised system will take time, creative thinking and momentous change. This report describes some of the wider challenges before looking in more detail at what might require innovation and change involving: people, process, commissioning and the market, technology.

Adult Social Care Funding – The Case for Change.

CareKnowledge Special Report 9, May 2008. This Special Report summarises and analyses the government's background report outlining the arguments for and against a range of options for funding adult social care.

Self-Directed Support - Core Elements and Issues.

CareKnowledge Special Report 8, April 2008. Examines the core elements of a self-directed support (SDS) model and looks at the opportunities and challenges it raises. This is the second CareKnowledge Special Report analysing personalisation and adult social care. The first set out the context for personalisation and self-directed support.

Children's Trusts : Duty to Cooperate.

CareKnowledge Special Report 7, April 2008. Summarises the proposals in the current DCSF consultation paper on Children's Trusts duties, including some important new initiatives.

Personalisation.

CareKnowledge Special Report 6, April 2008. This is the first in a series of CareKnowledge Special Reports that will look at the background and challenges of the government's forthcoming personalisation agenda.

Children's Services : what research is telling us.

CareKnowledge Special Report 5, February 2008. Provides analysis of each of several recent publications which focused on the next stage development of children's services and draws some attention to areas where there may be scope for cross-referencing of findings.

Adult Social Work Policy Update : what you need to know about quangos, deferred payment agreements, sheltered housing and free personal care.

CareKnowledge Special Report 4, February 2008. Provides a single point of access to an important range of publications affecting adult social care in Scotland.

State of the Nation : CSCI's Third Annual Report on Social Care in England.

CareKnowledge Special Report 3, February 2008. Focuses on CSCI's recent report for England, which is a seminal evaluation of the performance of adult social care services.



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Consultation from the Department for Education and Skills on a review of the law pertaining to physical punishment of children by their parents. [15-Jun-2007]
- [Working across children's and adults services: creating seamless services in the post ECM world](#)
Speech by Beverley Hughes to an LGA conference in which she highlight the need for good joint working between services for children and adults. She looks at disabled children's transitions, young carers, safeguarding children, and whole family approaches. [14-Jun-2007]
- [CareKnowledge Commentary: 3rd Quinquennial Report to the UN Committee on the Rights of the Child - United Kingdom](#)
This CareKnowledge Commentary provides an overview of the lengthy submission to the UN Committee on the Rights of the Child, which provides an exhaustive coverage of developments over the past five years. [01-Jun-2007]
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info@careknowledge.com

020 8973 1100



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