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## About the ALLIANCE

The ALLIANCE’s 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.

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## Introduction

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Part of the Changing Support, Changes Lives programme, which aims to build the capacity of individuals and providers to implement self-directed support, Creating the Connections is focused on increasing the collaboration between the self-directed support and health improvement strategy in the delivery of a person centred health and social care system. Taking this to the local level, Creating the CALL (Connections At Local Levels) aims to:

- ⤴ Take learning from the 'Building the Connections' event to develop an agenda for moving the discussion forward with people who use health and social care services at the centre.
- ⤴ Gather personal stories and lived experiences from individuals who have utilised self-directed support for the attainment of both health and social care outcomes.
- ⤴ Engage with individuals, supporters, providers, public bodies, and stakeholders at a local level to shape the design and delivery of joined up self-directed support.
- ⤴ Raise public awareness of the shift towards person-centred health and social care approaches through the co-production of service design and delivery.
- ⤴ Build momentum for a progression of health and social care self-directed support which recognises the individual assets of people with long term conditions.



This report compiles the views expressed during each event, giving a wide-ranging account of the various issues arising across Scotland as Self-directed Support is implemented. Given that each event took place in varied locations across Scotland, including the Islands, rural settings, cities and towns, opinions demonstrate a cross section of experiences of recent reforms to social care.

The report begins with a summary of each of the four events, starting with the Western Isles, to South Ayrshire, to Aberdeen, and ending in Falkirk. Emerging themes from all events are both unique to the area that is facing the issue, and shared across the country. Therefore the penultimate section highlights the key themes that have been learned as the issues within each event came to light.

Concluding the report, recommendations are made regarding the provisions and support that can be implemented at local levels to increase the capacity of services and providers to be well informed in their delivery of self-directed support and to empower people to be in control of achieving their outcomes.

## Regional themes

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### Western Isles

#### Transporting care

There are fifteen inhabited islands in the Western Isles covering 130 miles with an approximate population of 28,000 people. Providing consistent quality care in a person centred approach was reported by delegates to be one of the most pressing issues of ensuring self-directed support achieves its intentions of providing more choice and control to people on the islands. These issues are not new. Services have commonly had difficulty in securing provision for all those who need it, in all areas. Delegates highlighted examples of podiatry and community based health services being especially affected by the geographical restraints which could restrict access to people from more rural areas.

The concern relating to self-directed support on this issue was that it could leave individuals with the responsibility of securing their own support but without the appropriate choice of services to meet their needs in their areas.

#### Staffing Self-Directed Support

The Western Isles has an aging population and a declining population of people of working age. This has led to fears that there is going to be a deficit of people able to provide support and assistance to people with increasing support needs. It has even been suggested that a recruitment drive is required to attract people from mainland Scotland to fill the employment gap. From the perspective of the delegates the reality was of a decreasing workforce and a fear of being unable to support the needs of people in the community.



There was a noticeable call at each event that delegates believed that the solution to the staffing issues raised was the need for a *bank* of carers who could be utilised by people with self-directed support from all parts of the Isles. This raises the potential for consistent, reliable support staff who can deliver support based on a contractual relationship to the facilitating organisation of the bank. However at the same time this arrangement could have the potential for limiting people's choice and control, and decrease the flexibility that is afforded by self-directed support.

At the same time however, there are also concerns for staff themselves, the main worry being that being independently employed on the islands is not a secure situation for support staff. The example was given that a person being supported, employing their own staff, could immediately stop the support (through their end of life). While it was recognised that this could also happen for staff employed by the council, it was felt that this offered greater protection and therefore did not compromise the employment of support staff.

### Supporting health to support

Though it would seem that there are close ties between NHS Western Isles and the local authority services when it comes to dialogue, there is a lack of collaboration reported by delegates. It was described that this can result in delayed discharges from hospital of those who could benefit more from adequate social care support at home. This resonated across each of the events with claims being made that poor planning across the agencies had led to services being withdrawn from certain areas, leaving people unable to access appropriate health care. The response from the council being that with self-directed support individuals could effectively use their budget to meet their health needs, so long as it contributed to their positive social care outcomes. However, at a more strategic level it was felt that there needed to be a more collaborative and coordinated approach to the designs of support services in the future so that individuals with health and social care needs could be enabled to live independently with all their needs met. This was particularly pertinent for older people who wanted to maintain their living situation in their own home, but who had traditionally been forced to stay in hospital through a lack of creative support being available. One solution to this was to bring down the barriers between health and social care staff so that community care could be delivered on an outcomes basis without having to define the budgetary resources to achieve peoples' independence.

### Geographical choices

Beyond the issue of transport there is a fundamental issue that harks back to the original construction of direct payments. It may sound a far stretch, but the outback of Australia was one of the first locations where the principles of direct payments formed. Living far from a central city, the support available to people in rural

communities does not always provide the equity of support provision. Having the money and the control to arrange and manage one's own support was the founding notion of direct payments. In a similar fashion, living on low-inhabited islands off the west of Scotland can mean that services that are easily accessible and available in the central belt are not transferrable. While self-directed support does not directly change or impact on the social care provider landscape, it does have the potential for transforming the way that people access the support they need to maintain their livelihoods on the islands.



## South Ayrshire

The founding principles of self-directed support, choice and control, inherently mean that there will be different opinions and perceptions of its implementation, and opportunities from each individual. The 'Coming to a Common Ground' activity encouraged delegates to consider the opportunities, restrictions and challenges of self-directed support from their position



## A sense of hope

To start on a positive, delegates expressed support for the opportunities presented by self-directed support. Delegates from all sectors were broadly supportive of the principles that people accessing social care should have full choice and be in full control of their support, to enable their independence in their community. The broader remit of self-directed support in enabling families and carers to be included in the support arrangement was deemed to be a valuable development. It was felt that self-directed support would be an empowering mechanism for people in South Ayrshire to be more included members of the community.

## A sense of uncertainty

Even though the self-directed support strategy has been in place since 2010, there was a feeling of the unknown. Given that the legislation hadn't taken hold yet, there was some trepidation about the fundamental shift from traditional services delivery to individual procurement of support. This was primarily directed at a lack of clarity regarding the safeguards to ensure the livelihoods of both individuals needing support, and their workforce, are maintained.

## A sense of caution

Though there was general support of the principles of self-directed support, a common theme was of apprehension towards the implications of its implementation. The concerns over which were focused on the transfer of commissioning procedures which, delegates suggested, could risk the framework of support providers and their staff, and put unwanted pressure and responsibilities onto individuals. Included in this was a query over employees' access to training of caring duties, and employers' access to support with management and accountancy of direct payments.



The main focus of the event was on the potential opportunities self-directed support could bring to the empowerment of people in South Ayrshire. Taking a co-productive approach, delegates chose to concentrate on issues that would affect each agency in turn, and on issues to which each agency could have an impact.

Exploring the role of health first, while it was notably apparent that those working in health, and those with a perspective on health's involvement in the self-directed support process, felt a lack of responsibility due to the legal duties being focused on local authorities, there was a common consensus that self-directed support could only be truly person centred if there was a collective approach between health and social care to the attainment of individual outcomes. For this to happen, it was suggested that there should be stronger links made between the health service, local authorities and the third sector. It was felt to be beneficial that this was at a community level so that there was a joined up understanding of the local provision, in order to meet individual outcomes.

Discussing the role of the local authority, there was a strong feeling that there needed to be more transparent and clear communication on the implementation of self-directed support. It was felt by both professionals and individuals that there needed to be greater transparency over what individuals can and cannot do under self-directed support. While the principle of self-directed support would suggest that it is up to the individual to determine what support they need to meet their outcomes, there was a call from delegates for a signposting mechanism whereby individuals could find out what is available in their area before deciding on an option.

Providers seem to be more apprehensive towards the implementation of self-directed support for fear of changes to contractual arrangements between the local authority, the provider and the individual. For this reason it was felt that there needed to be more of a collaborative approach with local authorities and providers in coming to a common understanding of the implications for both parties. While this should be taken forward at a local level to ensure that there is a cohesive strategy for self-directed support implementation, it was also suggested that there needs to be a directive from Scottish Government assuring providers of their place in a competitive market.

## Aberdeen

Tension between the aspirational objectives associated with Self-Directed Support and the reality of diminishing budgets to support such a structure. It was thought that, while Self-Directed Support was not a disguise for cuts, that the timing of both agendas risked conflict.



Concern about the supervision of Self-Directed Support in preventing people from either being abused or abusing the system. While there is a strategy coming from the Scottish Government to promote risk enablement – the idea that individuals should be supported to take acceptable, proportionate risk in their daily lives – there was disagreement that Self-Directed Support would be a lever to increasing individuals' opportunities to take safe risks.

Questions over the appropriate use of Self-Directed Support were debated. Delegates on the one hand argued that, in the context of austerity, Self-Directed Support should be tightly focused on enabling people to direct the social care that was previously delivered by local authorities, while others suggested that Self-Directed Support should be seen as a mechanism to empower individuals to lead ordinary lives, whatever extravagance that includes.

## Key Issues arising

### Attraction and Retention of Staff

Aberdeen has a relatively low unemployment rate, at around 1.8 per cent for 2013/14. Much of the employment in the city is through the work within the oil and gas industry, which pays substantially more than the minimum wage or that offered by social care providers and local authority direct payments. For this reason, delegates pointed to the difficulties in attracting and maintaining staff to the social care

workforce. Part of this concern is being misappropriated to the inception of SelfDirected Support due to the individualisation of budgets which are lower than required to employ people in the Aberdeen area.

### Support Small and medium sized providers

The Social Care market in Aberdeen has been comprised of small, medium and large service providers under local authority block contracts for many years. There is a concern amongst small and medium providers that the council's approach to SelfDirected Support may present a challenge to the viability of continuing to provide services under a diminishing block contract budget. While the case was put forward that competition was the key to continuing to attract consumers of care providers within the new landscape of Self-Directed Support, it remained uncertain that providers could continue to offer services in the absence of secure future funding. Similarly, the same providers flagged the issue that Self-Directed Support is attracting larger providers to the areas that can deliver the care required on an individual level through a financially sustainable model that cannot be replicated by small and medium providers. However this is feared to be of a less quality than the bespoke services that can be offered by small to medium providers.

### Effective communication required

There is a general feeling that there has been a lack of consultation between the council, provider, the third sector, and individuals receiving social care. This has led to some trepidation among these groups that the implementation will limit their ability to enable individuals or be enabled to meet their social care outcomes. The main factors relate to the fear that Self-Directed Support could limit individuals' ability to purchase the right support within the budgets they are given, and the concern that a top down approach to implementation could stifle the empowerment of individuals to achieve their outcomes.



### Falkirk

The event in Falkirk included a selection of presentations from organisations across the district on key issues that matter to those requiring self-directed support.



## What Self-Directed Support means to me

Giving his experience and opinions of SDS, Walter Ramage spoke powerfully about his route to, and life directing his own support. He gave an honest account of the difficulties associated with living independently prior to getting a self-directed support budget, explaining the impact that this had on his work and family life. This laid the foundation for an overview of the benefits and opportunities that he has been able to access through employing a personal assistant with his direct payments, Option 1 of self-directed support. This included a positive message about the freedom and flexibility afforded through gaining control of the support arrangement. Walter also briefly touched upon the importance of the relationship between him and his personal assistant, in increasing his sociability. This is a major shift in the dynamic that was once prescribed between those requiring support from traditional services and those employed to offer it. It is hoped that Walter's experience encouraged delegates to consider the creative ways in which self-directed support can enable disabled people to live independently.



## Carer's perspective



Ian McCourt, a representative from the Princess Royal Trust, described the current framework of support for carers and the implication of SDS. The Princess Royal Trust aims *“To ensure that carers of all ages are recognised and valued, receive the information and support they need to allow them to care with confidence and in good health, and are empowered to have a life of their own outside caring”*. Identifying that there are approximately 20,000 in Falkirk and district, Ian highlighted the economic and social implications of having a carer workforce. With self-directed support being implemented for carers to access, Ian spoke of the potential opportunities for carers to be recognised as contributors to the independence of the people that employ

them in a more professional context, while acknowledging the relational implications of the dynamics that can arise, for example, from employing family members.

## Advocacy support – Forth Valley Advocacy

A running theme throughout the event was the principle that people accessing social care should access advocacy services, to ensure that their views are taken into account throughout the assessment and subsequent management of their self-directed support arrangement. Martine Turner from Forth Valley Advocacy expressed the importance of the role of an independent advocate in enabling individuals to maximise their independence.



Independent advocacy, in the context of self-directed support, offers people an impartial method of expressing their opinions during their engagement with social services. Forth Valley Advocacy, Martine explains, works with people going through the process to support them in preparing for meetings, understanding the information given to them, working through the person's support plan and the four options of self-directed support, and ultimately enabling people to make an informed choice over the support they require to meet their outcomes.

## Feedback

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“The personal experiences worked well, networking with other providers has improved and may lead to joint working”

“Opportunity to network, share ideas and knowledge and talk to service users. SDS allows providers to get to know service users”

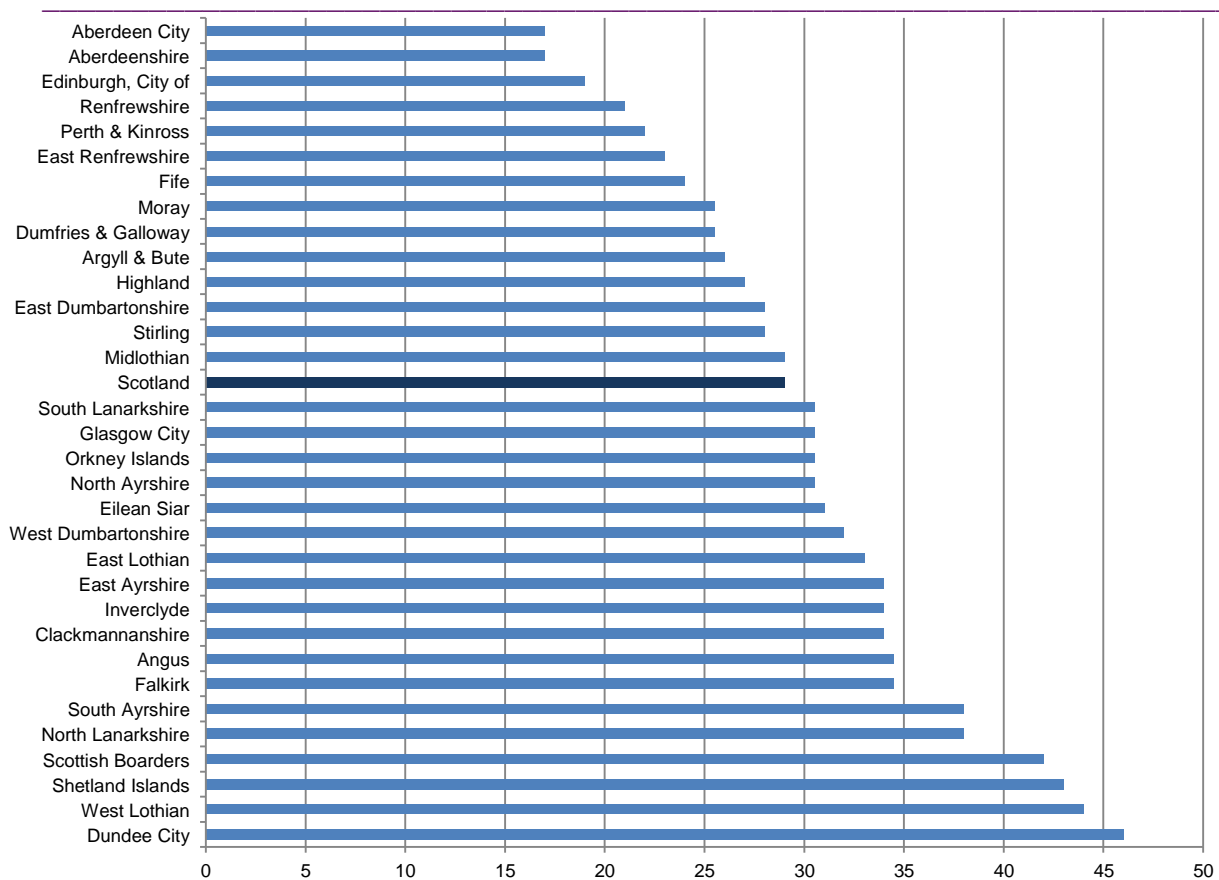
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## Cross-country issues

Across each of the four areas delegates at the events had shared opinions of the national implementation of self-directed support, which is affecting local areas in different ways. These issues include:

- Lack of clear information from the Scottish government to local authorities is having an impact on individual and collective confidence in the ability of either to deliver on the reforms for Social care as intended.
- There is a general impatience towards the implementation process of Selfdirected Support, with many
- Uncertainty remains over the future of a provider landscape to respond to the increasing relation of ways in which people using Self-directed Support can access provisions to meet their needs.
- There is a fear of declining workforces to meet the demands of an aging population and an increase in those who require health and social care support.

**Rates of Social Care Clients per 1,000 population<sup>1</sup>** puts into context the regional variation of potential individuals who are eligible to receive self-directed support.



1 Representative graph of Scottish Social Care survey, 2013

## Recommendations

***The strong sense of community aspiration for self-directed support is marked by the suggestion that there should be a locality based resource for professionals and individuals to explore the opportunities available through self-directed support.***

The following recommendations have been constructed in collaboration with the delegates to have attended the four events to take place across Scotland. They provide a framework for putting support in place at a local level to ensure individuals, third sector organisations, providers, and local authorities can give full effect to the intentions of the Social Care (Self-directed Support) (Scotland) Act.

## User Involvement

- Establish a user involvement pathway to encourage the greater participation of individuals in the local area to become key informants of self-directed support implementation.

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- Develop a bank of user experiences to showcase the positive opportunities that can be achieved through self-directed support.

## The Workforce

- Develop a comprehensive database of stakeholders in the implementation of Self-Directed Support who could receive regular updates on its progress and contribute to a single response to future plans.
- Explore recruitment drives with local schools and colleges to highlight the opportunities for younger people to seek employment within social care.
- Up-skill those working in local universal information and advice giving organisations with knowledge of self-directed support to be able to signpost people to agencies that can support their journey.

## Training

- Using the 'Everyone Together' model of training, facilitate community events for anyone with a vested interest in the outcomes of people with long term conditions, to up-skill the local population on the principles and practicalities of utilising Self Directed Support to achieve these.
- Plan six-monthly update events to maintain the connection between all the statutory partners in securing a long term coproduction policy for the implementation of self-directed support within an integrated landscape.

## Acknowledgments

The ALLIANCE would like to thank the third sector interfaces for their cooperation in holding the 'Creating the CALL' events. With their support and the impetus that came out of each event, it is hoped that connections within local communities will be made and a productive dialogue can begin to shape the implementation of self-directed support in their respective areas. Below are the main contacts in each area.