Piecing Together Person Centred Support

Joining up Self-directed Support within Health and Social Care Integration

An ALLIANCE Think Piece
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Overview

The ALLIANCE believes that integrated health and social care Self-directed Support (SDS) can empower and enable people who are disabled or are living with long term and multiple conditions to lead independent lives and be in control of the management of their health and social care outcomes.

This table demonstrates the similarities and differences that exist between the Social Care (Self-directed Support) (Scotland) Act and the Public Bodies (Joint Working) (Scotland) Act.

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Aims of Report

Since 2012, the ALLIANCE has been building the case for integrated SDS between health and social care in Scotland. In working with health boards, local authorities and third and independent organisations across the country, the ALLIANCE has gathered views and experiences to inform this Think Piece. Following the three aspirations outlined by the King’s Fund, the ALLIANCE promotes the implementation of SDS within integrated health and social care.

A King’s Fund report from 2011 identifies three potential benefits from integration:

Better outcomes for people, such as living independently at home with maximum choice and control.

More efficient use of existing resources by avoiding duplication and ensuring people receive the right care, in the right place, at the right time.

Improved access to, experience of, and satisfaction with health and social care services.

This Think Piece, ‘Piecing Together Person Centred Support’, seeks to initiate a dialogue between health and social care and their partnerships across Scotland around increasing the integration of SDS at an individual level. This report contextualises the landscape of integrated SDS with the following aims:

- To enhance understanding of the concept of integrated self-directed support.
- To set out the general framework in which self-directed support currently sits in relation to health and social care integration.
- To present examples of the potential benefits of integrated self-directed support for people with ongoing health and social care requirements.
- To address the current concerns being associated with proposals to integrate self-directed support.
It is encouraging to read such a helpful report from a body as important as the Health and Social Care ALLIANCE Scotland. Although the journey is long the direction seems clear - we need a system where people get support on their own terms - building on their strengths, on their connection to family and community. Traditional care services cannot deliver this, only an approach which shifts power and control to the person will work. However, the report also picks up many of the challenges that will need to be faced along the way.

The great divide between health and social care, and in particular the means-testing (or care tax) that still impacts social care, can only be healed by significant policy change. In time we will realise that we need to draw a new line with self-directed support on the one side and services that should be organised by the community (like emergency services) on the other. Hopefully policymakers will also see that the on-going use of means-testing in social care is holding back progress towards personalisation and integration.

There is still far too much stress on direct payments and not enough use of Individual Service Funds or other empowering approaches. People want flexible support - but they don’t always want to be controlling budgets or employing staff. The Scottish system of self-directed support opens up these other options - but there are still too few communities where these ideas are embraced.

This kind of approach is just as applicable to statutory services; for example it would be quite possible for the NHS to build self-directed support into its own mental health services.

There will also need to be change within our communities and at the interface between people and services. Local Area Coordination offers one interesting account of how support in community can be improved and reliance on services reduced. But there will also need to be innovations at the level of community nursing and general practice, in mental health services and in the voluntary sector. Peer support and advocacy will play a critical role; but much more innovation and experiment is necessary.

Overall what makes this report exciting is that it demonstrates that people themselves can see the way forward and they are willing and able to overcome the old barriers and distinctions that have often left self-advocates, disabled people, families and those with long term conditions divided from one another. With the leadership of the ALLIANCE I am sure we will see further progress in Scotland - and quickly.

Dr Simon Duffy
Centre for Welfare Reform
Introduction

Self-directed Support has the potential to transform the design and delivery of public services for people living with long term conditions across Scotland. Since the inception of its strategy in 2010, self-directed support has enabled people eligible for social care to have increased choice and control over the support they require to live independently. In practical terms, this has empowered people to employ their own Personal Assistants, arrange appropriate person centred agencies, and identify ambitious outcomes that recognise the value of disabled people and those living with long term conditions in Scotland.

The principles of health and social care integration are focussed on realising independence and equality for people who live with long term conditions. The fundamental ambition is to redress the imbalance of power between systems that have often limited people’s right to determine their own health outcomes, and people who want to interact with services on their own terms. A fresh approach needs to be taken, which appreciates that choice and control are the hallmarks of a society which respects the decisions of people who are disabled or living with long term conditions, and health and social care integration Boards need to be reactive to an increase in people demanding their right to this.

‘Piecing Together Person Centred Support’ takes a broad, evidence based look at the current context in which self-directed support sits and makes the case for individual integrated health and social care budgets. If Scotland is serious about reshaping care in favour of putting people at the centre, then we all have to think openly and talk frankly about the future of health and social care spending for future users of both services. While fear of fragmentation of the NHS and protectionism of perceived local authority controlled budgets persist on dominating the discussion, any attempt at reframing the way health and social care meets the demands of 21st century living will be stifled.

Many examples of where integrated approaches to SDS have been trialled, some of which are detailed within, demonstrate the possibilities available to people who have their own vision of how to manage their health needs and meet their outcomes. By focussing on the opportunities available to people through the lens of SDS, health and social care integration has the potential to deliver joined up support that people can manage effectively to achieve their own outcomes.

Ian Welsh,
Chief Executive of the ALLIANCE
The ALLIANCE’s ‘Creating the Connections’ Programme

‘Creating the Connections’ is a programme that aims to forge closer links and support a dialogue between health and social care with the voice of people who use support and services at the centre. This report aims to set an agenda for improving the framework for integrated SDS between health and social care.

Established in 2012, ‘Creating the Connections’ formed part of a larger programme to bring the third sector together in building the capacity of providers to implement SDS. Funded by the Scottish Government, Changing Support, Changing Lives is a consortium of third sector organisations promoting the value and principles of SDS (http://www.pilotlight.iriss.org.uk).

Through the ALLIANCE’s programme ‘Creating the Connections’, we aim to promote and establish a framework for providing a truly integrated approach to SDS to enable people who are disabled or living with long term conditions to determine their own health and social care outcomes.

Directing Outcomes

SDS epitomises an outcomes focussed approach to social care. The ALLIANCE advocates the widespread implementation of outcome focussed health and social care design and delivery. The foundation for this is a person centred focus on personal outcomes through meaningful conversations with individuals about what matters most to them.

We’ve got to talk about outcomes 2

- Introducing a focus on “personal outcomes” (or what matters to the person) into healthcare services presents a number of possibilities and challenges that vary both by context and by individual case.
- Focussing on “personal outcomes” can require radically different ways of thinking and practitioners need space and appropriate support to work through the implications.
- Working in an outcomes focused way entails involving the person in identifying, negotiating, shaping support and establishing their own contribution towards their personal outcomes.
Context for SDS and Health

The ALLIANCE’s vision

“The foundation of integrated SDS is based on a vision of 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 believes people should be central to the development of a person centred health and social care system, and choice and control are fundamental to people directing their own support.

However, the complexities of people’s lives, their changing circumstances, and fluctuating barriers to equality and evolving support needs, give reason to consider whether an integrated SDS model could offer bespoke support to a growing population of people with a right to live independently.

Without the money to have that daily physiotherapy, the process would have been much slower but the fact that I have a PA and can get maybe an hour or an hour and a half’s physiotherapy each day I have managed to reach a level of fitness and health that no one could have imagined for me four or five years ago.

(Omar Haq, Health and Sport Committee, May 2012)

The inception of jointly accountable health and social care services under the Public Bodies (Joint Working) (Scotland) Act 2014 provides an opportunity to take a fresh approach to embedding a philosophy that advocates individual choice and control over the management of support to achieve intended outcomes. Instead of being subject to service-led commissioning, which traditionally restricted aspirations, integrated SDS could offer people the freedom to design support that promotes their independence and health related outcomes.

This report considers the opportunities and challenges of designing and delivering health and social care services through a personalised approach to meet the changing needs of people who are disabled or living with long term conditions. The following gives a broad overview of the current landscape of SDS as it begins to be implemented and its potential future role within an integrated health and social care system.
Personalisation

Personalisation is the principle of enabling people to be equal partners in the development and delivery of services to provide support that meets their self-identified outcomes. The Scottish Government has long stated its commitment to embedding personalisation in the health and social care system.

"Personalisation should lead to services which are person centred (both around individuals and communities), which can change when required, are planned, commissioned and sometimes delivered in a joined up way between organisations."

(Scottish Government, Personalisation: A Shared Understanding, 2009)

The implementation of personalised services stretches across all types of support, whether that is services provided by local authorities or self managed support packages, and everything in between. Therefore the foundation of support delivery is based on the principles of personalisation through ensuring that people are enabled to attain the lifestyle they wish.

"A more personalised approach to supporting people can genuinely help to improve individuals’ autonomy and self-determination, as well as the quality of their lives. But personal budgets on their own will rarely be enough to ensure that people have the opportunity and support to achieve the outcomes they want. There is a risk that personalisation could leave individuals feeling isolated and taking atomised decisions that disempower them and their service workers, and fail to improve wellbeing. These risks may be intensified as funding is reduced for social care, if personal budgets are cut, or if support for budget holders is reduced or withdrawn."

(Social Care Institute for Excellence, Budgets and Beyond, 2011)

This quote serves as a reminder that the journey towards integrated health and social care SDS is part of a larger agenda to make society more equal and inclusive of disabled people. The Scottish Government’s vision for independent living states:

"Independent living means 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."

Every aspect of the ALLIANCE’s work is underpinned by these values, to ensure that the vision for Scotland’s health and social care agenda promotes a human rights based approach.
Political Perspective

Self-directed Support

Personalisation is the cornerstone policy of the Scottish Government’s reform of health and social care. The Social Care (Self-directed Support) (Scotland) Act 2013 enshrines choice and control into legislation, enabling people to access their right to direct their own social care. The ambition of the Act is to promote a wider community of people self-directing their own social care support.

SDS is a mechanism for disabled people, those with long term conditions, and their carers to live independently. International bodies, the United Nations and the European Convention on Human Rights, have determined that people with impairments, whether they identify as disabled or not, have the same rights as everyone to independent living. In order to secure their rights, disabled people must be able to determine their own lives.

SDS puts individuals in control of the resource for their support. Regardless of which option an individual chooses they should receive personalised support. Personalisation is the tailoring of support to meet the individual’s needs and aspirations.

Key Intentions of the Social Care (Self-directed Support) (Scotland) Act 2013

- Local authorities have a duty to have regard for people’s right to dignity and to participate in the community when delivering SDS.
- People who are eligible for support from social services can choose from four options of how to access that support:
  - Option 1 – People receive a direct payment to arrange and manage their own support.
  - Option 2 – People decide on the support they want and a third party manages their finances.
  - Option 3 – The local authority arranges a person’s support on their behalf.
  - Option 4 – People use a mixture of two or more options to meet their outcomes.
- Carers and families now have the right to SDS to enable them in their caring role by having support in place to meet their needs.
Health and Social Care Integration

The Public Bodies (Joint Working) (Scotland) Act 2014 is intended to bring local authority social services and NHS boards together to design, commission and deliver services that meet the needs of those in their communities. The key objectives of integration of health and social care is to achieve consistency of nationally proposed outcomes across Scotland so that people have a similar experience of health and social care services wherever they live.

“A requirement on Partnerships to strengthen the role of clinicians and care professionals, along with the third and independent sectors and people who use services, in the planning and delivery of services. SDS has been highlighted as a potential area for further extension and exploration as integration develops.”

“Personalisation is no longer only the domain of social work and social care. The Government’s NHS Quality Strategy has person centred care as a main theme and there is a clear desire to ensure that personalisation of health care evolves from this. The integration agenda offers a unique opportunity to merge this thinking around clear values and principles.”

(Personalisation and Human Rights, Chetty, Dalrymple and Simmons 2012)⁶

When considering the potential opportunities to integrate SDS into health, it is proposed that people could use personal budgets for non-emergency interventions (e.g. A&E, acute, and surgical procedures). There is a significant spectrum of options that support good health and enable people to live well with long term conditions, which could appropriately be accessed via an SDS model and could achieve better outcomes.

“...creative tension between the different budget headings and I think that one of the benefits that we will get from the integration of health and social care is that the different budgets will become a single budget. It will not be a case of whether a person can get a direct payment under the health service; a budget will be available to help to support people through social care assessments that have health elements as a result of both the bill and the integration of health and social care.”

(Michael Matheson MSP, Minister for Public Health (Scottish Government), Health and Sport Committee, 2012)⁷

The Public Bodies (Joint working) (Scotland) Act 2014 legislates for:

- Nationally agreed outcomes, which will apply across adult health and social care, and for which Health Boards and Local Authorities will be held jointly accountable.

- A requirement on Health Boards and Local Authorities to integrate adult health and social care budgets.

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There can often be a bit of creative tension between the different budget headings and I think that one of the benefits that we will get from the integration of health and social care is that the different budgets will become a single budget. It will not be a case of whether a person can get a direct payment under the health service; a budget will be available to help to support people through social care assessments that have health elements as a result of both the bill and the integration of health and social care.”

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Health and Social Care Integration and SDS

SDS is entrenched in the principles of being outcomes focused, person centred, self managed, informed and co-produced. All of which is encapsulated in the social model of health. SDS, therefore, sits alongside a range of legislation and strategies aimed at the greater involvement of individuals in the management of their own conditions.

As Alex Neil, the (then) Cabinet Secretary for Health and Wellbeing, affirmed, “self-directed support cannot be seen in isolation from integration and we cannot see integration as isolated from the person centred strategy. It is all part of the same plan to improve the quality of service delivery” 8. Formalising their intention, the Scottish Government stated in Scotland’s Draft Budget 2015-16 that they will “continue to support the implementation of legislation to introduce self-directed support in the context of integrated health and social care, enabling people to lead in directing their choice of care to deliver the best possible outcomes for them and their families and carers.” 9

The Scottish Government has developed a portfolio to explore the national implementation of SDS in health.

The Scottish Government’s response to the Health and Sport Select Committee’s Stage 1 report on the Public Bodies (Joint Working) (Scotland) Bill stated that:

“The Public Bodies (Joint Working) (Scotland) Bill will create an integrated health and social care budget and a single set of joint outcomes. In this respect, integration creates a positive policy environment for the Health Boards to play an integral part in SDS policy and practice. If we are to deliver the aspirations set out in the National SDS Strategy it is vital that we take full advantage of this opportunity. The Scottish Government will continue to foster effective links between the two policies via the following activities:

- A national “SDS and integration” working group which will help a) to inform the regulations and statutory guidance in support of the Public Bodies (Joint Working) (Scotland) Bill and b) to develop a national strategy in relation to the role of the NHS in delivering greater choice and control to individuals.

- A dedicated national lead on SDS and Health, based within the Scottish Government’s self directed support policy team.

- The potential for Scottish Government to fund dedicated SDS development officers within a small number of volunteer Health Boards will also be explored. This will enable the relevant Health Boards to develop detailed strategies and processes to underpin their role in SDS.” 10
Piloting SDS in health

Evidence of an integrated self-directed health and social support approach being implemented, nationally or internationally, is scarce. Yet, emerging research from pilots suggest that such an approach could have significant benefits for people and the services providing the support.

Findings from NHS Lothian and Fife SDS Health Test Sites

“... A study of 25 people across the Lothians and Fife tested the use of direct budgets being used to achieve their determined health outcomes. Participants were allocated a sum of money from additional health funding to spend on activities and equipment that had the potential of improving their health. From gardening tools and computing software to Personal Assistants and college courses, participants used their budgets creatively to source a variety of treatments that impacted positively upon their recovery to better health. On the whole, participants reported beneficial outcomes through being in control, but difficulty arose in the bureaucracy of managing the budgets. ”

(Blake Stevenson, NHS Test Site Evaluation, 2012)\textsuperscript{11}

Key learning conclusions

- The creative ways in which participants used their budgets to achieve life-changing outcomes demonstrated the low cost to benefit ratio that can be delivered through SDS.

- The main issue of the pilot was that the funding was additional to the base budget of the NHS. It presents an opportunity and a challenge to consider the restructuring of service design and delivery to support the transformation of medical provision to encourage self-determined outcomes.

- Practitioners felt that the process was time-consuming and overly bureaucratic, while participants required the additional support from their key-workers that they received during the pilot in order to manage their budget. This highlights the need of services to redefine their relationship with those who want to access self-directed health care.
Pioneering integrated SDS - East Ayrshire Pilot

Inspiring a fresh way of integrated working between health and social care colleagues, East Ayrshire Council have been piloting integrated approaches with people who had diverse health and social care outcomes. Based on the approach taken by Diversity Matters, to build a collective ownership of SDS, East Ayrshire Health and Social Care Partnership have trialled integrated budgets for people with a social care and/or health care support need. In partnership with the Community Brokerage Network, the trial has sought to find creative ways of meeting peoples’ desired outcomes through the support offered by both health and social care.

Two examples from the trial include a person recovering from substance misuse with a budget of just £250 and a mother who had a stroke requiring personal support on a budget of around £20,000 over the course of the pilot. These examples showed that the outcomes achieved demonstrated a major shift in the perception of required interventions. Rather than prescribing treatments and therapies according to a medical perception of successful outcomes, the trial found that more holistic approaches improved people’s overall wellbeing.

Outcomes from the trial pertained to the recovery model of health, whereby each of the people exemplified had the intended goal of returning to their lifestyles, or improving them.

For example, the participant who had had a stroke wanted to ‘regain her role as a wife/mum, return to work, and self manage her after-stroke condition’. This had implications for both health and social services in enabling her to realise her intended outcomes through adapting their mode of service delivery to reflect her needs.

“Self-directed support was the light at the end of the tunnel, as it allowed me to be mum again and bring my family back together where they belong.”

To enable the pilot to be a person centred, integrated experience for each of the participants, the East Ayrshire Health and Social Care Partnership (HSCP) adopted an integrated model of SDS. Through the learning from the pilot, the HSCP found that the approach had direct and indirect consequences for people who use support and services, the services themselves, and the wider community. These included:

- participants having fewer admissions to primary care.
- less need for social care intervention.
- services embracing SDS as an enabler to organisational partnership.
- community capacity being developed through participants’ inclusion.
Penumbra use a person centred, outcome focussed approach. Penumbra have a range of personal planning tools and resources to support this approach, enabling people to identify and plan for what is important for their own recovery journey.

Neil and his wife Eleanor live on the Isle of Lewis, Neil has had mental health issues for over 30 years, this is the story of their journey into recovery with self directed support.

Neil wanted to maintain his independence, and build his confidence after an extensive stay in hospital. Lately, he has planned numerous trips around the island with support. Neil has developed organisational skills that have directly contributed to him seeing more of the island, such as downloading bus timetables from the internet and keeping his diary updated with appointment and bus times.

SDS has given Neil the chance to plan and visit various places such as Tarbert, Callanish stones, Ness and Morvern Gallery, all of which he enjoyed. He desires to live a fulfilling life despite symptoms and has SDS support to visit the cinema, cafes, restaurants, art exhibitions and enjoy ordinary community based events.

Neil still wants to improve independence and increase his activities. He still has goals, such as writing a second book, and he has healthy aspirations, such as continued travel, both on the island and on the mainland. He realises that he has come a long way in the last 12 months and wants this journey to continue.

Neil states that this support “has participated in bringing us (Neil and Eleanor) together” which perhaps is the best way to highlight the importance of SDS and how it has helped Neil gain more control on his journey to recovery and increase his hope for the future.\[14\]

I was diagnosed bipolar in 1981, at the age of 29. Since then, apart from a spell of 13 years on the level, I have made more visits to hospital than I care to remember. These visits were usually compulsory, under a section, after my manic behaviour had exceeded the bounds of my family’s tolerance. Unlike many fellow sufferers, I have never truly enjoyed being high, as I know that the elevated mood will inevitably be followed by a lengthy depression.\["\]
Anecdotal Evidence – AHP perspective

A snap study of Allied Health Professionals (AHPs) and their awareness of SDS, conducted by the ALLIANCE at the Scottish Stroke Allied Health Professional Forum, sought to explore the current awareness of NHS professionals of integrated SDS. The results displayed in the following figure indicate that the current level of knowledge about SDS amongst AHPs is considerably limited. Almost half of all respondents said that they knew nothing about SDS.

What we have learnt from the SDS AHP scoping process?

While it was known that the AHP awareness level of SDS was generally low, it was predicted that it might be higher in the field of stroke. This belief was held as AHPs working with people living with stroke and their families are known frequently to engage in planning and support around rehabilitative and care outcomes that matter to people. However, our snap shot suggests this may not be the case.

SDS is at the centre of the change in culture towards personalised support within the health and social care agenda. Consequently AHPs working across all long term conditions need to engage both practically and theoretically with SDS. In order to enable this cultural change, AHPs require information and training on SDS and a range of supports to facilitate the adoption of outcome based approaches.
Learning from local levels

The current knowledge of SDS and integration suggested to the ALLIANCE that there was a need to engage with practitioners and people who access services at a local level, to begin a dialogue about the way forward for integrated SDS between health and social care. Between January and June 2014, the ALLIANCE held a series of events across Scotland that aimed to create connections at local levels. The following section summarises the key themes to emerge from the events to take place in the Western Isles, Aberdeen, Ayrshire and Falkirk.

Cross-country issues

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

- A perceived 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 SDS, with many delegates feeling frustrated with the lack of information and consultation on putting SDS into practice.

- Uncertainty remains over the future of a provider landscape to respond to the increasing range of ways in which people using SDS can access provisions to meet their needs.

- There is a fear of declining workforces to meet the demands of an ageing population and an increase in those who require health and social care support.

Feedback

“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.”

The full report is referenced\(^\text{15}\)
Recommendations at a local level

The following recommendations have been constructed in collaboration with the delegates who attended the four events that took 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 SDS implementation.

Develop a bank of user experiences to showcase the positive opportunities that can be achieved through SDS.

**The Workforce**

Develop a comprehensive database of stakeholders in the implementation of SDS 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 SDS 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 stake in the outcomes of people with long term conditions, to up-skill the local population on the principles and practicalities of utilising SDS to achieve these.

Plan six-monthly update events to maintain the connection between all the statutory partners in securing a long term co-production policy for the implementation of SDS within an integrated landscape.
Personal Health Budgets England

In planning for the future of the NHS, the Labour government in 2008 set out its strategy for increasing the quality of care for people with long term conditions. The Next Stage review included the introduction of a pilot to explore the potential opportunities for giving individuals personal budgets in order to take control over their own health outcomes.

The pilot, which ran between 2009 and 2011, was evaluated for its impact on individual health outcomes, cost efficiency and quality of life measurements. The evaluation discovered the following findings:

- Based upon quality of life and wellbeing indicators, the use of personal health budgets demonstrated that participants had increased.

- There was no direct impact on the health status of participants according to clinical tests, including no significant difference in mortality rates as compared with the control group.

- Participants who had greater knowledge of the budget amount, who had flexibility over how the budget was sent, and had greater choice as to how the budget was managed, proved to have better quality of life outcomes over the course of the pilot.

Following the successful evaluation of the pilot, the Department of Health announced in November 2012 that Personal Health Budgets will be rolled out from April 2014. From this point it is estimated that 56,000 people who currently receive NHS continuing healthcare will have the right to ask for a personal health budget.

A person has a right to request that their health care is provided through a personal health budget. Where this is agreed to, they have three options of how to receive the PHB, through a notional budget, a third party nominee budget, or a direct payment.

The Personal Health Budget approach has not been adopted by the Scottish Government.

For examples of people using Person Health Budgets in England, please visit: http://www.peoplehub.org.uk/
Scenarios

The following examples are fictional representations to demonstrate the potential of self-directed health and social care. They are designed to encourage people, including health and social care professionals, to think about the possibilities available to people who require health and social care support and influence the way we think about how people’s outcomes can be supported.

Jean
Jean is a 75 year old widow living in her family home in a small village. Since retiring, she continues to be very active in the community, volunteering and is a member of the church council. Recently she has had two falls resulting in trips to A+E. During her last visit to hospital she had an eye test, following which she is no longer able to drive and her falls have been linked to the onset of arthritis.

Through an integrated SDS health and social care budget, Jean could continue to be actively involved in the community by: accessing a fall prevention service run by the local leisure facility, contracting a taxi firm to maintain her links, employing an agency support provider to assist her with domestic tasks and accessing activities (such as swimming) that will ease arthritic flare-ups.

Calum
Calum is 49 years-old. He is a qualified accountant, used to exercising a high degree of control over his life. He lives at home with his wife and son. He has a progressive neurological condition; diagnosed five years ago, which has subsequently resulted in complex needs, including health needs and overnight support needs.

Through an integrated SDS health and social care budget, Calum could sustain his level of independence by: employing a Personal Assistant to support him with daily living, using Access to Work to maintain employment, purchasing therapeutic equipment to adapt his home appropriately and accessing mainstream therapies to remain active.

Dominic
Dominic is a 25 year-old man who lives alone, is at college part-time and is seeking work. He has a good relationship with his parents and sister who also live nearby. He has a learning disability and type-one-diabetes. He and his girlfriend would like to live together.

Through an integrated SDS health and social care budget, Dominic could live independently with: local authority transport to college, an agency support assistant visiting daily to track his sugar levels, co-produced recipes and funding to buy ingredients for an appropriate diet and Personal Assistant support with independent living skills.
Realising a shared vision

A fresh approach needs to be taken, which appreciates that choice and control is the hallmark of a society which respects the rights of people who are disabled or living with long term conditions. Public services need to be reactive to an increase in people expecting these rights to be recognised and supported.

A version of personalisation is already the goal of the Scottish social care system. But it is a goal the system fails to reach consistently. The 1968 social Work Scotland Act, which inaugurated modern generic social work, set the goals of social work that most social workers still ascribe to today...

(Chetty, Dalrymple and Simmons, Personalisation and Human Rights, 2012)\(^17\)

Potential joined-up outcomes for SDS may include:

- Disabled people and those living with long term conditions are able to enjoy their right to live independently through choice and control of their support.

- Disabled people and those living with long term conditions have access to integrated health and social care SDS.

- Person centred approaches are commonly applied to support people to achieve the outcomes that matter to them.

- Disabled people and those living with long term conditions have access to individualised information, and independent advocacy if they need it, to enable them to make informed choices about their support.

- The implementation process of integrated SDS should be determined by people who require funding from both health and social services. It will be important that there is an effective process of co-production with disabled people and those with long term conditions.
## Concerns

“Making individual budgets work will depend on a shift in thinking in three areas:

A shift in the balance of power between professionals and patients in favour of patients.

A shift from a system defined by the services it delivers to the health outcomes it secures.

A shift towards a whole person approach with one integrated budget per person covering all health and social care needs.

(Active Patient, emerging evidence, Vidhya Alakeson 2011)"

Widespread agreement exists that the principle of increasing choice and control amongst people who require social care should be enshrined in law. The following points summarise concerns discussed at the ALLIANCE’s event ‘The person, the whole person and nothing but the person’.

- Conflicts arise between the focus on improving outcomes through integrated support packages, which delegates seemed to be supportive of in principle, and the lack of an infrastructure able to facilitate such an approach.

- There has been a low take up of direct payments in social care in Scotland. A lack of aspiration for individualised commissioning of care and support could signal that there is less demand for personalised services in Scotland than in other parts of the UK.

- There is confusion about SDS in respect to the delegation of health functions; the notion that integrated SDS packages could enable people to employ Personal Assistants to undertake medical tasks. While this possibility has been available under Direct Payments since their inception, and more formally established through delegation of NHS funding under the 2002 Community Care (NHS) Act, there was concern that SDS could lead to health professionals being at risk should their medical tasks be delegated.

- For a health service that is publicly funded and budgeted on a care delivery model, the idea of Direct Payments being initiated in a health setting caused concern amongst NHS representatives. However, disregarding Direct Payments, health services already deliver options two, three and four of SDS by providing health care at home and outsourcing services to third parties to deliver health interventions.

- Since the inception of Direct Payments in social care, markets have evolved to include representation from the third, independent and statutory sectors, while in the provision of health care there is no appetite to transfer this approach to the NHS. However, this perception risks restricting the definition of health care only to medical or clinical treatment alone.
Opportunities

In a new era of integrated health and social care, Scotland has an opportunity to let go of traditional models of financial and resource-led commissioning of support for people who are disabled or living with long term conditions. The opportunity to create a bespoke experience, through which individuals can tailor their own support to reflect their lives, can be achieved by putting into action an SDS philosophy that values each individual’s contribution to an inclusive Scottish society.

There are key factors that could maximise the potential for SDS to transform the culture of separated health and social care into an integrated framework that aspires to achieve the objectives for individualised outcome-based support. These include:

- People who are disabled or living with long term conditions must be the driving force behind the creation of a support mechanism that enables their increased inclusion and independence.

- There must be a political and economic realisation of the social context in which people who are disabled or living with long term conditions contribute to the success of society. Therefore, the right to independent living and sustainable healthcare must penetrate every agenda for Scotland’s future.

- Audit Scotland’s 2014 report ‘Self-directed support’ suggests that strong leadership, which has the foresight and the aspiration to change their approach to reflect the new social environment in which disabled people have the autonomy, will be the making of the success of SDS.

“Key to supporting people to stay as healthy as they can is attention to psychological wellbeing, building social capital, and finding ways to look after their own health. These kinds of solutions and responses can’t be prescribed. They need to come from a deeper understanding of the person, and what they have and value in their life. This expertise is the person’s to bring into the conversation – a different conversation with a different power balance.”

(“Are personal health budgets the solution to integrated care?” Zoe Porter 2014)
Conclusion

The direction of travel, at a national, local, third sector and individual level, towards a person centred approach to health and social care suggests that integrated SDS could be a key mechanism by which holistic, human rights based outcomes can be achieved. With personalisation being the foundation of policy that promotes disabled people’s rights, embedding a framework of personalised experiences of health and social care would appear to be the natural evolution of SDS. While concerns should be acknowledged, the principles of choice, control, involvement and dignity, advocated by the Social Care (Self-directed Support) (Scotland) Act, offer a robust approach to responding to people’s right to independence and inclusion.

The ALLIANCE proposes that each partner in the integration of SDS contribute their expertise to its successful implementation in the following ways:

<table>
<thead>
<tr>
<th>Who?</th>
<th>Does what?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals</td>
<td>Identify the potential benefits that integrated SDS could bring through creative and flexible approaches to securing positive outcomes.</td>
</tr>
<tr>
<td>Local Authorities</td>
<td>Consider the potential opportunities that integrated support could offer people with health and social care outcomes by working more closely with colleagues in their respective Health Boards. Through exploring innovative approaches to meeting individual outcomes collectively, both services will be equally invested in securing the most beneficial outcomes for all partners.</td>
</tr>
<tr>
<td>Health Boards</td>
<td>Scope out the potential implications for service delivery by moving towards an integrated model of SDS through consideration of preventive approaches, reduction of dependency on traditional services and the lower costs associated with non-service led types of healthcare. Such an evaluation would benefit the development of a strategic directive towards integrated SDS.</td>
</tr>
<tr>
<td>Third Sector</td>
<td>Continue to innovate and develop person centred models of support based on choice, control and co-production. Promote and mediate a cohesive relationship between Local Authorities and Health Boards to develop integrated models of SDS. In acting as the facilitator to the integration of SDS, the third sector will be a key partner in promoting integrated outcomes for people living with long term conditions and who are disabled.</td>
</tr>
<tr>
<td>Independent Sector</td>
<td>The benefits of integrated SDS extend to individuals being able to choose non-traditional health preventative activities, including gym memberships, Riding for the Disabled etc. By opening up opportunities for meeting health outcomes, this sector can contribute to a variety of support options.</td>
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</tbody>
</table>
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 Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together over 1000 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

Since its formation in 2006, the ALLIANCE has built a strong track record in helping to shape and deliver policy, particularly in relation to self management, co-production, asset-based approaches and human rights. By harnessing the voice and capacity of people living with long term conditions and unpaid carers across Scotland, the ALLIANCE and its members contribute significantly to the drive for transformation in public services.

The ALLIANCE’s portfolio of work is strongly aligned to the Christie Commission agenda and the Route Map to the 2020 Vision for Health and Social Care.

The ALLIANCE will welcome any questions or comments on the Think Piece ‘Piecing Together Person Centred Support’, which can be directed to: info@alliance-scotland.org.uk

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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GET IN TOUCH

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