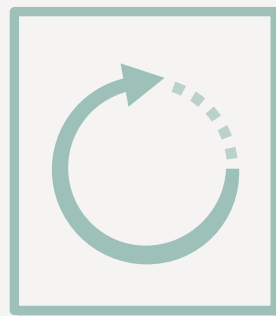
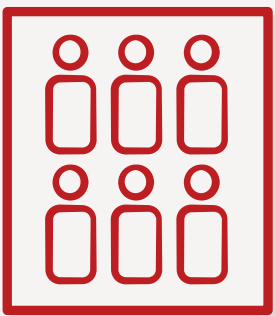
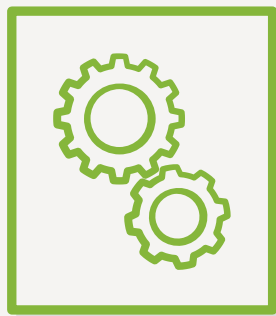
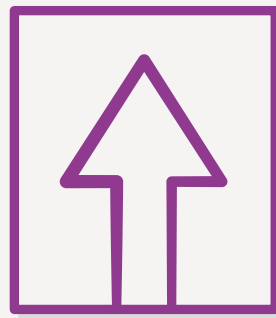
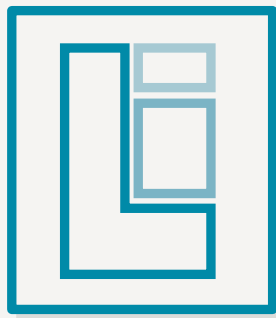


Living well with long term conditions

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# Twelve propositions for social care



**Revised discussion paper, September 2012**  
Authored by Dr Jim McCormick, for the ALLIANCE and  
its partners



All information was correct at time of original publication in 2012

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# Foreword

I am delighted to introduce this second iteration of the 12 Propositions for Social Care at a time of significant opportunity to improve the lives of people who use health and social care support and services in Scotland.

This report forms the foundation for a continuing collaborative effort, led by the ALLIANCE working closely with several of our members and partners and rooted in the experiences of people who are disabled or living with long term conditions.

The original 12 Propositions paper helped inform a national dialogue event held a year ago this month with the Cabinet Secretary for Health and Wellbeing, users of support and services and leaders from health and social care. Since then, the ALLIANCE and its partners have continued to develop dialogue on how principles of human rights, independent living and citizenship can help make a reality of the aspirations of the related agendas of Christie, Self-directed Support, self management and the Healthcare Quality Strategy, Reshaping Care for Older People and the Integration of Health and Social Care.

The direction of travel in Scotland is now arguably more encouraging than ever, spurred on in part by the combined fiscal and demographic challenges we face. There is a clear and shared commitment to putting people at the centre, supporting choice and control and maximising individual and community assets. The question is how to put this into practice; how to support our growing population of older people not just to remain at home but to enjoy high quality, independent lives; how to support people with complex needs, ensuring their position in society does not take a step back as funding cuts bite; and how to drive lasting, sustainable transformation in the design and delivery of our support and service landscape. This is made more difficult in the context of welfare reform, which the Westminster Joint Committee on Human Rights has suggested could undermine the hard-won right to independent living for disabled people.



As we engage with this panoply of activity and opportunity we must make sure the focus remains on the realities for people, families and communities and that their voices are the driving force for change. The third sector has a vital role in ensuring these voices are heard and that people are partners in policy, service design and delivery. The sector is itself a major provider of social care – accounting for over a third of all registered social care services – as well as providing the foundation for individual and community assets to flourish. Self management provides an example of the ability of the sector to support the capacity of people individually and collectively, for example through peer-to-peer support and networks.

I invite you to join the ALLIANCE and its partners in helping to shape a future in which people – be they older, younger, disabled or living with long term conditions – are equal, active citizens with access to support that puts them at the centre and enables them to enjoy their right to independent living and a high quality of life.

I would like to thank all those who have, and continue to, contribute to this work and in particular Dr Jim McCormick (Scotland Advisor to the Joseph Rowntree Foundation) who has facilitated, researched and written the 12 Propositions with a notable level of skill, dedication and insight.

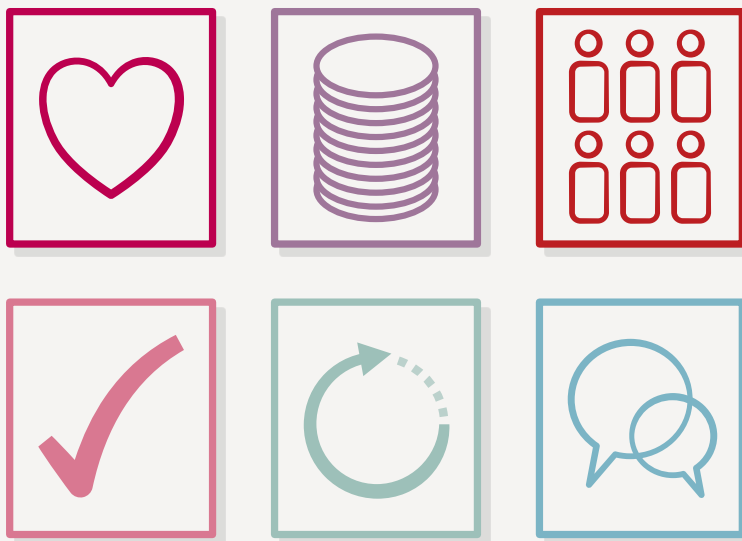


**Professor Ian Welsh OBE**

Chief Executive

The Health and Social Care ALLIANCE Scotland (the ALLIANCE)

October 2012



# 1

## First, recognise the context

We know that more people in Scotland are living with long term conditions, living for longer and often living alone. Long term conditions can be grouped – very broadly – into those which are:

- long term but often stable (e.g. life after a stroke)
- long term but with cycles of recovery, relapse and remission (e.g. mental health problems and physical conditions such as Multiple Sclerosis and COPD).
- long term and progressive (e.g. Parkinsons and dementia)
- linked (e.g. pathway from high blood pressure/cholesterol/obesity to some types of diabetes, stroke and vascular dementia)
- multiple (e.g. physical impairment following stroke; learning disability plus dementia). Multi-morbidity, where people experience three or more conditions together, is common. Almost three-quarters (74%) of people with heart failure, and two-thirds of people living with dementia (64%) or stroke/TIA (often called a 'mini- stroke') symptoms are in this position.

Almost half (46 per cent) of households with care needs contain only one adult. Many will be supported by a family member or friend. The latest Scottish Household Survey shows that many people have their care needs only partially met by formal and informal support. It also shows that three times as many adults are providing unpaid care to someone who doesn't live with them as do within the home.

The picture of an ageing population with growing care needs is familiar. So too are the constraints imposed by the state of public finances. Scotland's Chief Economist expects the decline in public spending to last at least 15 years. The equation goes like this: getting better outcomes from smaller budgets can only really be done by reducing need – or taking demand out of the system where possible<sup>1</sup> and by doing things differently.

In addition, care and support provide one essential tool among others, which ensure that people with long term conditions have equal access to society and can live their life in the way they choose, at home, at work and in the community. Without it, many people cannot enjoy the human rights they are entitled to:<sup>2</sup>

<sup>1</sup> L Bunt and M Harris with R Puttick (2010) Radical Scotland: Confronting the challenges facing Scotland's public services, London: NESTA

<sup>2</sup> ILiS (2011) ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD



**I couldn't have gone to university and gained my degree if it hadn't been for the flexible support package I got. Having the right support means I can enjoy the things others can, that we all have rights to. I could get the education I wanted, play an active part in my family and my community, hold down a full time job and basically live my life how I choose. With community care, I can play my part in society and enjoy the rights others take for granted<sup>3</sup>.**

In this context, it seems apparent that we are in the midst of an important conceptual shift – spanning self management, personalisation, independent living and preventative spending. The Christie and Beveridge Commissions go with the grain of what's already underway. Equally apparent, though, is how a broad consensus in favour of this shift runs way ahead of investment to make it happen. The Change Fund as part of Reshaping Care for Older People is an important mark of intent. The forthcoming Self-Directed Support Bill offers the clearest chance yet for Scotland to narrow the gap between promise and practice. But the principles of user control, voice and choice – and simply “being listened to and treated as capable adults” as carers’ groups put it – need to become the default mode for social care, not only expressed within the limits of a single programme or legislative plan.

Interviews conducted to inform this paper point to a very clear need for more flexible and responsive use of all care resources. We need to be able to “reach for the volume control not just the on-off switch” in assessing what we're each capable of, what our needs are and how to adapt our response over time. Despite progress led especially by the Independent Living Movement and by condition-specific organisations developing self management approaches which can be shared widely, we remain a long way from ensuring people get the right kind of support to stay well for as long as possible. Too often people receive inadequate social care and as a result experience complications, returns to hospital or enter residential care sooner than they need to. For many working age people with long term conditions, the care and support available to them determines whether they can go back to work, which in turn has a significant impact on their financial security and physical and mental health.



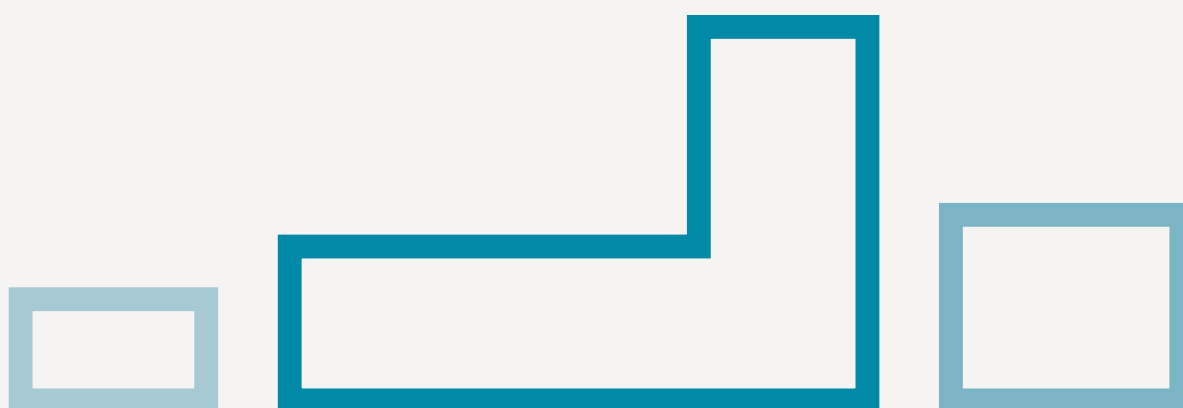
<sup>3</sup> From ILiS outreach event (2010)

## 2

# Adapt to emerging needs

One 'vital sign' of a better social care system will be its ability to adapt to emerging needs, including needs that may be long-established but neglected. It's striking, for example, that the experiences of children and young people with long term conditions, and parent carers, seem less prominent within our deliberations. There may be carefully designed clinical pathways in the NHS for children with complex health conditions, but what about families facing the most intensive, lifelong care responsibilities? How good is the support they can count on for everyday living? And what about transitions into the world of adult life, support and services? The work of the ALLIANCE<sup>4</sup> and others consistently shows that children young people who are disabled and/or living with long term conditions are less able to access the quality of life and opportunities available to their non-disabled peers.

Another challenge arises in the emotional and psychological support needs of people with long term conditions and unpaid carers<sup>5</sup>. These may arise in adjusting to a new impairment with little prospect of recovery, following some types of stroke for example<sup>6</sup>, or living with a degenerative illness. Depression may occur through loss of identity and independence or be linked to organic brain impairment. Older people doing most of the care for their spouse or grown-up children are much more likely to have poorer physical and mental health themselves. Support to relieve chronic stress on carers, for example by funding appropriate care and support to the person with the long term condition, or by supporting the carer themselves where this is the express choice of the person and their family, can improve their own quality of life and their ability to carry on giving care for longer.



<sup>4</sup> Seen and Not Heard (the ALLIANCE 2010) and "I want to be treated the same as my brothers" Views of Quality of Life from Children and Young People who are Disabled and/or Living with Long Term Conditions (the ALLIANCE/fSDC 2011)

<sup>5</sup> Emotional Support Matters (2011) the ALLIANCE and Scottish Government

<sup>6</sup> IRISS (2010) Life after stroke: the long-term emotional and psychological needs of stroke survivors and their carers, Insights No.6 [www.iriss.org.uk](http://www.iriss.org.uk)

## Stigma

Closely connected with mental health is the issue of stigma. Stigma remains a significant issue for people who live with long term conditions – both the stigma of physical or mental health conditions, and the stigma associated with identifying the need for emotional support. This in turn represents a major barrier to accessing preventative support. In the early stages, lack of accurate information or too much information, and patchy access to peer support may lead to fatalism about the chances of living well their condition. People with long term conditions also talk of the stresses involved in challenging social care provision that is inappropriate. For example, Denise's story was shared at the Social Care Dialogue Event:



**Is it right that we go to bed at 9pm? We need to be treated as equals. When I volunteer, I feel like I am contributing. I feel I have more control over my life outside of my home than in it, safer with strangers than with carers. When receiving care, you should be grateful...I don't want to complain, but if I don't will anything change? There are challenges when you have people in your home. That then becomes their workplace...I can't get better but I do want a better life. I wish for less prejudice. I have a disability and I have a degree...but still professionals hear what they want to hear.**

Other aspects of stigma and negative social attitudes raised by participants in the Social Care Dialogue Event include:

- Negative body image: "I have to cope with a changing body shape that makes it difficult to get clothes. If I was to allow myself to feel embarrassed I would never go out. A lot of people do hide away." (Denise's story)
- Loss of confidence and desire to go out, socialise, meet new people.
- Physical obstacles: limited mobility support, accessible transport and buildings.
- Negative assumptions held by people with long term conditions themselves of how others will respond.
- Media portrayals of disabled people and people claiming incapacity benefits as 'scroungers'.

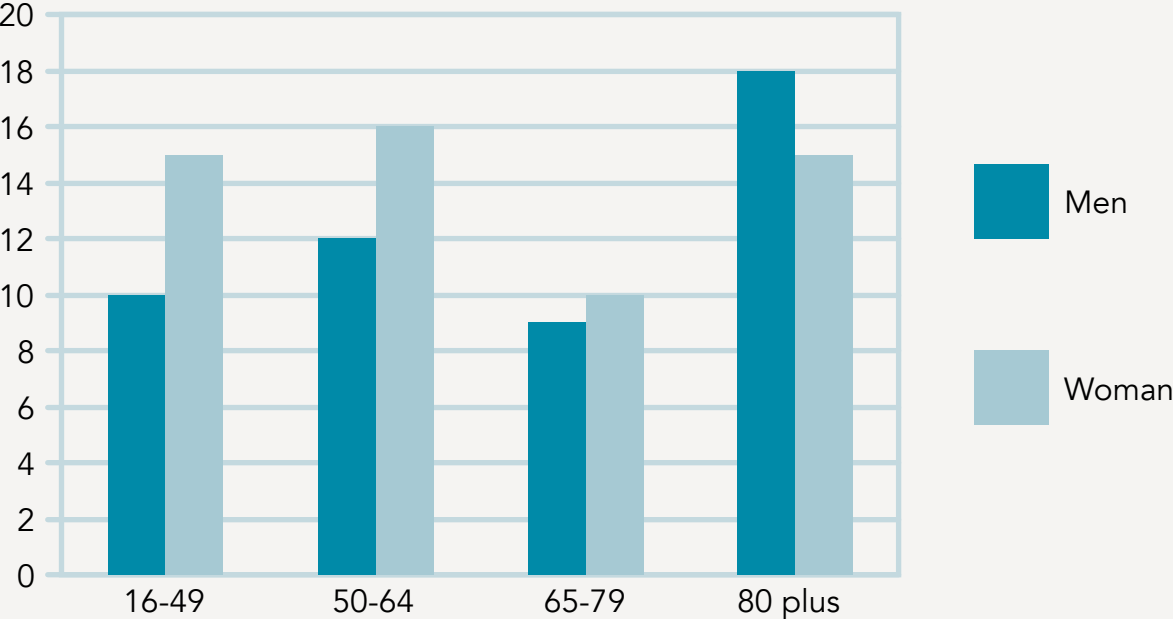


A time of recession and austerity is accompanied by generally harsher public attitudes towards welfare claimants. Independent living networks, along with many long term conditions organisations are at the forefront of moves to challenge negative attitudes, debunk commonly-held myths and overcome stigma.

However, if people, individually and collectively, are to address isolation and negative attitudes, they need support from local and national government along with the infrastructure to support them to make their voices heard.

In addition, the growing risk of loneliness might be regarded as a long term condition in its own right. Living alone but isolated from family and friendship support can't really be regarded as independent living. This isn't about "living alone or fending for yourself, it is about practical assistance to lead an ordinary life"<sup>7</sup>. There's growing evidence that social isolation in later life isn't just a risk factor for depression but dangerous for physical health and mobility<sup>8</sup>. Survey evidence suggests that older people are increasingly living well. Self-rated poor health grows with age, but more than 70 per cent of people in Scotland aged 75+ still rate their health as at least good<sup>9</sup>. However, a turning point occurs for some in their 80s when a marked increase in mental ill-health emerges (based on survey evidence from England)<sup>10</sup>.

**Mental ill health by age and sex (% scoring 4+ on GHQ12, England 2004-06)**



7 ILiS (2009) Essential Guide to Independent Living [www.ilis.co.uk](http://www.ilis.co.uk)  
8 See for example JRF's Neighbourhood approaches to loneliness programme [www.jrf.org.uk/work/workarea/neighbourhood-approaches-loneliness](http://www.jrf.org.uk/work/workarea/neighbourhood-approaches-loneliness) and the Campaign to end loneliness: connections in older age <http://campaigntoendloneliness.org>  
9 Scottish Government (2008) Scotland's People Annual Report: Results from the 2007-08 Scottish Household Survey, Edinburgh: Scottish Government  
10 DWP (2009) Opportunity Age Indicators: 2008 update (Indicator 12) Older People and Ageing Society Division, London: DWP

Depression at this stage is under-diagnosed in part because it is often viewed as a 'natural' or inevitable part of getting older. In fact, there are significant differences in personal resilience following bereavement for example and in quality of life among people living with dementia.

In the community, people with long term conditions of all ages value the mutual support that comes from being part of a peer group, member of a club or taking part in activities where they can contribute as well as get support:



**I am retired from work due to ill health but have various hobbies including cooking and photography. I am also an active member of the committees for two clubs. I have reduced income but also reduced expenditure as a result of not working. I play an active part in our local community and see myself as outgoing, happy, useful and helpful to others” (Strokesurvivor,manin his early 60s)<sup>11</sup>.**

Reciprocity is an under-valued element of care and one that is well evidenced by the Self Management Fund for Scotland<sup>12</sup>. Volunteering support, for example using telephone networks for people who are confined to their homes, demonstrates that people who receive social care can also provide support to others. And while supporting people's ability to stay part of social networks in the community is the best starting point of all, similar expectations should apply to other places where people are cared for including long-stay hospital wards and care homes. Recovery and rehabilitation are likely to be aided by stimulation. Too often, people experience stifling boredom, a lack of things to do, people to talk to and opportunities to be mobile. A commitment to involve volunteer befrienders and a duty to commission learning and leisure activities should be considered as an essential part of the role for these service commissioners<sup>13</sup>. It is important that we recognise that, with support to participate, people with long term conditions can be contributors to society not just beneficiaries as is often assumed.



<sup>11</sup> Case study provided by Stroke Association Scotland

<sup>12</sup> Impact, Evaluation of the Self Management Fund for Scotland [www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)

<sup>13</sup> J McCormick with J Clifton, A Sachrajda, M Cherti and E McDowell (2009) Getting On? Wellbeing in Later Life London: IPPR

# 3

## Start with Rights...

Past efforts to improve public policy – in education, health, welfare – have appealed to the enlightenment of policy-makers, the goodwill of practitioners, the return-on-investment case to budget-holders and, at times, to public outrage at the position of vulnerable people. These are legitimate elements of any push for reform. But they are best viewed through the sharply-focused lens of citizenship. Taking a human rights-based approach to social care doesn't get us off the hook of making hard choices on resource allocation, but it does offer more fertile ground in which to embed progress.

This is not only about how we make decisions and allocate budgets, but about the end outcome for service users. Social care should be understood as a means to a greater end of living well. So, the test of social care effectiveness will include:

- does adequate care and support help to empower people to make choices about their lives, not just about their care?
- can they exercise their rights as citizens, as members of families, communities, as employees and learners and so on?

When the Joseph Rowntree Foundation began its programme for older people with high support needs, A Better Life, it quickly concluded that the standard currency of the debate – concepts like dignity and respect – wasn't tough enough<sup>14</sup>. These are valuable qualities to be promoted, but they involve relying on others to bestow them. So, we take our chances that a skilled social work manager or homecare worker will have the empathy and time to demonstrate them. But what about when this fails?

A right-based approach can help to clarify expectations of fair, consistent and respectful experiences and of redress when standards fall below this. It offers a coherent values base to reform social care in order to "empower citizens and unlock them from the failings of past systems, rather than locking them into a new system that lacks a clear vision" (Chetty et al, 2012 p.2) and "there is significant scope for the Convention rights within the Human Rights Act to be better understood and applied more consistently to advance the personalisation agenda.

<sup>14</sup> JRF programme A Better Life [www.jrf.org.uk/work/workarea/better-life](http://www.jrf.org.uk/work/workarea/better-life)



All of the human rights protected by the European Convention on Human Rights (ECHR), in the Human Rights Act and in subsequent ratified Conventions belong to people with long term conditions:

- Article 14 of the ECHR states that “The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination”.
- The right to participate is expressed in several protections within the UN Convention on the Rights of People with Disabilities (UNCRPD).
- Article 19 of the UNCRPD says that for people with long term conditions to equally enjoy the rights laid out in the ECHR, states must ensure that people “have a right to live in the community, with the support they need and can make choices like other people do”.
- Social care in the community is thus essential for the equal enjoyment of human rights among many people with long term conditions<sup>15</sup>.

Progress to embed human rights has arguably been reflected to a greater degree within health services than social care. The Patients Rights (Scotland) Act (2011)<sup>16</sup> clarifies the principles and standards that everyone who uses the NHS in Scotland can expect, including treatment times and the right to give feedback, express concerns and make complaints. Conversely however, the concept of Independent Living (in its full sense of active citizenship, rather than only as short hand for living at home) currently has more traction within social care. Eventually, the logic of integrating health and social care services should mean that rights-based approaches are applied more evenly across health and social care and that combined resources are allocated together through service commissioning and as individual budgets, real or virtual, through self-directed support (see Proposition 4).



<sup>15</sup> British Institute of Human Rights (2006) Your Human Rights: A Guide for Disabled People

<sup>16</sup> <http://www.scotland.gov.uk/Topics/Health/PatientRightsBill/WhatDoesTheBillMean>

Progress can be seen in the Rights to Independent Living advocated by Independent Living in Scotland (see box)<sup>17</sup> and Inclusion Scotland, through application of the United Nations PANEL approach to human rights for people with dementia and the emerging debate on the right to self-assessment in social care. However, an example from Independent Living in Scotland offers one experience of care assessment falling far short:



**The whole [assessment] process and my own principles confirmed my belief that community care assessments were too focused on feeding, cleaning and toileting people and that they often failed to account for people's social needs, to take a holistic approach...Community care for me...was about giving people the resources to lead an independent, flexible, full lifestyle and this is why I believe firmly that the individual must have the right to self-assess. I think to understand the importance of community care we must appreciate this: it is not a service that should exist to allow people to exist, it is one that should exist to allow people to live<sup>18</sup>.**



## Principles of Independent Living

Independent Living means having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.

With such support, disabled people can exercise their rights and duties of citizenship via their full and equal participation in the civic and economic life of Scotland – thereby changing the public misperception of them as being a drain on society's resources rather than an active contributor.

The principles of independent living - freedom, choice, dignity and control - do not only relate to specific services and provisions for disabled people, but to the whole of disabled people's interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life<sup>19</sup>.

<sup>17</sup> Jim Elder-Woodward (2011) 'Happiness and the Good Life' Speech to Campaign for a Fairer Society conference, 15 April

<sup>18</sup> Case study of Pam (2009) submitted by Independent Living in Scotland

<sup>19</sup> ILiS (2009) The Essential Guide to Independent Living

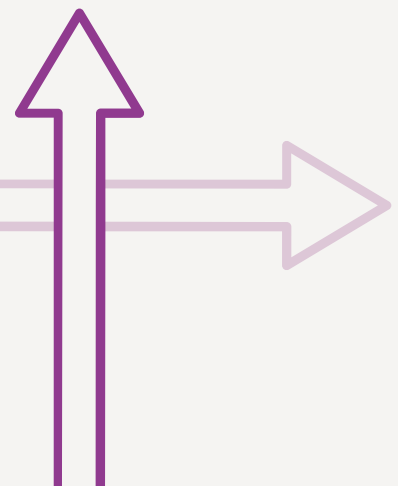
These principles are underpinned by the following 14 basic rights.

- **Full access to our environment**
- **Fully accessible transport**
- **Technical aids and equipment**
- **Accessible and adapted housing**
- **Personal assistance**
- **Inclusive education and training**
- **An income, including from the state-benefit system for those unable to work**
- **Equal opportunities for employment**
- **Accessible and readily available information**
- **Advocacy and working towards self-advocacy**
- **Counselling, including peer counselling**
- **Accessible and inclusive healthcare provision**
- **Communication and appropriate support for communication**
- **Civic participation**<sup>20</sup>

Before long, the stuff of rights to voice, choice, participation and so on bump up against rationing of care budgets. In many parts of Scotland, a ratchet effect is underway which leads local authorities to raise the threshold for basic homecare support (see box). Care packages for those with higher support needs are at risk, low-level/preventative support is being reduced and other needs go unmet. The recent Audit Scotland report on Social Care Commissioning confirmed that across Scotland eligibility criteria is being raised and charges increased. In order to protect care packages for those with higher support needs, lower-level support with a preventative value is being reduced or at risk of being withdrawn<sup>21</sup>. Embedding human rights and citizenship in decision making, assessment and service commissioning, procurement and delivery is even more crucial in this context.

<sup>20</sup> ILiS (2009) Essential Guide to Independent Living [www.ilis.co.uk](http://www.ilis.co.uk)

<sup>21</sup> Commissioning Social Care (March 2012) Audit Scotland



An example of the impact of this in practice can be seen in a consultation on care needs among people living with severe ME in Scotland conducted in Autumn 2011. Among its findings were:

- Almost all respondents needed help to care for themselves. Some found that the level of care required fluctuated, depending on the course of the illness. More than a third were relying on their spouse / partner or other family as primary or sole carer.
- Less than 10% of respondents were in receipt of local authority care/support, but around a quarter of respondents had some experience of local authority care previously – often negative. There was a perception that the needs of people with severe ME are not understood and that local authorities believe people with other illnesses and disabilities are more in need of their services.
- Most used the services of personal assistants, cleaners or other paid support staff. A quarter of respondents were paying for support staff from their personal income, no matter how limited, because they lacked access to appropriate funded care support.

## Social care and severe ME<sup>22</sup>

The following box contains some direct quotes from people living with severe ME and their carers:

### Care services lacking knowledge of condition

“

**I tried Local authority but had to give it up. The staff had no idea re. ME! They were loud; turned up at unexpected times and knew nothing about special diets.**

“

**I would rather go unwashed than put up with abuse from [care services]. You are constantly assessed/disbelieved and made to feel an undeserving burden to them. No privacy and totally humiliating. In [local area] the quality of staff is appalling....I'm too ill to be disturbed/woken up to deal with an unsympathetic person. I pay for someone to come in and help me out of my own benefit money. At least that way, I won't be abused but I can't afford to have them as often as I need to.**

<sup>22</sup> Examples from people with severe ME and their carers, submitted by the 25% ME Group

## Care packages under review or stopped

“

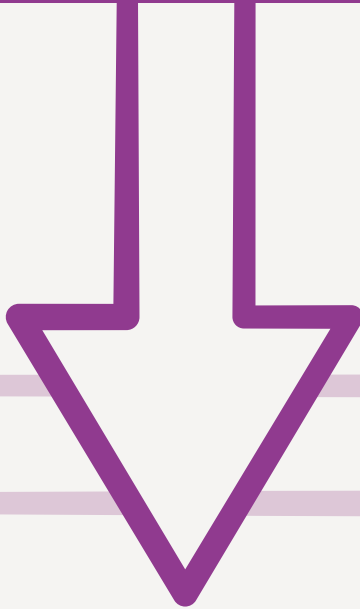
Short breaks service gives me 4 hours per week. This has been under review for about 15 months as the council want to halve the service because of cost involved. No decision has been made...The stress of not knowing the outcome is extremely wearing.

“

Care stopped on review after made complaint about home help and social worker.

“

My Care Services were recently stopped, even though I am no better. I had been receiving help at home from the local authority for over 20 years. I am now paying privately for home care.



## Unpaid carers

“

My family take care of me. Medical personnel have no conception of how ill this disease makes me feel and care staff have a disturbing apathy towards it. We'll go it alone as a family for as long as possible.

“

Local authority budget could run to only 4 hours care per week, contracted privately. I paid the remainder myself. Frequent change of personnel was tiring and stressing. My partner (now retired) cares for me full time.



More starkly, the case of *R (McDonald) v LB Kensington and Chelsea*<sup>23</sup> reveals how a stroke survivor was denied night-time support to go to the toilet by one of the most affluent councils in the UK. Taking the case to court, her appeal was lost on the grounds that providing continence pads for overnight use was sufficient to meet her right. Contrast this with the successful legal challenge by prisoners against slopping out. Their rights to dignity and hygiene were enforced when Justice Ministers and Prison Governors had failed, underlining the point that rights are not divisible according to where we happen to live. With this test case in London established, how will Scottish councils respond? And how can we embed citizenship in good decision-making – by negotiation and with consent – rather than having to resort to the law to secure our rights?

Amid this set of challenges, the Scottish Human Rights Commission's initiative Care About Rights offers a promising approach for social care in Scotland (box), both for care users and the care workforce.

## Care About Rights

Evaluation of the Scottish Human Rights Commission's Care About Rights project demonstrates the value that a human-rights based approach can bring to care and support services<sup>24</sup>. Between 800 and 1,000 care workers and managers have received training using the FAIR model (Facts, Analysis, Identification, Review).

This approach assists social care workers to involve service users, their families or their advocates in decision-making and deliver more personalised services, thus helping to shift the power balance in relationships between providers and users. Follow-up survey showed more than half said they were better able to involve care users and a further third said they expected this would happen in future. Care plans had been enhanced, even if the agreed approach did not change significantly, and the satisfaction of both care users and the workforce increased. The authors recommend that using person-centred, human rights based approaches becomes a core competence for the care workforce.

Rights-based approaches like Care About Rights need to become the norm. The consequent principles, values and ultimately legal protections should serve as the primary reference point for Health and Social Care Integration, Self-Directed Support and future reforms.

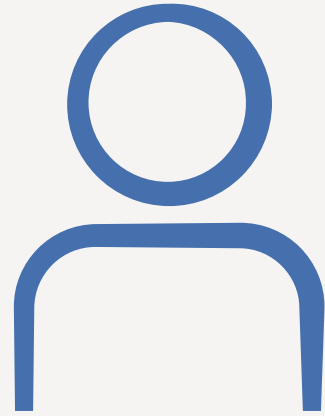


<sup>23</sup> L. Clements (2011) *Social Care Law Developments: A Sideways Look at Personalisation and Tightening Eligibility Criteria*, Elder Law Volume 1 Jordans: pp 47-52

<sup>24</sup> Kavita Chetty, John Dalrymple and Henry Simmons (2012), *Personalisation and Human Rights – A Discussion Paper*, The Centre for Welfare Reform, May 2012 [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

# 4

## ...And apply personalisation with a purpose



'Personalisation' and 'person-centred' approaches are increasingly the stuff of public service reform in Scotland. Can we safely assume these are good and helpful aims in their own right – or do we need to consider the assumptions and goals embedded within them? What's the point of personalisation?

The roots of personalisation can be found in the Independent Living Movement and, in part, from the values and principles of the social work profession. As part of the 21st century Social Work inquiry, Charles Leadbetter set out five types of personalised support ranging from services that are more 'user-friendly' and give users more say in how they are run to genuine co-production of services and enabling society to organise itself. The spectrum thus runs from improving current services to transforming whole service systems.

Despite these origins, a clear desire within personalisation to improve systems by placing individuals at the centre has lacked a consequent stress on their human rights. As a result,



**...much of the new autonomy proposed through personalisation has the feel of a set of 'privileges' that can be variously afforded, denied or withdrawn by professionals acting on behalf of the state through local government." (Chetty et al, 2012)**

The emerging National Person-centred Health and Care Programme (developing under the auspices of the Healthcare Quality Strategy and due for launch in autumn 2012) is a further opportunity to embed human-rights consistently across support and services.



## 4.1 Personalisation, independent living and integration

The Scottish Health and Social Care Integration agenda offers a valuable opportunity to apply the best thinking and practice on personalisation, but only if integration is rooted in a clear set of values and principles (a sentiment strongly echoed in the shared statement on Health and Social Care Integration<sup>25</sup> developed by the same partnership of organisations that have shaped this report). Lothian Centre for Independent Living offers clarity here: the most important of these is to expect personalisation to support people to achieve independent living. Personalisation should thus be approached explicitly as a means to this end rather than an end in itself. And this, in turn, is only likely to happen consistently by applying human rights based approaches (See box).

### Personalisation: on the road to Independent Living?<sup>26</sup>

Many disabled people in Scotland identify 'independent living' with getting on with their lives without having to negotiate continuous obstacles imposed by society. In contrast, 'personalisation' and taking a 'person-centred approach' are considered as terms developed by care professionals. These may be more enlightened than what has come before, but they tend to lack a clear connection with rights expressed in everyday living. Many disabled people focus on achieving independent living as the overall aim.

Independent living is more than the individual service user's relationship with a particular service. It is about removing barriers within each area and in connection with others. With the Social Model of disability at the core of thinking and action, personalisation would become a process on the way to delivering something bigger. To live an independent life, where people have choice and control over the way they live, is not something that can be defined by professionals but a common human desire. How services support people to achieve independent living is a key process, but only a process.

Making personalisation the aim of integrating health and social care services, education or housing is thus likely to limit our ambition. Instead, independent living is about ensuring that the services which many disabled people rely upon actively remove barriers and open up opportunities - and that professionals become, themselves, agents of change alongside disabled people. Rooting personalisation within the social model of disability and independent living principles will lead to a shift in understanding and relevance to practitioners.

Personalisation needs to be seen as one important element on the road to making independent living the focus of strategic decisions at national and local level, and the practice focus of managers and front-line workers. If independent living is the goal, then personalisation becomes meaningful and relevant to the process. In that context, necessary changes (and difficult decisions) in service planning, development, commissioning and evaluation can be approached with a common understanding of independent living as the goal.

<sup>25</sup> Integration of Adult Health and Social Care in Scotland: A Shared Statement from Third Sector Organisations (July 2012) Published on [www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)

<sup>26</sup> Based on 'Personalisation and Independent Living – are they connected?' Paper submitted by Florence Garabedian, Lothian Centre for Inclusive Living

In response to the Scottish Government's consultation on Integration of Health and Social Care, third sector organisations have called for:

- A duty on proposed Health and Social Care Partnerships to demonstrate due regard for human rights.
- A focus on the leadership role of people using services, including their involvement in improvement, scrutiny and evaluation.
- Full involvement as voting partners in strategic planning and investment decisions made through joint commissioning, and in locality planning processes.<sup>27</sup>

And in its submission to the Scottish Parliament's Public Audit Committee inquiry on integration, the Coalition of Care and Support Providers (CCPS) distinguishes between barriers to closer partnership working that can be addressed by legislation (structures and processes) and others (notably cultural differences) more amenable to staff development, better management and leadership approaches. The integration agenda should not focus narrowly upon technical matters that legislation can address.

Much third sector provision takes place 'upstream', helping to prevent escalation of need and reducing demand for more costly and complex services later on. Fully integrated health and care budgets ought to reduce the likelihood of 'cost-shunting' between local government and NHS budgets, but it should also encourage greater focus on the third sector's role in keeping people with long term conditions well and safe. Many discussions on integration have as their goal closer working arrangements between the NHS and local government, but most social care support is provided by families, unpaid carers, the third sector and private sector organisations. A wider form of integration is needed – with a deeper set of partnerships.

The initial focus of integration is upon reshaping older people's services. This is essential, but the potential benefits of integration for people of working age with impairments, mental health problems and other long term conditions, as well as for children and young people, need to be worked through as well. The main reasons for integration for this wider population are not related as closely to the acute health sector as for older people and it is essential that 'broad integration' is pursued on an all-age basis. Finally, integration will work best for people with long term conditions if it is designed to make delivery of Self-Directed Support easier.



<sup>27</sup> Integration of Adult Health and Social Care in Scotland: A Shared Statement from Third Sector Organisations (July 2012) Published on [www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)

## 4.2 Through the lens of Self-Directed Support

Self-directed support (SDS) represents a clear means to extend personalisation and creates a solid platform to build on. In line with the case developed so far, it should be implemented in a way that enables independent living and expresses human rights principles:



**The SDS Bill is intended to empower more people in Scotland to direct their care – to have informed choice and control about how their support is provided – and thus represents a major opportunity...There is a risk, however, that unless deliberate steps are taken to address the human rights deficits and power imbalances, there will be too narrow a focus on the system and process changes required to implement the mechanisms of SDS; and existing managerial and clinical models of service delivery will persist<sup>28</sup>.**

The Self-Directed Support (SDS) Bill (still progressing through the Parliamentary system at the time of writing) is thus a significant moment for Scottish policy-making. What kind of reform is called for, and to what end?

Participants in this project used different images. Some see SDS as ‘a battering ram’ into a system that is stuck. Others see it as ‘a scalpel’ to be used with skill, or use the metaphor of acupuncture in order to improve flow within a care and support system that is blocked. Either way, SDS needs to be part of a profound shift in culture, assumptions and behaviour on the part of service commissioners and providers in how capacity and need are defined; how support is sourced; and how services involve citizens.

Self-Directed Support is widely seen as a major force for change. The Self-Directed Support (SDS) Bill seeks to establish a legal right to informed choice and greater control over the type of support used by people with social care needs. Greater use of Direct Payments is one of four options (see below) on a spectrum which includes the local authority continuing to commission or provide care services directly and intermediate levels of user involvement. The Bill<sup>29</sup> sets out the Scottish Government’s aim of making it easier to secure rights, support independence and greater participation as long as the principles of informed choice and control are implemented in both process and outcomes as planned.

To have genuinely informed choice, many people will need timely access to independent information and guidance when support options are being considered. The Bill recognises this but underplays the need for advocacy to support the choices people make. This is important for all users of SDS but particularly important for people with communication impairments, learning disability or simply due to frailty and lack of family support. A crucial part of this is also peer support, so that people can not only see the potential in what is possible, but can learn from the ways others have managed and used their support. There is no recognition of this in the Bill.

<sup>28</sup> Chetty et al (2012), p.17

<sup>29</sup> Scottish Parliamentary Corporate Body (2012) Social Care (Self-directed Support) (Scotland) Bill, 29 February; and Scottish Parliamentary Corporate Body (2012) Social Care (Self-directed Support) (Scotland) Bill: Policy Memorandum, 29 February

Nor does the Bill address the need for emotional, psychological and mediation support, for example in families where care users, carers and other family members may have quite different views of the best outcomes. But it does propose a new power for local authorities to meet the assessed needs of carers using a range of options under SDS. This power represents a step further towards the rights of carers being recognised more fully, though it is not a duty.



Overall, the SDS Bill may represent the best prospect available to shift the balance of power towards users of support and services, not just the balance of care towards home and community. SDS also represents a vital mechanism to enable people to combine formal services and other support (for example from family, peers or local community) to produce the best outcomes and value.

The ALLIANCE and its partners believe a robust approach is needed to ensure:

- sufficient investment to build up independent advice capacity;
- training for both social care and NHS staff on how to implement SDS well;
- greater clarity over the interplay between SDS and the Reshaping Care for Older People, Health and Social Care Integration and Person-centred agendas;
- independent evaluation of progress and pressure to reduce variations in performance across Scotland including national measures of success; and
- ongoing involvement of those using care & support and their carers, at local and national levels, including as part of local strategic commissioning processes.

On the second of these points, participants in the Social Care Dialogue Event in September 2011 were keen to stress that the social care workforce, numbering almost 200,000 in Scotland across private, public and voluntary sectors, often perform roles that are low paid, carry low status and attract too little support. Audit Scotland's inquiry into social care commissioning<sup>30</sup> reminds us that those employing paid care workers (with the exception of Personal Assistants) must comply with Protecting Vulnerable Groups (PVG) regulation and qualification-based registration with the Scottish Social Services Council (SSSC).

**30** Audit Scotland (2012) Commissioning Social Care [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk)

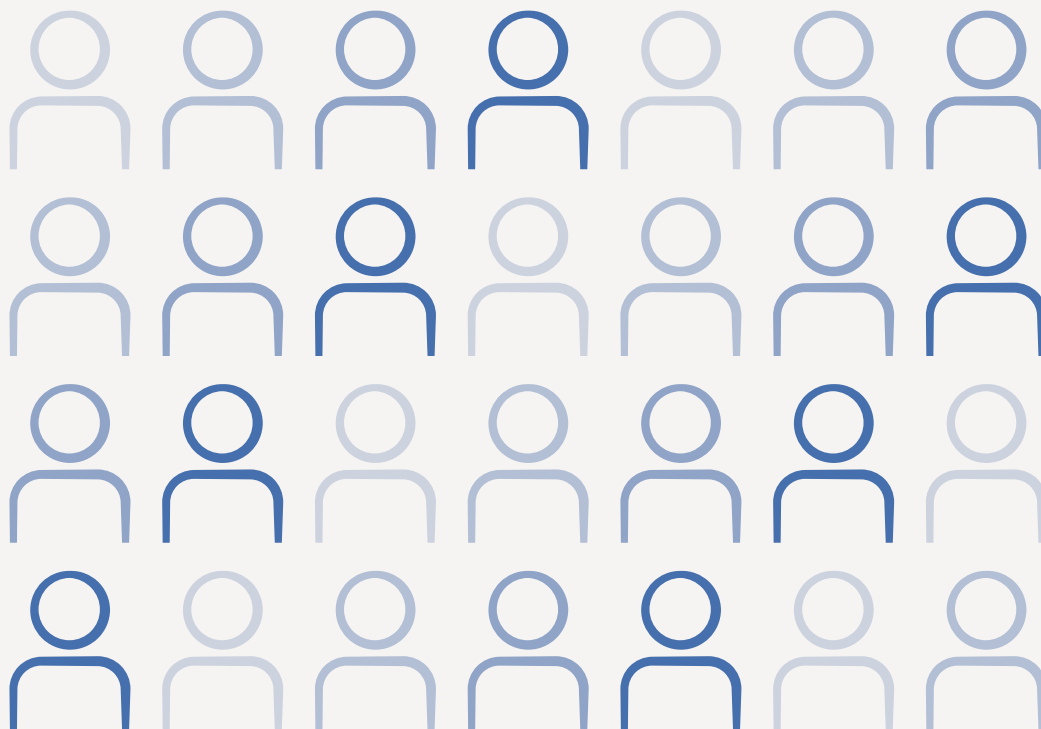


**It seems to be a race to the bottom in terms and conditions for staff – to get the most for least. This has serious impacts on the quality of staff.**

Third sector focus group participant, quoted in Audit Scotland Commissioning Social Care Report<sup>31</sup>

The rights of staff need to be protected as well, to ensure the rights of those they support are secured. So, as well as training in how to demonstrate the SDS principles on an everyday basis and how these apply specifically to people with long term conditions, in-work poverty needs to be tackled through paying a living wage and opportunities for skills progression for care workers. Rights-based approaches need to sit within a framework of responsibilities which places the individual's choice and control at the centre of decision-making while balancing this with responsibilities to safeguard the individual from harm, the broader public interest and the rights of others including those unregulated parts of the care workforce<sup>32</sup>.

Although our focus is upon social care, people with long term conditions want to live fulfilled lives where rights, independence and participation are reflected in other areas. Housing and transport were identified as particularly important, especially in rural and remote areas. The recent housing strategy for older people<sup>33</sup> provides an opportunity to extend investment in lifetime housing with appropriate local support to disabled people and people of all ages with other care needs. Further work on housing adaptations and equipment is underway. The interface between housing support, extra-care housing and social care is one that ALLIANCE members should explore further, for example through the work of Care & Repair agencies.



<sup>31</sup> Audit Scotland (2012) Commissioning Social Care [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk)

<sup>32</sup> Chetty et al (2012)

<sup>33</sup> Scottish Government & COSLA (2011) Age, Home and Community

## Experiences with Direct Payments

One of the four options within SDS is to receive a Direct Payment (DP) where people can source and pay for their preferred package of care and support. A very small number – about 4,400<sup>34</sup> – have Direct Payments currently. Most people use support delivered by a private or third sector organisation commissioned by local authorities. The biggest potential with SDS may be to expand the use of intermediate care options, where people take on more control through informed choice and combine elements of directly-purchased support with other care services. Although based on a small number of cases, it's worth considering the experiences of people with long term conditions who use Direct Payments. Many report feeling in control of their lives again as a result of the greater flexibility in care achieved:



**When I had agency care, I was miserable. I saw so many different carers, each one of whom I had to teach how to look after me, and I had little control over when they came and what they did. Now I know exactly who is coming when, and I am in control over what they do and when. I am happier to have the responsibility of managing a group of carers, to cover all my hours, and who I have chosen by interview...I am so fortunate to have found caring, loyal and flexible staff. New carers learn from each other, and all have absorbed a lot of information about my condition, and it affects me. This system works for me<sup>35</sup>.**



In some cases, people may come into contact with a very large number of home-care workers over a short space of time<sup>36</sup>. Alzheimer Scotland has assessed the experiences of a group of people with dementia and their carers using Direct Payments as part of a pilot initiative in Ayrshire, identifying the potential as well as the drawbacks of this option for a group of people who would normally have little choice of care services<sup>37</sup>.

Some see individual budgets including Direct Payments as a 'positive disruption' to the social care market. By devolving control to people with long term conditions and carers over how budgets are used, new patterns of demand and supply are likely to emerge. Block contracting of short home care packages would then be eroded and the sense of empowerment or user control increase. The cost/benefit balance for individual budgets is touched upon later (see proposition 8).

<sup>34</sup> Audit Scotland (2012) Commissioning Social Care [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk)

<sup>35</sup> 'My experience of Direct Payments' by Lyn, ME Quarterly

<sup>36</sup> 'Aberdeen dementia patient had 106 carers' 18 May 2012 [www.bbc.co.uk/scotland](http://www.bbc.co.uk/scotland)

<sup>37</sup> Alzheimer Scotland (2011) See Let's get personal - personalisation and dementia and Taking Charge - a short guide to self-directed support for people with dementia and their carers.



However, some are concerned that, if left to the market only and in the absence of clearer guidance on commissioning and planning, the positive scope of SDS – or personalisation more broadly - may be undermined. For example, we have heard from a mother diagnosed on the autism spectrum who has at least one child with an autism diagnosis. Her concern is that personalisation approaches may fail to support the family unit if each person is being treated as an individual with their own 'personal' plan. Family, peer-group and potentially community based models of support may be equally valid ways for people to make the most of personalisation.

And other reservations have been expressed. The very low take-up of Direct Payments reflects limited awareness among users and reluctance among providers, as well as negative experiences of trying to apply and giving up. One woman contrasted her positive experience while living in South-East England with the hurdles encountered when she moved to Scotland:



**Even the person at the care agency was absolutely convinced that [the Council] were trying to stop people because it was so complicated – it wasn't just me – normal, well people looked at it and blanched – "I couldn't do that." How anyone could think that anyone who is ill enough to need care could do that is beyond me... I was presented with awful material that reflected a horrible attitude – prospective applicants are treated like criminals as the attitude seems to be that you are going to try to rip them off. The amount of feedback required was worse than doing a tax return<sup>38</sup>.**

In terms of recovery and preventing further ill health:



**If [care] services had been in place, my health would have improved. Now I need more help rather than less. What time and energy I've had has been spent on trying to survive and get the basic care. I wanted to be putting my energy into getting better<sup>39</sup>.**



<sup>38</sup> Direct Payments case study submitted by The 25% ME Group

<sup>39</sup> Ibid.

We know that awareness and take-up of Direct Payments is lowest of all among frail, isolated people including older people who lack informal support. People who live alone or are very ill may lack the support that others can count on to make the process work:



**In theory direct payments is a brilliant idea [but]...it turns ill people into employers. Keeping up with the administration side is very tiring. More of a problem is the stress associated with all aspects of recruiting and supervising a carer in your house. If you are only having a few hours each day it is very difficult attracting applicants. I have had two amazing personal assistants (one was a friend before) and three who were really awful...actually disabling me. They made my life very, very unpleasant. I lost a lot of sleep, so became even weaker, less able to do things and depressed. Getting rid of them was extremely stressful. I am now back to just having agency care. At least if they send someone I don't like, I can refuse to have them again!<sup>40</sup>.**



We also know that even when Direct Payments usually work well, people can still end up with poor experiences if they need to go into hospital. To understand the scope and limits of this form of SDS, it's important to delve below the surface of these experiences to consider why they occur. Rather than seeing a specific option as positive/negative or better/worse than others, we need to switch our focus onto appropriate options based on informed choice with guidance and ongoing support where necessary.

By placing the emphasis on informed choice as the new default setting within social care, SDS can take us beyond a debate about single solutions. Whichever options are chosen, SDS must push ahead with cultural change in how mainstream care services support people with long term conditions. Where people lack the capacity to speak up for themselves, are too fearful to speak up or just too grateful for any care support, independent information, guidance and advocacy can assist people to achieve the best form of care. User-led organisations and condition charities can provide a vital role here. Although investment to build this kind of capacity could be viewed as diverting money from frontline care and support, the aim should be to invest in achieving better outcomes and value for money by ensuring care is appropriate.

<sup>40</sup> 'My experience of Direct Payments' by Wendy, ME Quarterly.

## All-age integration, all-age SDS

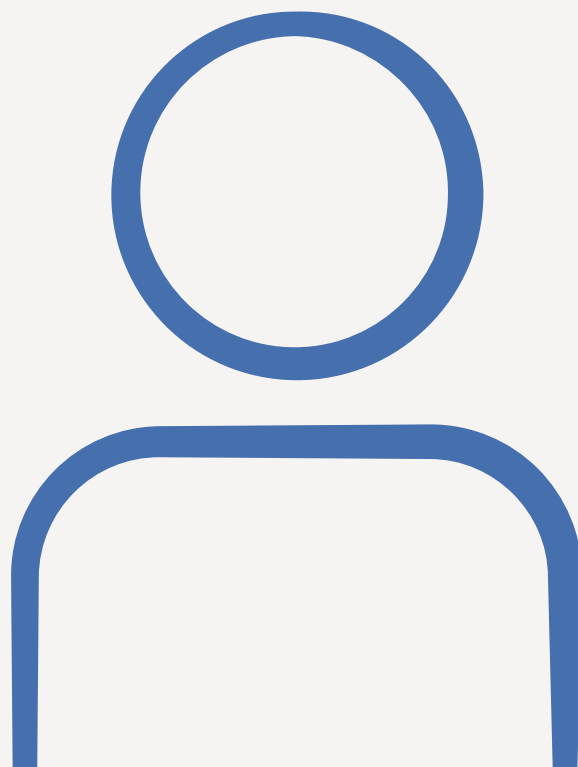
We need to avoid the risks of:

- achieving integration for older people's health & care, but without properly extending the principles of Self-Directed Support principles to older people;
- pursuing the SDS principles for adults aged under-65, but without the integration agenda working to address their needs.

Both integration and SDS strategies need to be understood and delivered as all-age reforms.

In addition, person-centred approaches are becoming more evident in other ways. Talking Points offers a well-developed model for embedding a personal outcomes approach within services, and for supporting individual health and social care practitioners to work in a person-centred way. Talking Points was developed within social care settings but there is now work being undertaken to explore its use within health services. (The NHS Quality Strategy also adopts person-centredness as a key principle). This is being taken forward by the ALLIANCE, in partnership with the Scottish Government (Joint Improvement Team and Better Together) and others at the direction of the Quality Alliance Board. Talking Points has been evaluated by IRISS See:

<http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/>



## 5

## Decide what kind of prevention we seek



Prevention – and specifically preventative spending – has quickly become a guiding principle in discussions of Scottish policy. Encouraged by the independent Beveridge Review and Christie Commission, as well as the Finance Committee’s work at Holyrood, prevention may be written in as a permanent strand in the Scottish Government’s Economic Strategy. This is driven by the projected 11% cut in public spending by 2014-15, but it would be a mistake to see prevention as just about saving money. Applied with care, it should also contribute to better outcomes – for example, by ensuring people receive support at the right time, when they can benefit most, in order to recover or stay well for longer. Getting better outcomes can only be done by reducing demand where possible<sup>41</sup> and by using the available resources we have more productively. The third sector has a significant role to play in providing a wealth of low-level, low-cost support that enables people to manage long term conditions and maintain their health and wellbeing, while the contribution of the independent sector as the largest provider of care services needs to be understood more clearly as well.

We need to ‘unpack’ the concept of prevention further if it’s to be useful in reforming social care. For example:

- From a whole population or public health perspective, high blood pressure, cholesterol and obesity are risk factors in some cases of stroke, diabetes and vascular dementia.
- On an everyday basis, boosting the protective factors that enable us to live with long term conditions also feeds into managing future demand, for example support to widen and maintain social networks, take exercise and access “that bit of help” with gardening, housework and simple repairs. We know a lot about the importance of friendship ties and leisure interests in enabling people with dementia to stay active in the early stages of the disease. Alzheimer Scotland propose a three-person team made up of a CPN, social worker and link worker supporting around 150 people with dementia in the early period following diagnosis. The team would be “skilled in both dementia practice and person-centred approaches...planning exceptionally high quality and creative personal support solutions for each person”<sup>42</sup>.
- In turn, these can help to delay the need for higher-cost care. Prevention might mean deferred use rather than never having to use day-care, go into hospital or residential care.

<sup>41</sup> L Bunt and M Harris with R Puttick (2010) *Radical Scotland: Confronting the challenges facing Scotland’s public services*, London: NESTA

<sup>42</sup> H. Simmons (2011) Speech to Glasgow Dementia Convention, March.

- The extent and cost of service use can also be reduced by investing in the sustainability of unpaid care. Preventing carers experiencing crisis is an integral part of the agenda. For example, support for the family of people affected by stroke is linked with a reduction in depression of up to 27% and a reduced need for physiotherapy<sup>43</sup>. The projected doubling in homecare budgets through Reshaping Care for Older People (RCOP) is a major opportunity to ensure support becomes more responsive and enabling.
- And where people are already part of the social care system, secondary prevention can stabilise or reduce demand over time, for example by cutting the risk of another stroke and through targeted support for re-ablement (see box).

## Homecare re-ablement

Homecare re-ablement provides a relatively new focus on helping people to recover their ability to take care of themselves on a daily basis following a period of illness or incapacity. Typically, a six-week period of support is provided to help with washing, dressing, cooking and toileting. At this point, a fresh assessment of capacity and need takes place. The evaluation evidence from Edinburgh (after 12 weeks)<sup>44</sup> and five English local authorities<sup>45</sup> (after 1 year) is broadly positive. Re-ablement led to a 60% decrease in the cost of care services used over 12 months compared with conventional home care users. These lower costs were offset by the higher cost of the re-ablement itself, so net savings were marginal. However, quality of life measures were higher than in the control group. In future, the longer-term benefits of re-ablement remain to be tracked and its impact in extra-care housing and residential care compared with that in 'ordinary' housing.



<sup>43</sup> Princess Royal Trust for Carers and Crossroads Care (2011) Supporting Carers: The case for change

<sup>44</sup> IRISS (2010) 'Effectiveness of re-ablement services' Insights No.3 [www.iriss.org.uk](http://www.iriss.org.uk)

<sup>45</sup> Glendinning, C., Jones, K., Baxter, K., Rabiee, P., Curtis, L., Wilde, A., Arksey, H. and Forder, J. (2011) Home care re-ablement services: investigating the longer-term impacts, Research Works, 2011-01, Social Policy Research Unit, University of York, York <http://php.york.ac.uk/inst/spru/pubs/1905>

# 6

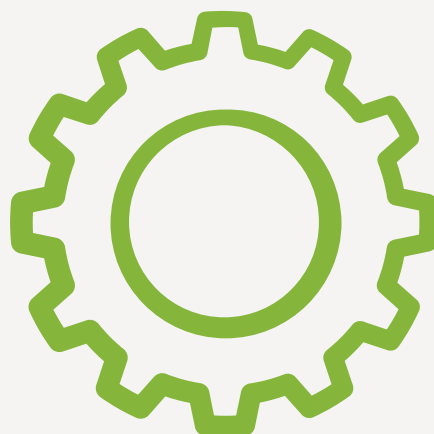
## Balance generic and specific approaches



One tension running through social care is how far generic approaches can be expected to work for people with different conditions types – and for that matter, different experiences of the same conditions. Good generic approaches like person-centred planning and a focus on independent living will apply to all long term conditions. Generic advocacy networks can work with condition specialists (both professionals and peers) to extend their support to people who might otherwise not be able to access it. Examples include the Stroke Association’s partnership with the Scottish Independent Advocacy Alliance which helps local advocacy organisations to provide appropriate advocacy services to stroke survivors; including those with communication difficulties.

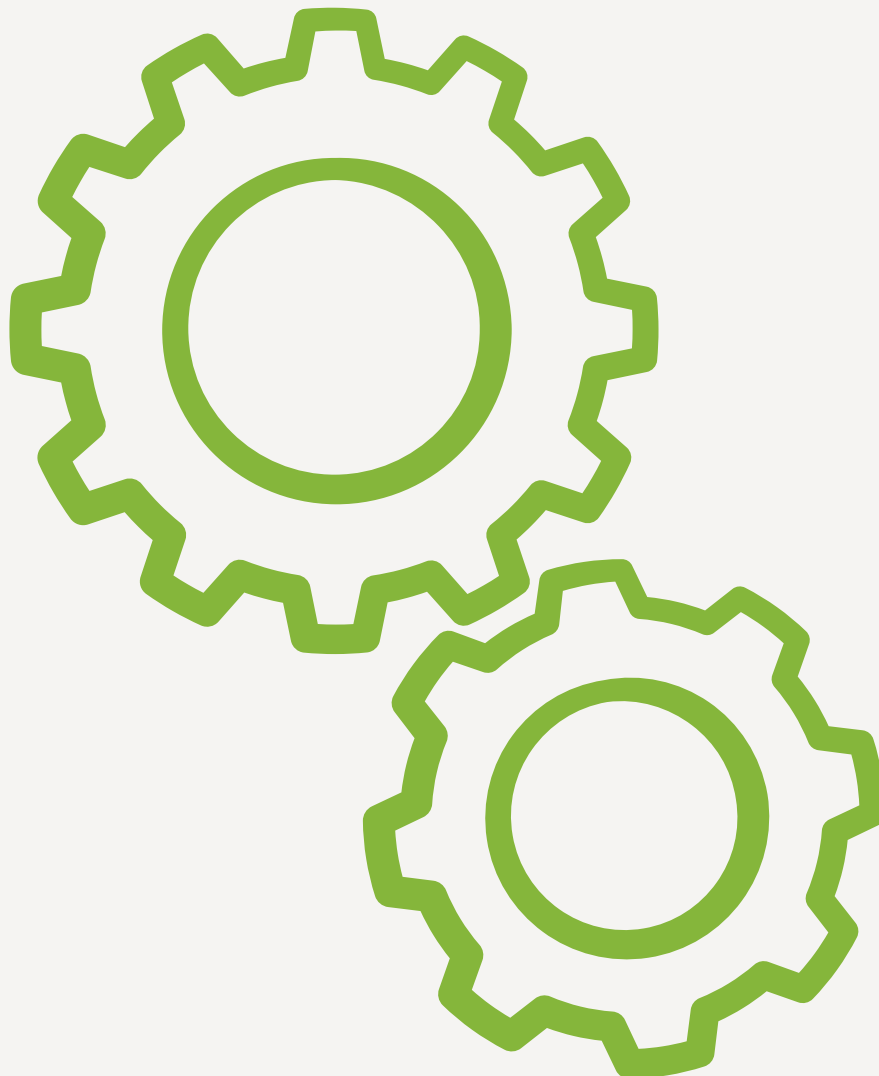
One motivation for this project is the view that the NHS tends to see only the clinical dimension while, for the bulk of service users, social care tends to focus on basic ‘time and task’ activity to enable people to function. Both of these have an important place in the mix (see proposition 7), although home-care visits of only 15 minutes are likely to be inadequate in many cases. Neither is adequately skilled in addressing the changing emotional and psychological side of the care equation, or in ensuring the right to participate in society is secured. More insight within the NHS on what it takes to live well, and within social care on common features of specific conditions, would help. Examples include:

- Risks to personal safety for people with Alzheimers as their condition progresses.
- Undiagnosed depression among Stroke survivors and their carers related to identity shift and sudden changes in roles.
- Unpredictable medication needs among people with Parkinsons disease.



These circumstances are not unique to each condition, but they illustrate the need for social care providers to understand and address possible consequences. Social care staff may be unable to give medication if someone can't self-medicate due to cognitive impairment or reduced dexterity and medicines aren't pre-packed or are needed on a responsive basis (e.g. due to increased pain). Home carers may be well-placed to spot the difference between having depression and just a bad day, but may not feel skilled or authorised to act.

25Condition organisations take different approaches to improving specialist knowledge in the community as well as in hospitals and care homes, including specialist nursing staff, developing training guidance in partnership with NHS NES, awareness-raising for Social Work managers and homecare staff. There's a strong case to develop care qualifications that enable practitioners to address more complex circumstances, rooted in rights-based approaches like the FAIR model (Proposition 3). The Intermediate Care capability framework serves as a 'multi-agency novice' to the expert practitioner framework, adopting 10 essential shared capabilities for staff. However this is done, investment is needed in self management, peer support and training for unpaid carers at the same time.



# 7

## Create a system for wellbeing - not just better social care services

Putting these elements together – rights, personalisation, prevention – we have a picture emerging that adds up to more than social care reform. ‘Social care’ will probably keep an in-built default to the ways things have usually been done for most service users. Even ‘service users’ becomes a tricky concept, implying that we make use of something that exists ‘over there’, that’s already prepared. When we’re getting better at defining outcomes, it might be better to set our sights on the contribution that social care ought to make to our lives.

The approach suggested is:

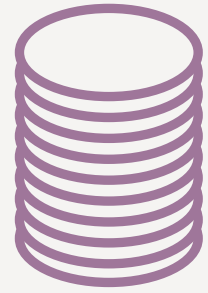
- we apply ourselves to putting these attractive elements into practice, consistently well
- we add in a more sophisticated approach to health care which is able to address complex and multiple conditions in the round
- we recognise that time and task activity is often necessary to enable people to function but time committed is often inadequate and it isn’t sufficient to help them live well
- we strive to go beyond the limits of ‘social versus medical models’, recognising the inherent dangers of vacating the pitch when it comes to how the NHS also needs to be personalised for people with long term conditions and impairments
- we share the common goal of living well and independently for as long as possible with long term conditions
- and we create a system for wellbeing to express this goal...
- which spans the dividing lines between age groups, physical and learning impairments, physical and mental health conditions...
- with social care reforms being one significant contributor to a system for wellbeing.



This points to an understanding terms like 'independent living' and 'empowerment' not as ends in themselves, but as rights through which we manage to live well with long term conditions whether the pathway we are on involves recovery, stability, degenerative or terminal illness. The policy goal of enabling people to stay in their own homes - 'supported to enjoy full and positive lives in their own home or in a homely setting' - lacks sufficient emphasis on getting out, being involved in the community and maintaining social ties. It might in some cases be shoring up loneliness or increasing the stress upon carers. When we check against the goal of wellbeing, we're prompted to look at what kind of support could enable someone to get out of the house safely, be involved in the community or get respite when it would seem easier in the current system, at some level, not to. Defining our goal as a system for wellbeing is not about semantics or avoiding hard choices. Nor is it in any way a new idea. Instead it requires us to change what we invest in and how we judge effectiveness; the mix of people involved and the relationships between them; and the governance system that underpins the shift. We consider these elements next.



## 8



## Use money for change

To begin with, money needs to follow the best of the evaluation evidence available. After more than a decade of policy-makers signing up to the mantra of ‘what works’, it’s striking how the evidence rarely plays more than a minor role in long-term change. Of course, evidence isn’t all that counts. It’s not value-neutral, it’s never definitive and there are usually risks in translating findings from pilots or test cases into mainstream practice. But it ought to count for more. Many large-scale policy evaluations come from England and it’s understandable – if often mistaken – to assume a different policy environment means the evidence is not directly relevant. Usually, there are enough good insights to enable Scotland to adapt the evidence when appropriate. Even where we do have robust, home-grown evidence, we may be unable to track whether this has influenced investment decisions in local authorities<sup>46</sup>.

Evaluations of social care change tend to look at both the overall costs/savings and the benefits in psychological wellbeing, capability, satisfaction and feeling in control of daily life. Budget savings can be found across various elements of a programme even if total net savings are relatively small or appear over a period of years. More significant savings include the social return on investment attributed to greater capacity in Carers Centres<sup>47</sup> and the early planning approach advocated by Alzheimer Scotland soon after dementia is diagnosed<sup>48</sup>. It is estimated that a delay in using long term care of four weeks would fund post diagnostic support for a year.

In many cases, the quality of life benefits are significantly higher than any net savings, so that the chances of deferring or avoiding high-cost care later (i.e. outwith the scope of most evaluations) are increased. The limited evaluation evidence we have to date on individual budgets in England suggests that overall service costs are only slightly lower for budget-holders compared with others using traditional care services, but on a cost-effectiveness basis many outcomes are better. The table (over) gives a brief summary of evaluation findings on homecare re-ablement, self-assessment and individual budgets<sup>49</sup>.



<sup>46</sup> For example the Working for Families programme: see findings on the implications for policy and practice by Ron McQuaid and colleagues at Napier University: [www.jrf.org.uk/publications/how-parents-escape-recurrent-poverty](http://www.jrf.org.uk/publications/how-parents-escape-recurrent-poverty)

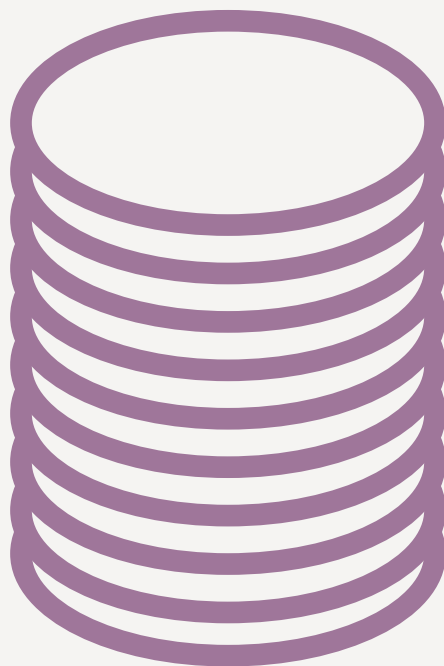
<sup>47</sup> J. Clifford, C Theobald and C Mason (2011) The Princess Royal Trust for Carers: Social Impact Evaluation of five Carers’ Centres using Social Return on Investment, The Princess Royal Trust for Carers

<sup>48</sup> See for example Henry Simmons (2001) speech to Glasgow Dementia Convention, March

<sup>49</sup> IRISS (2010) ‘Effectiveness of re-ablement services’ Insights No.3, ‘Self Assessment’ Money Matters case study 6 and ‘Individual Budgets’ Money Matters case study 7 [www.iriss.org.uk](http://www.iriss.org.uk)

Other relevant evidence includes:

- A Finnish approach to dementia family care co-ordination: providing intensive community-based support delayed early admission to residential care. After two years, the likelihood of being in residential care was the same as for the control group<sup>50</sup>. The longer-term outcome does not diminish the savings and benefits achieved in the first two years.
- A large-scale telecare approach in two English counties ('Safe at Home'): reduced stress on carers, helping 60% of people with dementia to remain at home after 2 years compared with 25% in the control group<sup>51</sup>. Findings from the Delivering Assisted Living Lifestyles At Scale (DALLAS) telecare initiative in Scotland will increase our understanding of effective approaches in different places/circumstances<sup>52</sup>. A recent summary of evidence by IRISS identifies the benefits of telecare for unpaid carers<sup>53</sup> and concludes that the input of carers into telecare service design and delivery is necessary to ensure that outcomes for carers (and those cared for) are maximised and sustained.
- A community network of mental well-being cafes and related activities for older people in Bradford ('Health in Mind'): a ten-year programme including specialist support for people with dementia and for Asian elders. After five years, the benefits outweighed the costs with substantial savings projected after ten years<sup>54</sup>.



**50** T Poole (2006) Dementia Care, Background paper to Securing Good Care for Older People, Wanless Social Care Review, London: The Kings Fund, p.11 [www.kingsfund.org.uk/publications](http://www.kingsfund.org.uk/publications)

**51** T Poole (2006) Dementia Care, Background paper to Securing Good Care for Older People, Wanless Social Care Review, London: The Kings Fund, p.12 [www.kingsfund.org.uk/publications](http://www.kingsfund.org.uk/publications)

**52** See Joint Improvement Team for information on the DALLAS programme <http://www.jitscotland.org.uk/publications-1/telecare/>

**53** IRISS (2011) Supporting unpaid carers: the benefits of telecare Insights 08 <http://www.iriss.org.uk/resources/supporting-unpaid-carers-benefits-telecare>

**54** IRISS (2010) 'Health in Mind' Money Matters case study 3 [www.iriss.org.uk](http://www.iriss.org.uk)

Type of support	Evaluation findings
<b>Re-ablement</b>	Re-ablement led to a 60% decrease in cost of care services used over 12 months compared with conventional home care users. These lower costs were offset by the higher cost of the re-ablement itself, so savings were marginal. Quality of life measures were higher than in the control group.
<b>Self - assessment</b>	Self-assessment pilot for older people with low-level needs: this approach was 70% cheaper than a care manager assessment, while satisfaction levels and the cost of services used were similar.
<b>Individual Budgets</b>	IBs found to be most effective for psychological well-being and social care outcomes for mental health service users, then for younger people with physical disabilities and least so for older people. Overall costs are only slightly lower than for the comparison (non-IB) group, but feeling in control of daily life was significantly higher.

What might we conclude from this brief look at evaluation findings? First, we need to take care not to extend the evidence too far. For example, the self-assessment example in the table showed significant costs savings and take-up of a wider range of light-touch support services at an early stage - but only for older people with low-level needs. It would be mistaken, to say the least, to move all older people inquiring about social care over to self-assessment and expect a 70% cut in assessment costs. Second, we need to be patient and measure impact over time. An early evaluation of Bradford's 'Health in Mind' programme would have looked much less promising than the picture by the fifth year.

If we have decent evidence of approaches that deliver better outcomes and either cost less or are revenue-neutral, why aren't they the norm? In part, this must reflect the in-built tendency for systems to replicate themselves. In Scotland, policy-makers are acutely aware of the costs locked into default use of hospital for emergency admissions among the over-70s<sup>55</sup>. The Change Fund to reshape older people's care is a brave attempt to provide bridging finance for community alternatives. An indication of whether the tide is turning will be when it's easier to get rapid 'step-up/step-down' social care and essential medical support in the community

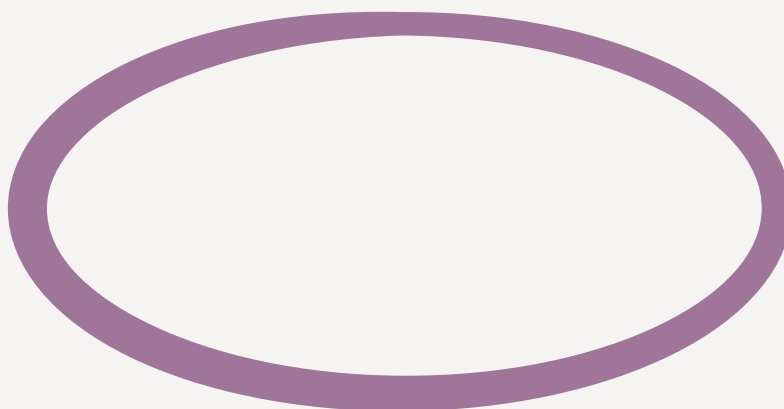
<sup>55</sup> Evaluation of the Partnership for Older People's Projects (POPP) in England showed positive cost-benefit returns on local support for prevention, but the savings remain with the NHS. See McCormick et al (2009) *ibid*. Also see IRISS (2010) 'Southwark Hospital Discharge' Money Matters case study 8 [www.iriss.org.uk](http://www.iriss.org.uk)

overnight and on weekends than to get a hospital bed; and easier for someone with dementia to access a more flexible support package rather than taking the 'care escalator' from a few hours of home-care straight into residential care. Ultimately, the more flexible use of home-care, extra-care housing and residential care – including short-term rehabilitation – depends on service commissioners (see proposition 12). As early signs of progress, the time spent as emergency hospital admissions by people aged over 75 fell by 6.5% in the year to November 2010 and the proportion of people aged 65 and over admitted as emergency inpatients more than once within a year fell in the same period after rising steadily in the previous decade<sup>56</sup>.

In the meantime, a consistent message from respondents to the project was: beware competition for less money between people with different levels of need (low-moderate versus acute); condition types; and age groups. While there is strong support for reducing demand through the approaches discussed here, there is also concern about the short-term threats: "It's going to get rough out there."

Faced with the current content, it seems clear that we should broaden the lens to consider the full set of resources – money and people (proposition 9). More investment will be needed beyond the Change Fund to ensure low-level support is not neglected. It's possible that ambitious thinking on social impact bonds will deliver for social care in future. But before then, alternative priorities could be set within future Scottish spending reviews to ensure a bigger budget for prevention – not just ear-marked within the existing social care budget, but looking across the full devolved budget.

Given the significance of social care in protecting human rights of people with long term conditions, it is not self-evident whether and how far the costs should be passed to the care user. This agenda sits within the context of tightening resources, but equally should be understood for the role it plays in protecting rights. For this reason, we need a more open debate on both the value of social care and the way we should pay for it in Scotland. An independent inquiry into social care funding for all ages, not limited to paying for older people's care, would be a logical move ahead of SDS being implemented and in particular to grapple with the issues of Health and Social Care Integration in a context where health services are universal and free of charge, whereas social care services are rationed and charged for.



<sup>56</sup> See Scotland Performs indicators [www.scotland.gov.uk/About/ScotPerforms/indicators](http://www.scotland.gov.uk/About/ScotPerforms/indicators)

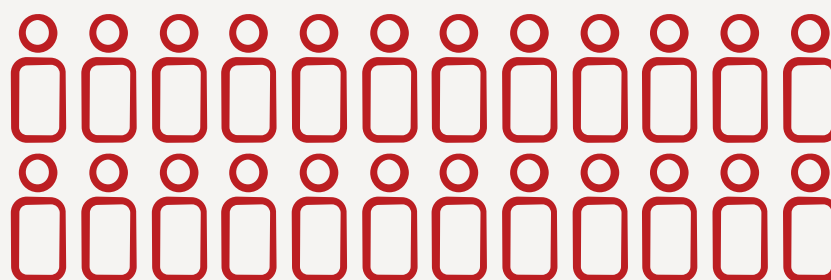
# Involve people for change

Where should responsibility for change be located? We need to take action at all levels to achieve better outcomes. Where appropriate, this starts with self management support for people with long term conditions. The Self management Fund run by the ALLIANCE makes clear that self management doesn't mean individuals are on their own, but that their everyday expertise in living with a condition is the best starting point. Group-based approaches to self management may work best for people with communication and sensory impairments, such as the Lifestyle Management Programme developed by The Thistle Foundation to achieve "coping, control and confidence"<sup>57</sup>. There's good evidence, too, that practical training for carers can relieve stress and make care-giving more sustainable. So, combining the themes of prevention and rights, we might regard support for self management and carers as the absolute essentials of the system.

Peer networks – both face-to-face and on-line – can provide a different quality of support to complement other services. There are good examples of condition-specific models of peer- to-peer support creating opportunities to volunteer for people with long term conditions, such as Chest, Heart & Stroke Scotland's Stroke Voices programme; working with Carers Centres to enable parents of children with autism to improve support where it's been lacking; and partnering with independent advocacy networks (e.g. Stroke Association) to extend advocacy support to those who might otherwise lack access.

## Self management Champions

The Voices Scotland Team within Chest, Heart & Stroke Scotland (CHSS) has developed a Self management Champions module which is an extension of training offered under the Voices Scotland Programme for chest, heart and stroke patients. This training has wider applications and the Scottish Government has asked CHSS to offer this flexible resource to other ALLIANCE member organisations. See: [http://www.chss.org.uk/voices\\_scotland/projects\\_under\\_development/#self](http://www.chss.org.uk/voices_scotland/projects_under_development/#self)



<sup>57</sup> [www.thistle.org.uk/our-services/health-wellbeing/lifestyle-management](http://www.thistle.org.uk/our-services/health-wellbeing/lifestyle-management)

## Peer-support online

For a small input of encouragement and co-ordination, peer support can deliver significant benefits as parent carers across Scotland have found by joining a Facebook support group to exchange know-how on helping their families cope better with autism<sup>58</sup> By gaining practical knowledge from other parents, one woman posted: “I feel like I’ve got my son back.”

A growing number of Disabled People’s Organisations in Scotland offer peer support within a non-impairment specific framework. These organisations are controlled by disabled people and driven by the insight that disabled people and those living with long term conditions are best placed to make decisions about their lives. By working across many kinds of impairment, they aim to support the whole of someone’s life including condition specific support, whilst also working to change the mindset of policy-makers and practitioners that a person’s impairment defines who they are and what they can do. These organisations work collectively to change the policies and practices that disable them and to promote independent living<sup>59</sup>.

We have referred previously to various key-worker models being supported by condition charities as the community ‘anchor point’ to ensure people with long term conditions have local access to the support needed. Key-workers may be specialist or more generic advisers. Charities can learn a lot from each other about effective approaches. These include the Stroke Association’s Local Life After Stroke services<sup>60</sup>, Alzheimer Scotland’s post-diagnosis support teams, outreach work by Carers Centres with condition charities and Parkinsons UK community nurses. The striking feature from these examples is the need to extend successful approaches further: they are not searching for a model that works, but resources to ensure more of their target groups benefit from them.

This leads us again to the social care workforce which delivers home-care, residential care and is involved in planning care in hospitals, as well as the growing network of Personal Assistants employed using individual budgets. They span public, voluntary and independent sectors and so face different environments in terms of pay, conditions, training, progression and relationships with the people they support. Whatever type of integration we opt for, and whatever variations in the balance of care exist across Scotland, we should ask a common set of questions:

- Does the provision of social care express the values and ethics contained in the earlier discussion of rights, personalisation and prevention?
- Are we developing the skills of everyday co-production between the workforce, people with long term conditions and their carers?
- How good is our workforce training and development at encouraging reflective practice, empathy and problem-solving?

<sup>58</sup> Example submitted by the Princess Royal Trust for Carers

<sup>59</sup> ILiS (2010) It’s Our World Too

<sup>60</sup> [www.stroke.org.uk/in\\_your\\_area/scotland/local\\_life\\_after\\_stroke\\_services/index.html](http://www.stroke.org.uk/in_your_area/scotland/local_life_after_stroke_services/index.html)

Structural reform should be seen as a possible means to an end rather than a solution in its own right. Whether transferring the front-line social care workforce from local government to the NHS is good for people with long term conditions depends on the type of culture change it is intended to prompt. For too long, it can be argued, policy-makers have focused on tinkering with the remit and geographical scope of organisations rather than looking at the culture and behaviour within them. So, within the current system it is possible to have significant variations in the quality of care provided by the same workforce, in the same neighbourhood or the same care home, and between personal assistants. It doesn't just reflect management and leadership roles, critical though these are in improving workforce culture and thus the quality of care received, but the personal qualities people bring to work:

- One example involves a cleaner who became the home-help to an older woman following a stroke and later became her main carer. More important than qualifications or experience of working for a care agency was the dedication and trustworthiness demonstrated. In this case, a lot of upheaval and cost were avoided by taking an informal, self-directed approach to care<sup>61</sup>.
- Managers and frontline staff in three Scottish care homes were able to transform the quality of night-time care by making simple, low-cost changes to the living environment based on feedback from a team of researchers working alongside them on the night-shift<sup>62</sup>. The changes didn't come about due to a new policy, inspection or regulation but a commitment to find practical solutions to long-running problems.

Finally, there's the issue of the wider population. Between the family, the state and the services it commissions from other sectors, what's the community stake in social care?<sup>63</sup>

Such questions start to bump up against the Prime Minister's Big Society ideal. In Scotland, this is usually given short shrift for two reasons: it is argued that we already have a big society thanks to the commitment of volunteers in every community, school, church and workplace; and politicians stand charged of hypocrisy – third sector services would be spared the worst of the spending cuts if they truly believed in a big society. And yet, this can't be enough as a response to David Cameron. There are genuine questions to be addressed here:

- Will self management plus prevention plus personalisation be enough to deliver better outcomes with less money?
- How far is it desirable or practical to increase the social care workforce to meet future need?
- Is there scope to adapt practice from other countries which recognises the contribution of volunteers/befrienders, for example the time-banking currency established 20 years ago in Japan (see box)?

<sup>61</sup> Case study submitted by Linda Jane McLean (2010)

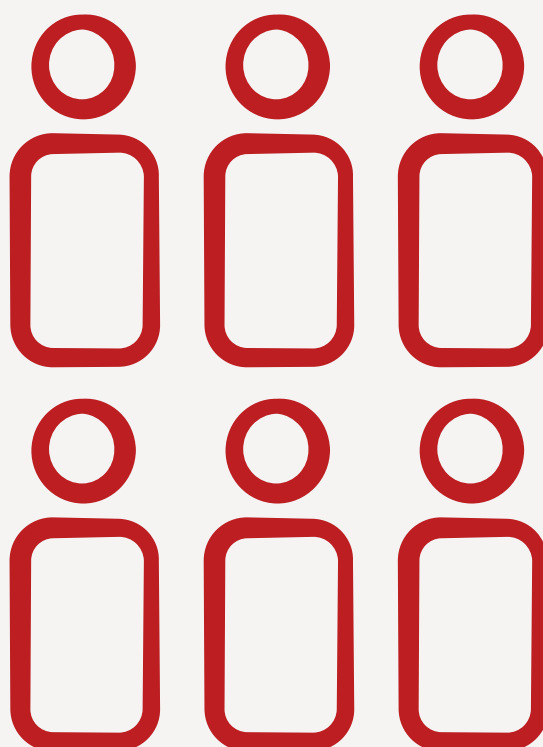
<sup>62</sup> Diana Kerr, Heather Wilkinson and Colm Cunningham (2009) Supporting older people in care homes at night, York: JRF [www.jrf.org.uk/publications/supporting-older-people-care-homes-night](http://www.jrf.org.uk/publications/supporting-older-people-care-homes-night)

<sup>63</sup> David Brindle (2008) Care and support - a community responsibility? York: JRF [www.jrf.org.uk/publications/care-and-support-community-responsibility](http://www.jrf.org.uk/publications/care-and-support-community-responsibility)



## Timebank for community care (Japan)

- Japan has a significantly older population structure, with the care system placing strain on public finances.
- But it also has the highest levels of life satisfaction among the over-65s in OECD.
- Japan introduced a 'care currency' (Hureai Kippu) in 1991 exchanged through a timebank for older people's care<sup>64</sup>.
- Volunteers earn credits which can be transferred to provide care for older relatives or banked to provide their own care in future. It helps ensure care is available for families living far apart.
- This example shows how one country has responded to the pressure of providing good enough social care by focusing on everyday relationships. Rather than adding more complex and costly services through the state, Japan has established an innovative means of contribution and exchange. This has helped to strengthen social ties and encourage communities to play more of a role, knowing that their efforts are recognised and credited.
- It could provide a foundation for anticipatory care (low-level focus on prevention) elsewhere.



<sup>64</sup> Jonathan Clifton (2009) 'Lessons from abroad: ageing and wellbeing in an international context' in Getting On? Wellbeing in later life, pp. 27-38, London: IPPR.

10

## Shape governance for change



Respondents to this work believe the Scottish Government has a very significant role in shaping the future of social care. Interviewed shortly after the Dilnott Commission reported<sup>65</sup>, the UK Government's decisions on paying for long-term care and on welfare reform are seen as equally important, though respondents were not yet clear how the consequences would affect policy choices in Scotland. For now, the main concerns relate to the changing local governance landscape.

Frustrations were expressed about the way in which the Concordat may be driving major care inequalities due to the ratchet/ration effects noted previously. Since care packages apply only to the local authority making the assessment, someone with support needs is likely to feel unable to move to another area in case their support is put at risk – with potentially significant consequences for employment, education and family commitments.

Concerns are raised as well at the apparent contrast in standards of accountability applying to local government compared with the third sector. Meanwhile, the NHS is managed more directly and tightly by the Scottish Government than councils. Local democracy is valued, but has its limits. Ring-fencing of budgets has been reduced substantially but not removed completely – and the rationale for deciding when it should apply isn't clear. Most respondents would welcome an offer of 'help and hassle' from the Scottish Government in response to local authorities which take a short-term approach to cutting costs and raising eligibility thresholds, and dialogue on:

- Which differences in social care assessment, eligibility and service charging are regarded as just variations or unacceptable inequalities?
- How much variation is too much?
- How should we act if voluntary approaches (e.g. sharing good practice, user voice) to improving social care are inadequate?



<sup>65</sup> Commission on Funding of Care and Support (2011) Fairer Care Funding, The Report of the Commission on Funding of Care and Support, London: Department of Health [www.dilnotcommission.dh.gov.uk/our-report/](http://www.dilnotcommission.dh.gov.uk/our-report/)

Let's return briefly to the Reshaping Care for Older People Change Fund. It is regarded widely as the right approach in principle. In fact, top-slicing of resources to demonstrate local care alternatives is seen as a useful model to apply in other cases. But some early

35 experiences have been less promising. There's concern that local plans don't always have a clear connection to evaluation evidence or to national commitments on long term conditions, dementia, stroke and so on, prompting respondents to ask:



**if my local authority and Health Board still don't know what their priorities should be for older people, why are they in the lead on the Change Fund?**

Third sector organisations are involved in formal sign-off of local plans, but don't always feel the partnership with the statutory sector is well-balanced.

As the Change Fund progresses, a tight focus on better outcomes is needed and the various pathways towards achieving them – or theories of change – should be explored as well. Otherwise, the common fear is that it will lead to not enough change. Allied to this is the need for better ways to assess patterns of investment/disinvestment, and the extent to which funding is being used to produce transformation in outcomes versus funding current provision. If we are truly committed to the bold change envisaged by Christie, a far greater proportion of funds needs to be directed to low-level, light-touch support which keeps people well and out of high-cost care services for longer. Much of that community capacity exists within the third sector.

So it's not surprising that condition charities and Disabled People's Organisations believe they could make a greater impact on the Change Fund than they are currently able to. The sector's own response to this concern has been to work with the Scottish Government to secure funding to set up a new resource within the ALLIANCE. The Change Fund: Enhancing the role of the Third Sector Programme<sup>66</sup> is working with the sector, including with the local Third Sector Interfaces, to maximize the potential contribution of the third sector within the Reshaping Care agenda.

In its next phase, the Scottish Government could test out different partnership types across Scotland – the third sector and independent providers could take the lead in some places, with the onus upon the statutory sector to demonstrate what it can contribute. There are substantial variations in capacity, quality and innovation within each sector. The Change Fund needs to invest where the expertise is.

The legacy of the Change Fund – in particular the joint commissioning strategies being developed by local partnerships – will be vitally important to ensuring a sustained shift towards preventative investment.

<sup>66</sup> <https://www.alliance-scotland.org.uk>

# Improve the improvement cycle

Scotland has an elaborate network to promote improvement in care and support. At the core of it is a growing emphasis on reflective practice and self-evaluation supported by the Scottish Social Services Council (SSSC). In addition, the roles of scrutiny and regulation are combined with a stronger focus on improvement within the new Care Inspectorate. And the Scottish Public Services Ombudsman (SPSO) acts as a place to resolve complaints when cases escalate. And yet, progress towards consistently good experiences and outcomes could be embedded more firmly. Rather than 'flogging the system' harder, other resources which can provide timely, light-touch checks and balances are freely available but often neglected. These are the experiences of people who draw upon social care support, their carers and advocates.

Yet, our methods of hearing people's views are sometimes partial and not very effective. Can we safely assume that a postal survey conducted by a home-care provider generates an accurate picture of satisfaction and concerns? How do we get to hear the views of people with communication or sight impairments? Or those who are reluctant to express their disappointment? Often low-cost, practical ideas to improve care and support services can be found by seeking feedback in more creative ways. And concerns can be resolved quickly without becoming full-blown complaints. A more powerful improvement cycle can emerge from genuine engagement with people with long term conditions, trained to support peer groups, take part in improvement training and inspection visits, as well as a right to access advocacy and befriending support for frail and vulnerable people who lack good enough support networks of their own.



# Collaborate across long term conditions



The final proposition involves long term condition organisations seeing each other as partners in the culture change sketched out here. Much of this collaboration is already being very clearly driven by the ALLIANCE but there is scope to further maximize the value of partnership. This work itself also reflects a strong relationship between the long term conditions and disability sectors:

- Better knowledge exchange: exploring support models following diagnosis is one example. What are the generic approaches to maintain everyday support networks and functional capacity as long as possible, how far can they be applied and which are specific to certain conditions?
- New groupings of related condition charities might generate fresh insights, e.g. on communication impairment across conditions which is poorly understood by social care and falls between different branches of medicine (neurology, geriatrics, 37psychiatry); and common pathways through a condition might become a useful basis for collaboration (e.g. conditions which people can recover from; or are recurring; stable; degenerative; or terminal), crossing familiar boundaries between physical and mental conditions.
- Making common cause in representations to government, donors and wider campaigns: the Care and Support ALLIANCE brings together more than 50 organisations with administrative support from Carers UK. It has managed to speak with an authoritative voice to successive governments, recently urging cross-party support for most of the Dilnot Commission's recommendations<sup>67</sup>. A similar grouping of environmental NGOs proved influential a decade earlier on the UK Government's approach to climate change.

<sup>67</sup> Commission on Funding of Care and Support (2011) Fairer Care Funding, The Report of the Commission on Funding of Care and Support, London: Department of Health [www.dilnotcommission.dh.gov.uk/our-report/](http://www.dilnotcommission.dh.gov.uk/our-report/)

# Post-script

The propositions on social care are set out here to spark debate. But their worth can only be judged in how they are tried and tested. They need to be applied with purpose. Participants in the Social Care group convened by the ALLIANCE are clear that all roads lead back to commissioning. How care and support are commissioned has a critical bearing on people's experiences. The work of CCPS (Coalition of Care and Support Providers in Scotland), following a definition offered by ADSW, guides us to take a broad, long-term view of commissioning which can't be reduced to service procurement and delivery. This spans:

- future scenarios on demand/need
- what may emerge as 'next practice' not just replicating current good practice
- community assets
- capacity and quality within sectors
- application of good evidence
- co-production with users and carers in design, delivery, evaluation and improvement

Once of the biggest challenges for social care commissioning (particularly in the context of self-directed support) is how to combine formal services and non-commissioned support to produce the best outcomes. At an individual level, SDS provides a means for doing this, but we need to grapple with how designing a local landscape of care and support encompassing: formal services provided by all sectors; individual, family and community assets; and the vast array of low-level, preventative support such as self management and peer support.

Audit Scotland's recent review of commissioning<sup>68</sup> stresses that effective strategic commissioning is not something that councils can do on their own. It has to be integrated not only with Health Boards, but also with third and independent sector partners, and also with service users, carers and wider community interests. The current experience of non- statutory providers, in the main, is to be on the receiving end of commissioning, rather than feeling any ownership of the process. Change is needed if we are to make fully flexible use of all resources, from small amounts of unpaid care through to residential care capacity. For example, Scotland aims to expand care at home and housing support and reduce repeat hospital admissions among older people. As people live longer with complex conditions, the need for short-term use of residential care for respite and rehabilitation could grow. But such needs will only be translated into service choices if commissioners will the ends. The requirements of accountability and transparency upon public commissioning bodies need not conflict with more open and creative partnerships.

<sup>68</sup> Audit Scotland (2012) Commissioning Social Care [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk)

Finally, we are reminded by an assessment of rights/responsibilities and risk/regulation across the four countries of the UK of two important messages<sup>69</sup>. First, the sum total of resources to be invested in a better system of social care is not fixed and is a matter of priority-setting. Those approaches which reduce demand, prevent harm, keep people well, enable self management and so on can either be resources adequately (and thus create longer-term savings) or delivered on a shoe-string. Our focus need not – cannot – be narrowed down to redistribution within the current, declining care budget. And second, our approach to risk needs to change as well. Living well matters as much as living safely. Kavita Chetty and her colleagues (2012) highlight the difference between ideals and actions:



**Social work is formally committed to delivering a set of goals which embrace the ideas of person-centred support – and yet the system works to a completely different logic to control risk and resources (p.16).**

The various propositions in this paper need to be considered in the context of a different debate about risk and regulation, rooted in public views on appropriate risk-taking as a vital element of informed choice.



<sup>69</sup> David Wiseman (2011), A four nations perspective on rights, responsibilities, risk and regulation in adult social care, JRF Scoping Paper, Joseph Rowntree Foundation, September 2011 [www.jrf.org.uk](http://www.jrf.org.uk)

# Feedback

This work is being taken forward by a broad partnership of organisations and individuals. This second iteration of the 12 Propositions for Social Care draws discussion stimulated by a previous draft, along with a large, national dialogue event (held September 2011), roundtable with senior leaders in the Health and Social Care Integration agenda and above all, the lived experiences of people who are disabled and/or living with long term conditions.

This work sits in the context of the Christie agenda and is intended to contribute to thinking on: improving outcomes, including supporting human rights and independent living; building capacity of individuals, families and communities; shifting to preventative investment; integrating services; and developing a sustainable approach in the face of falling resources and rising need.

The ALLIANCE is committed to continuing this dialogue on social care to better support people with long term conditions. This paper is intended to stimulate argument – dissent as well as consensus – to inform future activity. Your comments are very welcome to:

- Professor Ian Welsh OBE (Chief Executive, the ALLIANCE)
- Shelley Gray (Former Director of Policy and Communications, the ALLIANCE)
- Jim McCormick (Author)



# About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

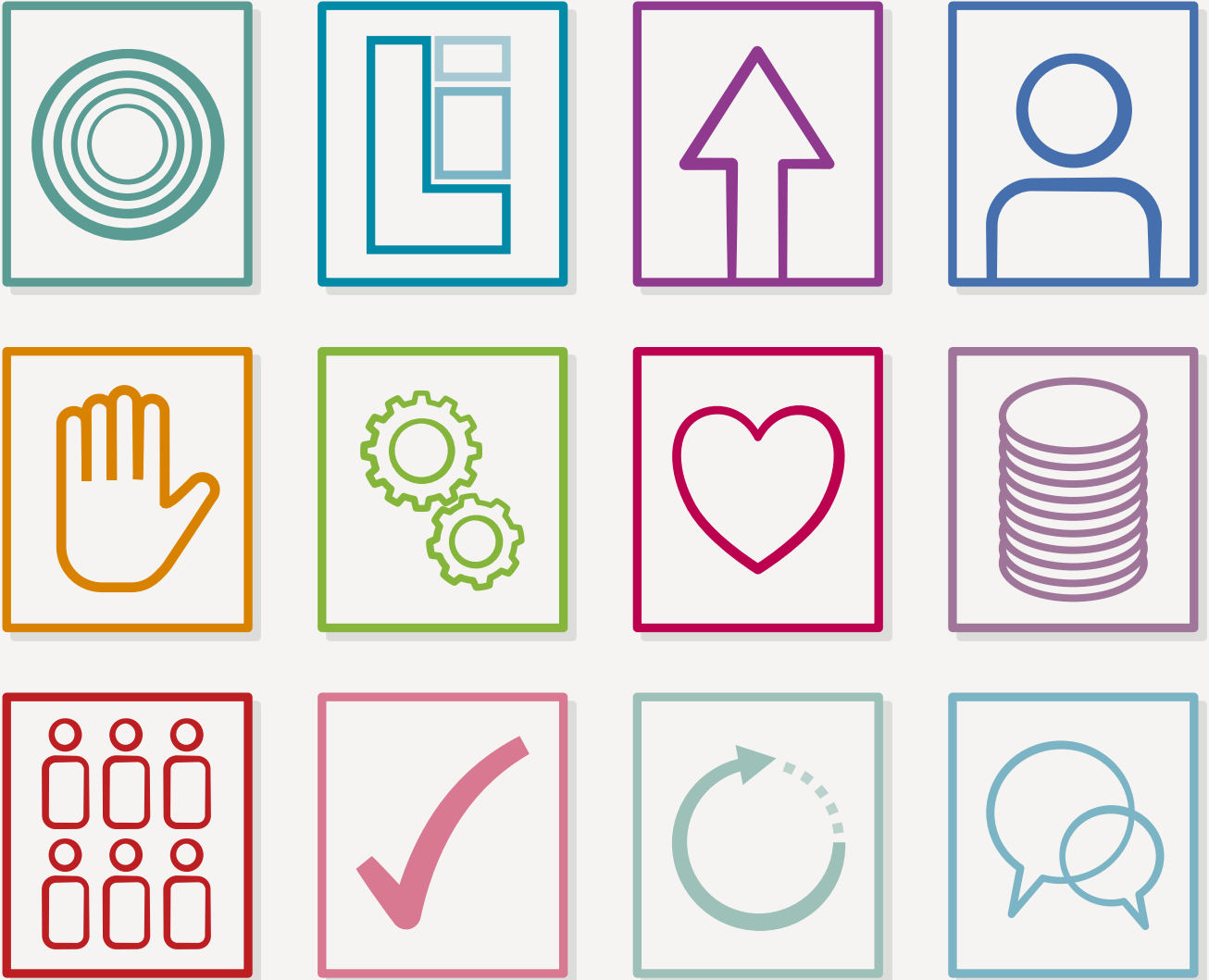
Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



**ALLIANCE**  
HEALTH AND SOCIAL CARE  
ALLIANCE SCOTLAND  
people at the centre



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