The Solutions Series is a number of pop up think tanks that bring people together in coproduction, to seek solutions to a specific barrier to independent living.

This is the first report in the Solutions Series.

Personalisation and independent living for disabled people - the report
“The Solutions Series – Personalisation and independent living” was a solution focussed, pop up think tank on Personalisation and independent living.

This report reflects the discussion on the day and not necessarily the views of the authors, the Independent Living in Scotland (ILiS) project.

| 1. Background to the Solutions Series | 3 |
| 2. The issue: Personalisation and independent living | 4 |
| 3. The discussion | 5 |
| 4. The solutions | 12 |
| 5. Next steps | 15 |

Appendix 1
Personalisation & independent living: a background | 17 |

Appendix 2
list of participants | 21 |

Acknowledgements

ILiS would like to express our thanks to all the participants for their contributions to the discussion. We would especially like to thank Professor Nick Watson, Chair of Disability Studies, Strathclyde Centre for Disability Research, for agreeing to chair “The Solutions Series: Personalisation and independent living”.

Thank you also to Kainde Manji for reporting and editing support.

Look out for more reports from The Solutions Series at www.ilis.co.uk
1. BACKGROUND

The Independent Living in Scotland (ILiS) project is working with the Scottish Government, disabled people and other key stakeholders to make the strategic interventions that will make independent living the reality for disabled people in Scotland.

Between 2012 and 2015 ILiS will host “The Solutions Series”, a series of unique, solution focused discussions – ‘pop up think tanks’ – designed to bring together Disabled People’s Organisations, academics, public service leaders and other key experts from across Scotland and beyond. The series will develop solutions through discussion and debate, working towards achieving the reality of independent living.

Each pop up think tank in The Solutions Series will consider, and seek solutions to, a specific issue thought to prevent or hold up the progression of independent living in Scotland.

A report, capturing the solutions offered, will be published after each pop up think tank in the series. This will be used to promote wider awareness and understanding of the issue and to influence and direct change at national and local level.

This is the report of the first in The Solutions Series: “Personalisation and Independent Living” which took place on International Day of Disabled People, 3rd of December 2012 in Glasgow.

The Solutions Series: “Personalisation and Independent Living” was chaired by Professor Nick Watson, Chair of Disability Studies, Strathclyde Centre for Disability Research. A full list of participants is provided at appendix 2.
2. THE ISSUE: PERSONALISATION AND INDEPENDENT LIVING

The issue of Personalisation and independent living as a question for discussion was arrived at through a combination of desk based research and conversations with Disabled People’s Organisations (DPO’s), academics, experts, social work managers and people committed to the outcomes of either Personalisation or independent living, or both.

This concluded that a focus of Personalisation in recent years has been largely process driven (e.g. Resource Allocation Systems, the provision direct payments etc.). Such a focus risks both social workers and users becoming bogged down in process. This can result in both the link between the shared values and aspirations of professionals and service users and the potential positive outcomes of Personalisation for independent living, being ‘lost in translation’.

By allowing personalised processes to occupy our decisions and space to consider social care, the systems developed to redistribute current resources, such as allocating ‘individual budgets’ have evolved without careful consideration of the efficacy of the overall funding system. Both disabled people and decision makers have argued that this has limited the success of Personalisation and detracts from the positive outcomes possible which could be achieved with an alternative approach more suited to the original intentions of Personalisation.

For more detail of this analysis please see appendix 1.
3. THE DISCUSSION

The specific aim of “The Solutions Series: Personalisation and independent living” was to bring together people with relevant interests and responsibilities in relation to Personalisation, radical social work and independent living, to resolve these issues and to consider the following broad questions:

a) How best to root Personalisation in its true values and goals, building on the shared aspirations of both the social work professional and the Independent Living Movement (ILM)

b) How to ensure that the focus for social care follows from this and moves away from a service orientated structure; focussed on process; to one that is focussed on the individual, and their independent living outcomes that support citizenship and human rights?

The Solutions Series event on Personalisation offered key stakeholders, a space for high-level discussion. The conversation was wide-ranging and presents a useful starting point and direction for further work.

5 key themes from the discussion:

a) The history of Personalisation, and working towards a shared understanding of the term ‘Personalisation’

b) Resource distribution; entitlements and the conflict between individual and collective entitlements’

c) The role of Personalisation in citizenship

d) Creating opportunities to support choice, control and citizenship

e) Where power lies
3. THE DISCUSSION

a) The history of and developing a shared understanding of the term ‘Personalisation’

It was clear that there was a diversity of understandings of Personalisation which can cloud the issue. People saw it as both a broad and narrow concept. One participant contended that it is meaningless, a ‘ghost term’. They went on to argue that it has become a term used to bind an empowering agenda championed by disabled people about independent living and collective change embodying choice, control, entitlements and rights, into an agenda limited to choice and control only. This resulted from a need to make the agenda politically palatable against a backdrop of austerity measures.

Others felt that Personalisation embodies neo-liberal consumerist assumptions – “the pursuit of economic goals at the expense of social or ethical concerns about service provision”¹. Despite this divergence, there is also well-documented common ground between the goals of Personalisation and independent living that seeks to achieve full and equal citizenship for all. It was suggested though, that the current top down, individual and consumerist approach to social care which focuses on personalising budgets, resource allocation and the care ‘market’ – hinders this achievement.

“I’m embarrassed by the term, you personalise your number plate. It’s not a new thing: it was a term that built on the politics of the time, using some of the ideals of the Independent Living Movement”.

1) http://en.wikipedia.org/wiki/Anti-consumerism
b) Resource distribution; entitlements and the conflict between individual and collective entitlements

It was agreed that ensuring the original entitlement based vision of the Disabled People’s Movement is prevalent within a managed and effective system was challenging. This challenge is exacerbated within the context of the cuts affecting disabled people and their services. Specifically, the tension around the diversity of needs among different groups of, and individual, disabled people and the issue of how to cater to all of them in austere times was a cause for concern.

Two fundamental issues were considered: what level of support should be funded e.g. life and limb or independent living; and the relationship between making support available to many – through equitable, yet thinner, spreading of resource – and the implication this has for current users who may, as result, lose some support yet be asked to pay more for what they do receive.

The approach of cash strapped Local Authorities (LA’s) of responding to new need by top-slicing existing packages of support was raised as a cause for concern. It was felt that such an approach transfers the burden of making cuts from the LA to the individual, as it is the individual who then has to secure the support needed, for less. Not only does this conflate Self-Directed Support (SDS) with cuts, but it is against the principle aims of Personalisation. Resources are distributed, not on the basis of what each individual needs to be an active and equal citizen, but on the basis of providing everyone with some level of support, however inadequate or inappropriate that level is. This results in substandard outcomes for everyone.

It was thought that the Resource Allocation System (RAS) used by some LA’s in making these decisions was not delivering what was hoped of it. Instead it was seen to be over complicating the process of resource distribution, “causing as many difficulties as it resolves”.

It was argued that decisions about resource allocation cannot and should not be made at an individual level. It was suggested that such decisions require political
c) The role of Personalisation in citizenship

It was widely agreed by participants that the goal of Personalisation (and SDS as a vehicle for it) is citizenship and that this needs to be underpinned by clear rights and entitlements. It was felt that this should be achieved by providing genuine opportunities for individuals, supported by processes that can monitor outcomes effectively. However, there were fears that the current rationing of resources results in the multi-dimensional and collective aspects of equality and citizenship being ignored. Decisions are being made, not on the basis of rights, citizenship, entitlements and the progression of these, but on the basis of equitable allocation of resources across all users.

A preferred approach is a system that is underpinned by rights and entitlements. A focus on independent living, underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was thought to be a desired goal. It was felt that this needs a move beyond individualism and market based solutions of Personalisation, to collectivism. This requires people in power to listen, learn and change.

Given the current funding system, it was recognised that this also needs a review of how we fund social care more generally – this is considered in more detail at section ‘d’, below.
d) Creating opportunities to support choice, control and citizenship

The discussion of resource allocation, and the crisis in funding in such austere times, highlights the need to consider using resources differently and on a larger scale i.e. not just at the end user level but taking into account all the resources available from the whole population:

"under the old system, we’d just be looking for things to shut. Now we are looking at divvying up resources as best we can"

It was agreed that “divvying up” resources in austere times should not be about asking the individual to deploy – or in some cases ration – their reduced budget. Instead this should be about changing the nature of the relationship between the state, the individual and society. Genuine and meaningful coproduction of decisions on how resources are allocated, in a way that supports wider independent living, was felt to be a positive way of achieving this aim.

There was some debate as to whether encouraging innovation and strengthening the role of communities might undermine the collective nature of current provision. It was argued by one participant that it might precipitate the end of socialised social care. A public tendency to a ‘small-c-conservatism’ around the issue of disinvestment in current provision e.g. the closure of day centres allowing investment to re-deployed to the individual, was also acknowledged. This is despite the fact that disinvestment has emerged from a belief in equal opportunity and citizenship. This conservatism can lead to a “knee jerk reaction to disinvestment” particularly from carers of disabled people. Such responses can prevent delivery of the innovative solutions needed to realise independent living, and may result in tensions that undermine the public buy-in needed to support disinvestment.

The interdependency within communities was recognised in this context. Not only are there resources within communities that can be deployed to support the citizenship of disabled people, but importantly that disabled people have a contribution to offer their communities.
3. THE DISCUSSION  Continued

However it was felt that this latter point was not acknowledged widely enough. It was agreed that where the contribution of disabled people and their organisations is valued and supported, it can flourish, for example in determining the distribution of social care resources. This can enable the much-needed public narrative around disinvestment to be developed, countering the “knee-jerk conservatism” noted previously.

However, it was also widely agreed that closing services in the name of disinvestment alone would not result in mainstreaming or community empowerment. The need for legitimate, accessible, rights based alternative options that are accessible to all who need them, and available on the basis of entitlement to a minimum level of support, was considered essential. However, it was also agreed that it is difficult to develop these where the focus is on process rather than on independent living.

e) Where power lies

To support the systemic change needed, it was suggested there is a need to establish where the power lies. Disabled people have been calling for independent living for a long time, but there was concern that they still do not control many of the mechanisms that are supposed to deliver this. It was felt that disabled people need to have a greater stake in these mechanisms to deliver the change needed. However, the narrowing focus on individual need risks eroding the structure needed to enable this to happen in the longer term and it was felt that this results in a system that, while purporting to be empowering in reality acts to further disempower disabled people.

The funding of DPO’s was thought to be crucial in this. Where funding to DPO’s is cut, disabled people lose peer support, routes to collective action and thus the power in their communities needed to support the change required. Some participants believed the answer to this lies in asking users to pool their budgets to buy services through DPO’s. However, others argued that this wrongly assumes that underfunded DPO’s are on a level playing field with other providers in
3. THE DISCUSSION Continued

an increasingly competitive market. It was agreed though, that DPO’s need to widen their approach so that they are better able to provide for broader constituencies of disabled people than they currently do; including by connecting with other groups of people who may frame their requirements in different language or who may not define themselves as disabled people e.g. people with learning disabilities or mental ill health.

The gap between policy and its delivery was thought to affect where control lies. It was agreed that the intention of personalised systems is to empower the professional and the individual. However, it was noted that the systems and processes in place to support Personalisation often act to disempower the end user, as noted above, but also the front line social worker. There is a perception that social workers hold more power than they do but one participant felt that they hold increasingly less power and often feel that they have “insufficient flexibility to make the common sense decisions” they would wish to.

It was argued that this may be the result of the real power lying in the hands of the chair of Resource Allocation Committee. The individual and the front line professional are instead left with “pretend power”, which some argued is more disempowering than having no power at all.

Others argued providers hold power. The system is increasingly focused on market principles rather than outcomes, enabling the provider to drive up the cost of care. It was argued that this belief was skewed and that in reality, the motivation of providers to seek more money for care was to secure better and more support for the individual.
4. The Solutions

After consideration of the challenges to the shared vision of Personalisation, the chair turned the focus to the solutions.

i. Consistency of understanding is crucial

It was felt there is a need to prevent our social care system from developing around a “nonsense shadow concept” of Personalisation. Instead we must create a vision based on the original intention of early thinkers in this area. This vision should be based on collective empowerment, rather than the individual based empowerment that has become embodied in the meaning of Personalisation. It is also important that this be based on what will be politically acceptable to all those involved.

1) There must be a shared vision for social care, centred on a human rights based approach.

It is important to be bold and brave about what is expected in order to make this happen.

ii. A holistic approach without silos (and engaging health)

To ensure the vision becomes a reality, it must be supported by a holistic system combining health and social care, and SDS.

2) The Integration of Health and Social Care is a significant opportunity to achieve the holistic system desired and should be taken advantage of.

iii. The solution must be one that is based on clearly articulated entitlements

There is a need to strengthen the meaningfulness of ‘the entitlement to support’, and to clearly determine what these entitlements are. They should, at the very least, support citizenship with rules for eligibility and systems that support genuine possibilities, underpinned by the UNCRPD and a human rights based approach.

3) It was agreed that ILiS should work to build broad support among human rights organisations in Scotland in advocating for entitlements to social care that support citizenship with rules for eligibility and systems that support genuine possibilities, underpinned by the UNCRPD.
4. THE SOLUTIONS

4) To support this, the development of a funding mechanism that clarifies entitlement is needed. This must avoid some of the shortcomings of the current RAS’s and should cater to the diversity of different support needed, rather than merely allocating the same to everyone regardless of need. This entitlement should be clearly defined and based on the principles of citizenship and independent living.

iv. Coproduction, community capacity and changing the nature of the relationship between the individual and the state

5) Co-production is essential to ensure such a system shares power among users, policy makers, front line staff and the local community. This requires changing the nature of the relationship between the individual and the state. Crucially this is more than a case of ensuring support is right for one individual. Rather, it is about ensuring we get it right for everyone.

6) DPO’s should be central to this process and should be given adequate support (and funding) to enable them to participate.

As well as supporting DPO’s, there is a need to give confidence to front line staff.

7) Improving the management of financial considerations and supporting a common sense approach to enabling different solutions that can go beyond narrowly drawn personal care can empower social workers and enable flexibility in how budgets can be used.

5. A framework to develop a citizenship approach to our system of social care

8) It is important that this vision for social care – based on citizenship and independent living – is clearly defined and broadcast over and over again. It will require a clear framework with clearly laid out routes to the solution desired. It must also be underpinned by a consistent citizen-focused rights based approach.

People are wary of the unknown, and providing a clear vision of an alternative, with case examples of where it works and what it looks like, will reassure people and help to minimise opposition to the approach and to the disinvestment needed.
4. THE SOLUTIONS *Continued*

It was felt that this would need to follow a twin track approach: push the discussion forward at a high level with decision makers; and also work for a groundswell of popular support. This also requires recognition of the contribution of social workers and frontline professionals as key allies as well as of users of services – both of whom can act as drivers and role models for change.

As well as setting out clear entitlements to support, based on human rights, the strategy must be monitored against a coproduced set of criteria e.g. how inclusive it is, how much does it cost etc. so that progress can be considered.

**vi. Disabled People’s Movement (DPM) need to engage politicians in this approach**

9) The DPM need to look to the politicians to put this citizenship based approach on the political, as well as the executive agenda. It was suggested that ILiS could work with MSPs and Councillors to develop strong political foundations to deliver this in a way that is going to be acceptable to Government, and politicians of all parties.

**vii. Use the Vision for independent living to embed this**

10) It was suggested that ILiS should act as a vehicle to promote a human rights based approach to entitlements and a citizenship model of social care, utilising the Shared Vision on Independent Living.

The Vision sets out the Scottish Government, CoSLA, NHS Scotland and Disabled People’s aspirations for independent living in Scotland. It is co-signed by the Scottish Government, CoSLA, NHS Scotland and the Disabled People’s Movement.

**viii. A Social Care Commission**

It was clear that funding restraints pose a significant challenge to progress.

11) It was suggested that a Commission on the future of funding for a system of social care based on citizenship and independent living, was needed.

It was thought that this Commission could look in detail at how we are going to develop, sustain and support a system of entitlements based on human rights and that it was essential that this was done on a macro level.
It was clear that the shared goal of professionals and users of social care is that of citizenship and human rights.

However, it was also clear that ‘Personalisation’ – a system based on individual allocation of resource, with processes that support that – not only does not deliver this goal, but also disempowers both the professional and the user. It was agreed that a preferred way forward was to:

> Secure a shared vision for a system of social care based on human rights, citizenship and independent living

> Take advantage of the current progress on the Health and Social Care Bill as a significant opportunity to achieve the holistic system desired

> Support and resource a system of coproduction that ensures power is shared among users, policy makers, front line staff and the local community – this includes supporting DPO’s to engage in this

> Develop both a clear set of coproduced entitlements to realise this vision and a funding mechanism that supports such entitlement

> Empower the professional by supporting them to manage financial considerations that support a flexible, common sense solution to support planning

> Develop a framework, outlining the route to a system of social care based on citizenship and independent living, including a coproduced monitoring mechanism

> DPM should work collectively with MSPs and Councillors to develop strong political foundations to put this citizenship based approach on the political agenda

> ILiS should promote a human rights based approach to entitlements and a citizenship model of social care, via the Shared Vision on Independent Living

> Set up a Commission on the funding of a social care system based on citizenship and human rights to consider at the macro level, decisions on funding needed to underpin this approach

> Identify vehicles – organisations, individuals etc – to progress these solutions
ILiS will work with key stakeholders to progress the solutions suggested, including through the Independent Living Programme.

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Personalisation and independent living

What is independent living?

Independent Living is defined by disabled people and their organisations as:

“disabled people of all ages 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”.

For many disabled people, this practical assistance and support (the basic rights of independent living², underpinned by the principles of independent living, freedom, choice, dignity and control) is essential for them to exercise their rights and duties of citizenship, via their full and equal participation in the civic and economic life of Scotland.

Without it, many disabled people cannot; live free from discrimination and harassment as the Equality Act 2010 asserts, enjoy the human rights they are entitled to³ on an equal basis to others – as set out in the Human Rights Act and the European Convention of Human Rights, nor contribute to a wealthier and fairer, healthier, safer and stronger, smarter and greener Scotland⁴.

Independent living thus promotes a modern understanding of disability and disability equality that can support policy and practice to protect the human rights of disabled people, by recognising the essential role of “material support” in ensuring disabled people can “participate in society and lead an ordinary life”. Also, the role independent living plays in protecting the human rights of disabled people is recognised and underpinned by international human rights and equalities obligations to which the UK and Scotland are party.

APPENDIX 1

The Solutions Series: Personalisation and independent living – a report (Jan 2013)
This includes the recognition that all of the rights in the European Convention on Human Rights (ECHR) and domestic Human Rights legislation belong to disabled people and that these are further strengthened and contextualised by the rights set out in the UNCRPD.

For many disabled people, care and support is one of the essential ‘ basic rights, or practical supports, that ensure they can participate in society and live an ordinary, or indeed extraordinary, life and thus enjoy their basic human rights as equals to others in society.

**What is Personalisation?**

Personalisation was first written about by Leadbetter in 2004, who described it as:

> “...putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value (Leadbeater, 2004)”

Building on this focus to put the ‘user’ at the heart of decision making, the Social Care Institute for Excellence describes Personalisation as the need to think:

> “…about public services and social care in a different way – starting with the person and their individual circumstances rather than the service”.

The Association of Directors of Social Workers in Scotland also highlight the need to change the relationship between the state and the individual in the provision of social care:

> “…The Personalisation of social care will help people be supported to live the lives that they want to live. From being passive recipients of services, people will become increasingly involved in shaping the support they require to achieve mutually agreed outcomes. Personalisation fundamentally moves the location of power, decision-making and expertise from the system to the people who may need support”.

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6 http://www.scie.org.uk/topic/keyissues/Personalisation
7 ADSW; “Personalisation: principles, challenges and a new approach; a statement by the ADSW”, 2006
They also highlight the role that Personalisation has to play in supporting the outcomes of citizenship and participation of disabled people, in the same way as disabled people see independent living. ADSW state the importance of embracing:

“...concepts of citizenship, inclusion and the uniqueness of the individual as a means of enabling people to fulfil their potential within their own communities. People who need support to get on with their lives should have the same opportunities as everyone else to exercise choice and control, for example over where they live; to belong and contribute to a social network and community; to have something meaningful and rewarding, rather than time-filling to do. It is the practical application of principles and values that aim to support, encourage and assist individuals to retain, reclaim or discover elements of themselves that are essential to their humanity.”

Duffy takes all of these aspects of ‘Personalisation’ and highlights the obvious relationship between the principles and values of it to both the origins of social work and of the aspirations of the Disabled People’s Movement for independent living. In doing this, he describes the similarities between the values and principles of Personalisation and independent living and their respective proponents.

He goes on to argue that as well as being seen as a driver for a more empowering system of care and support, the potential for Personalisation to support citizenship should be better understood and promoted by both recipients of care and professionals involved in it so as to embrace these relationships.

However, he also points out that there is a focus on the processes of Personalisation (e.g. Resource Allocation Systems, the provision direct payments etc.) necessitated by increasing demands on resources and systems in general. He argues that such a focus means social workers and users alike can

8 ADSW; “Personalisation: principles, challenges and a new approach; a statement by the ADSW”, 2006
get bogged down in process, which can result in the link between their shared values and aspirations, and the potential positive outcomes of Personalisation for independent living, being ‘lost in translation’. He argues that this can result in professionals seeing their role as ensuring “that finite resources produce best value for people as individuals in relation to outcomes”\(^\text{10}\) rather than ensuring the outcome of independent living and the delivery of the values of Personalisation support.

This polarisation has the potential to create a systematic culture of resistance from both the professional and the user, to an otherwise well intentioned philosophy\(^\text{11}\).

Indeed some could argue this has happened already. Many have conflated the roll out of SDS in Scotland with a cuts agenda. In some cases this has resulted in the successes of SDS, and its potential, being overshadowed by the issue of funding for social care, which is should be independent of the mechanism chosen to deliver it (e.g. SDS).

In this way, the focus on process detracts from the broader issue of funding for social care in general, which, many have argued\(^\text{12}\) is in crisis. This entrenching of professional focus on process and rationing rather than the more outcomes focussed independent living can leave the professional disempowered, as well as leaving the user with unmet need.

By allowing personalised processes to occupy our decisions and space to consider social care, systems have developed to redistribute current, restricted resources, allocating ‘individual budgets’ – however inadequate – without regarding the overall funding of the system which many have argued and limits the success of Personalisation.

\(10\) ADSW; “Personalisation: principles, challenges and a new approach; a statement by the ADSW”, 2006


\(12\) ILiS (2010); “ILiS response to the COSLA consultation on charging for social care”
## APPENDIX 2 - PARTICIPANT LIST

<table>
<thead>
<tr>
<th>Title</th>
<th>First name</th>
<th>Surname</th>
<th>Position</th>
<th>Organisation</th>
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</thead>
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*The Solutions Series: Personalisation and independent living – a report (Jan 2013)*
Solution Series: 1

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