Children in Scotland
every child - every childhood

Self-Directed Support (SDS)

Developing independent information and support for children, young people and families on Self-Directed Support

Stage 1 report (Spring- Summer 2013)

The Scottish Government

Contents

Introduction

Children in Scotland has been funded by the Scottish Government from 2013-15 to help implement the Scottish Government's commitment to the provision of **independent information and support** for children, young people and their families on **Self-Directed Support (SDS)**.

We will be developing recommendations for independent information and support for children, young people and families on SDS. This will include a programme of consultation and engagement with children, young people, families and other stakeholders to develop these recommendations and ensure effective implementation of SDS.

The first stage of this work has incorporated three elements:

- To review the current availability of independent support and advice for children, young people and their families
- To review the current literature about the preferences of children, young people and their families in relation to securing information and support
- To raise awareness of the range of support available to children and families.

This report provides a summary of the work that has been accomplished in this initial period.

What is 'independent' information and support?

Independent support is "support which:

- Enables the person to make an informed decision about how they wish to use Self-Directed Support funding;
- May assist them to manage such funding and how it is used on a day-to-day basis; and
- May provide relevant support services; such as training or peer support opportunities; but which
- Does not provide 'hands-on' care or related tasks as a 'care provider' and
- Which does not have a vested interest (financial or otherwise) in how the person chooses to use their Self-Directed Support budget."

This definition has been developed by Evaluation Support Scotland and is the definition we will be using for the purposes of this work.

What is 'Self-Directed Support (SDS)'?

Self-Directed Support (SDS) allows people to choose how their support is provided to them by giving them as much ongoing control as they want over the individual budget spent on their support.

In other words, SDS is the support a person purchases or arranges to meet agreed health and social care outcomes.

SDS includes a number of options for getting support. The person’s individual budget can be:

- Taken as a Direct Payment (a cash payment)
- Allocated to a provider the person chooses (sometimes called an individual service fund, where the council holds the budget but the person is in charge of how it is spent)
- Or the council can arrange a service for the supported person
- Or the supported person can choose a mix of these options for different types of support.

This definition has been taken from the Scottish Government’s Self-Directed Support (SDS) website.
www.selfdirectedsupportscotland.org.uk

Reviewing the current availability of independent information and support on SDS for children, young people and their families

The aim of this initial stage of work was to review the current availability of independent information and support for children, young people and their families on Self-Directed Support (SDS) and related issues.

A short survey was developed to determine availability and demand for this information and support across Scotland.

In order to gauge the current provision and demand for independent information and support we identified various groups and individuals to contact to complete this survey – and separated them into five distinct groups.

Five separate lists were developed:

1. **Organisations potentially providing independent information and support on disability issues and SDS to both adults and children and young people** (Appendix 1 provides a list of all those who were contacted)

   Sourced from Children in Scotland members and contacts, user-led organisations who were members of Self Directed Support Scotland, and others who defined themselves as organisations providing independent support and advice on disability issues/SDS. This included Direct Payment Support Services, Centres for Inclusive Living, and also disability-specific third sector organisations. This survey was sent to a total of 58 organisations. We received 32 returns.

2. **Organisations potentially providing information and support on disability and SDS - provider or potential provider organisations (Not independent)**

   Sourced from Children in Scotland members and other organisations in Scotland who may be providing information and support on SDS to children and young people and other groups, but who are also *providers* or potential providers of SDS services. They are not independent as per the definition of Independent Support on page 3). This included local carer centres across Scotland. Although they did not fit the definition of ‘independent’, many of these organisations may be providing or being asked for information and support so we felt it was important to survey them at this stage. The survey was sent to a total of 47 organisations. We received 23 returns.

3. **Organisations providing general information and support to children, young people and families in Scotland**

   These organisations were recognised as general sources of information and support to children, young people and families in Scotland and were not disability or SDS-specific. They were included in this survey to gauge what information and support they provided and whether SDS was being raised as an issue. This also included contacting a sample of Citizens Advice Bureaux in 29 of the 32 local authorities. These were selected to be contacted as they had their contact details readily available online. This survey was sent to a total of 73 organisations (55 were Citizens Advice Bureaux). We received 23 returns.

4. **Local Coordinators**

   These contacts were identified through the Scottish Consortium for Learning Disability[1] website. A survey was sent to contacts in all 32 local authorities. Some were Local Authority employees, others were third sector employees. This survey was sent to 78 individual contacts. We received 18 returns from 14 Local Authority areas.

5. **Local Authority leads for SDS**

   Self Directed Support Scotland (SDSS) provided us with the most up to date list of identified local authority leads for SDS. The survey was sent to contacts in all 32 local authorities (two have shared social services). This survey was sent to 34 individual named contacts. We received 11 returns, all from different Local Authority areas.

Surveys were sent to a total of 290 contacts on Wednesday 8th May, 2013. Respondents were asked to return surveys via SurveyMonkey or email by Friday 24th May. The deadline was extended to Friday 31st May. A total of 117 responses were received.

The five surveys were similar but slight adjustments were made in order to ensure they were as relevant as possible for each recipient list. Appendix 2 includes each of the five surveys in full.

Survey findings

List 1

Organisations potentially providing Independent information and support on disability issues and SDS to both adults and children and young people

32 responses were received to this survey.

The majority of the organisations who responded provided information to children and young people (79%, n=22), to parents/carers (89%, n=25) and to professionals (82%, n=23). Most of those responding were either a national (Scotland) or local organisation (usually covering one or a few neighbouring local authority areas).

Organisations were asked about the topics they provided information and support on. The most common response (80% n=24) was SDS, followed by disabilities (63%, n=19). A smaller number provided information and support on education, welfare/benefits,

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[1] http://www.scld.org.uk/local-area-co-ordination/what-local-area-co-ordination

employment and more health-specific information. Other issues mentioned here were advocacy support and social work.

Organisations were asked which format they provided support in. Telephone, face-to-face and email was the most common format (90%, n=26). 83% (n=24) provided services via a website and a smaller number (45%, n=13) via social media e.g Twitter and Facebook. A majority provided information in alternative formats to meet any language and communication needs. It was noted this was often ‘on request’ or ‘if required’.

Organisations were asked if they ran any specific support groups – most commonly these were for parents or carers (87%, n=13). A small number ran groups for children and young people (40%, n=6) or professionals (27%, n=4,). A few respondents mentioned that they provided or were in the process of setting up peer support.

There was a fairly even split between those who directly provided children and young people with information (54%, n=15) and those who did not (46%, n=13). We also asked if they provided any other services to children, young people and families. Responses included workshops, family support, educational materials and special events.

Organisations were asked how often they were asked about or provided information and support to children, young people and families on SDS. The most common responses were occasionally (58%, n=15), followed by frequently (27%, n=7) and never (15%, n=4). A couple mentioned they expected these requests to grow in number.

Respondents were asked if they would direct children, young people and families to other organisations for more information on SDS. 26 responded. Self Directed Support Scotland, Lothian Centre for Inclusive Living, Glasgow Centre for Inclusive Living and other local or condition-specific organisations were the most commonly cited organisations.

75% (n=21) said they needed more information on SDS and children and young people. 25% (n=7) did not. They were asked what information they required. Responses included “*everything*”, “*anything*” “*A LOT*” and few would turn down any extra information on the topic.

Organisations were also asked if they had any work planned on this issue prior to the SDS Act being implemented in 2014. Many were at very different stages. For example, some were responding to consultations, whilst others had received funding to do specific pieces of work. One organisation suggested that: “*Training should be given FREE to Third Sector support orgs*”.

In the other comments section some respondents noted they would welcome opportunities to meet with other organisations and discuss SDS.

List 2

Organisations potentially providing information and support on disability and SDS - provider or potential provider organisations (Not independent)

24 responses were received to this survey.

Most of these organisations were national (Scotland) while a couple were national (UK) or local organisations. They provided a wide range of services – most commonly family support and information and advice. A significant number provided training and carried out policy/research work. Other services mentioned were SDS, social care and housing.

When asked whether they provided SDS services, 73% (n=16) of those responding said they did. For some this was information, and for others personalisation was at the core of their organisation with services tailored to the individual. Of these 16,15 provided SDS services for children and 12 provided them for adults. Two commented that services were more developed for adults than for children and young people. For those who didn't currently provide SDS services, three planned to offer them for children (and two for adults) in future.

Organisations were asked how often they were asked about SDS or provided information and support on SDS to children, young people and families. 56% (n=10) were asked occasionally and 22% (n=4) frequently. 22% (n=4) were never asked about these issues. Issues they were asked about included: general enquiries; concerns over budgets; how to access that organisation's services; and the whole SDS process.

Respondents were asked if they would direct children, young people and families to other organisations for more information on SDS. 15 people responded to this question and cited a range of organisations. Some were happy to handle most requests themselves, while others signposted to independent organisations such as Centres for Inclusive Living and local carers centres. Some offered a range of signposting including independent, third sector and statutory services.

79% (n=15) of respondents' organisations needed more information on SDS and children. Information that would be useful included guidance, how local authorities would be responding to their SDS responsibilities and practical advice on expanding or improving their services. One respondent wanted more information on how it has worked for families and legal requirements around individual service funds. A number were open to receiving information on all aspects of SDS.

Organisations were also asked if they had any work planned on this issue prior to the SDS Act being implemented in 2014. 16 people responded to this question. 3 respondents mentioned they were heavily involved with preparing strategies for the roll-out of SDS. Most were planning work with members and families. A number mentioned continual learning and a need for information.

In the other comments section one respondent mentioned "*attitudes and activity very different across local authorities - Moving at very different paces - Some far more inclusive of partners than others*".

List 3

Organisations providing general information and support to children, young people and families in Scotland (List 3)

21 responses were received to this survey.

These organisations tended to provide information and support to children and young people, parents and professionals. Two qualified that this was only available to those over the age of 16. There was a fairly even split as to whether these organisations were local or national (Scotland and UK).

The organisations gave information and support on a wide range of topics affecting children and young people rather than one issue in particular. These issues included child law, consumer topics, additional needs, health, benefits, relationships and children's rights.

Organisations were asked which format they provided support in – most commonly this was via telephone (90%, n=18), face-to-face (80%, n=16) and by email (75%, n=15). Social media was not commonly used. Just over half (58%, n=11) provided information in alternative formats to meet any language and communication needs. It was noted that this was sometimes dependent on resources available.

Only a small number provided any support groups (three for parents, two for professionals and one for children and young people). They were also asked if they provided any other services for children, young people and families. Other direct services included holidays, advice and signposting, and legal assistance.

Organisations were asked how often they were asked about, or provided information and support to children, young people and families on SDS. The most common responses were 'occasionally' (58%, n=11), followed by 'never' (32%, n=6), and 'frequently' (11%, n=2).

Respondents were asked if they would direct children, young people and families to other organisations for more information on SDS. 18 people responded to this question. Those organisations they would signpost to included: Self Directed Support Scotland; local agencies; health professionals; and national agencies/organisations providing SDS.

63% (n=12) of respondents said they would like more information on children, young people and SDS – most commonly this was leaflets, general information and regular updates. One commented that: "*The Scottish Government could do more to make sure that 'live' versions of the legislation is available online to those with an interest...".*

Local Coordinators (List 4)

18 responses were received to this survey. Of these, 15 said they provided information and support to parents, 12 to children and young people, and 11 to professionals.

Coordinators were asked which topics they gave information and support on. For some, this was anything and everything they were asked about. More specifically this was anything relevant to people with a learning disability. Five of them specifically mentioned providing information on SDS.

Organisations were asked which format they provided support in. Most commonly this was face-to-face, telephone and by email (n=16, 14 and 12). Seven ran specific support groups or networks for parents, five ran them for children and young people and two for professionals. A couple mentioned developing groups for young people and two mentioned specific SDS networks:

- "SDS users support network - all parents/carers who come though it's open to all."
- "I have been running SDS Network meetings 4x a year, however, the take up is very poor. We as a team, are planning on sending out a survey to find out what they would prefer."

A majority (11 out of 15 respondents to this question) said they provided information in alternative formats and languages – generally in an easy-read format. Organisations were asked if they provided other services to children and families, and responses included holiday schemes, and community work and support.

These respondents were most likely to be asked 'frequently' about SDS for children and young people (n=10), five were asked occasionally and two were never asked. One commented:

"Our role is mainly to take the mystique out of SDS and explain how easy it could be to manage. We give examples pertinent to the case on hand."

The advice they were asked for generally centered on the 'how does it work and how I can I do it?' However one local coordinator (a local authority employee) said they had never been asked about SDS by a young person or their family.

One commented that awareness was good, but implementation was less clear.

Respondents were asked if they would direct children, young people and families to other organisations for more information on SDS. 17 people responded to this question. A range of organisations and individuals were mentioned here, depending on what was required, including local authority staff or teams including social work, Centres for Independent Living, and care providers.

When asked if they needed more information on SDS and children and young people, eight respondents said yes and eight said no. Information they needed included leaflets to hand out, good examples, how processes work, advice on employing staff, and more specific information for certain groups such as young children, rural areas, and involving children in decision-making processes.

Organisations were also asked if they had any work planned on this issue prior to the SDS Act being implemented in 2014. 16 people responded to this question and mentioned ongoing development work, keeping up-to-date, and training work. One respondent (non-local authority employee) said: "All my colleagues and I have been trained as SDS Champions."

In the other comments section, responses included:

- "There still seems to be a reluctance by parents to grasp SDS."

- "Whilst SDS is an exciting and creative way towards independence for people it is still a daunting prospect for lots of people and possibly not appropriate or manageable for a selected few."

- "We would be very interested to be connected to other areas where SDS for children is being piloted or implemented."

Local Authority leads for SDS (List 5)

11 responses were received to this survey, from 11 different local authorities. This was a disappointing return and we would hope to engage with more local authority contacts across the life of this project.

Respondents mostly provided information and support covering a wide range of SDS topics to children (80%, n=8), parents (90%, n=9) and professionals (90%, n=9). Some presently provided advice on direct payments but were developing this into a wider service. One local authority has commissioned a third sector service provider to develop a resource allocation system.

In terms of the format that information was provided in, 89% (n=8) provided information by telephone, 78% (n=7) by website, 78% (n=7) face-to-face and 56% (n=5) via email. Two respondents mentioned leaflets and one was developing a web-based information system to complement other formats.

Leads were asked if this information was provided by local authority staff or if other organisations were funded to do this. Primarily, it was via local authority staff or by both local authority staff and others.

Respondents were asked if they would direct children, young people and families to other organisations for more information on SDS. Eight people responded that they signposted to a range of local and national organisations so were aware of places to signpost.

Four respondents ran support groups or networks for parents, one for children and two for professionals. Some were developing their support services.

86% (n=6) of respondents said they provided information in other formats/languages and some were developing this. Future work the local authorities were undertaking included an information pack for children on SDS.

56% (n=5) of respondents said they were asked frequently about SDS and 44% (n=4) said they were asked occasionally. One said they were not asked very often. They said they were asked about a wide range of issues relating to how SDS worked.

56% (n=5) of respondents said they would like more information on SDS and children, including good practice examples and how SDS might work for children in need.

Other recent work on current availability of independent support and advice for children, young people and their families

In April 2013 Self Directed Support Scotland (SDSS) published the findings of their survey to identify and profile organisations currently supplying advice and information on SDS to service users and the general public.

The full report can be found at:

http://www.sdsscotland.org.uk/imageuploads/Final%20Mapping%20Report%202013.pdf

A key finding was that 69% of all organisations supplying information and support on SDS work with children or young people. A higher percentage work with older adults or working age adults.

In terms of geographical scope, 39% of all organisations providing information and support on SDS work across one local authority area only; 37% work in more than one local authority area; and 24% provide information and support across Scotland. The greatest concentration of service providers (44%) were in the Glasgow City Council and Edinburgh City Council areas, with significantly fewer agencies located in Scotland's other cities and towns. This may lead to a gap in supply and demand if information requirements around SDS grow in areas outside of Scotland's two major cities. This mapping study also identified how information and advice were being provided and any gaps in provision. Only 60% of organisations are providing general information on SDS and the percentage was much lower for specific elements of information and advice regarding SDS.

The survey findings also contributed to the creation of a national interactive tool - the Self-Directed support (SDS) information support database - which allows users to search for support and information providers. One of the search fields is 'works with children and young people'.

The ALISS (Access to Local Information to Support Self Management) website is another place where people can search for local support and information on self-managing health conditions. The Coalition of Care and Support Providers in Scotland (CCPS) will be mapping voluntary sector care and support providers which will eventually link into ALISS. CCPS will also be producing a users' guide on SDS, for which Children in Scotland are sitting on the advisory group.

Conclusions on current availability of support

Our surveys aimed to review the current availability of independent support for information for children, young people and their families around SDS. The large number of organisations identified as potentially providing information on SDS and the responses received indicate that availability could be described as patchy. These results indicate that SDS is most commonly being raised 'occasionally' with a wide range of existing support and information organisations rather than 'frequently' or 'never'.

A number of organisations are preparing for the implementation of the SDS Act in 2014 and there is an eagerness for more information on SDS as it applies to children and families. Very few responding organisations would turn down more information and assistance. Practitioners and information providers made various suggestions about what would be useful to them.

The findings of this survey, and the work done by SDSS, also indicate that there is no single, central place that organisations can direct or signpost families to for information and support on SDS. Some areas of the country are well served by, for example, Centres for Inclusive Living. However, there is no obvious national source of independent information and support on SDS for children and families. Developing such a service or source would therefore be beneficial to Scotland’s families.

Review of current literature on what is known about children, young people and their families' preferences in relation to securing information and support on SDS

The About Families Partnership between the Centre for Research on Families and Relationships, Parenting Across Scotland and Capability Scotland, recently concluded its 3-year programme of work. This aimed to support voluntary and statutory sector organisations to develop evidence-based services to meet the changing needs of parents and families, including those with disabilities. The partnership identified and investigated four key parenting topics and produced reports and shorter briefings on each of these. One of these topics was 'Parenting and Support', published in October 2012, which gives us up-to-date findings on how families seek, experience and manage support.

It was revealed that families often have differing definitions of needs and support to those of professionals, with 'expert' help most commonly sought for specific issues like education and health rather than general parenting support. Professional help may also have stigma attached to it, with outside help sometimes viewed as a last resort. Parents often saw family members and friends as the natural first place to seek support, particularly when they live close by.

About Families found that: "Services and information are most effective for parents when they are joined up, straightforward, responsive to different circumstances, abilities and backgrounds, build on what parents already know, and delivered through trusting and supportive relationships." Information and support needs to be related to their circumstances rather using a 'one-size fits all' style or programme.

There are particular obstacles for BME families (including language and cultural barriers) and for disabled parents whose support needs may change when they have a child. The research found that: "Some parents of disabled children find that developing strategies for communicating with professionals (such as being assertive) can help them to access the kind of support they need. This means that some parents feel more able to communicate effectively than others." They also found challenges for fathers accessing support as many services and parenting supports are aimed at mothers.

Parents also access informal support networks, which can be promoted and combined with social supports to create and sustain a support network that fits their needs.

About Families made suggestions on good practice for information and support. This would include:

- A holistic approach, which recognises family circumstances
- A strength-based approach
- Support which is joined-up, individualised, and builds on existing knowledge, rather than one-size-fits-all
- Trusting and supportive relationships

- Ways of addressing the range of practical barriers, which can prevent participation in services.

For parents of disabled children, good practice would entail seeing “the child first and the condition after”. There was also some reported dissatisfaction with the time it took for families with disabled children to access services like respite care. In one study, just over a third of these parents felt they had access to the information they needed about parenting a disabled child. Many said they find it difficult to know where to start to look for information and tend to explore a range of sources before they find the information they require. Professionals were felt to be unhelpful or unforthcoming in providing information. In terms of format of information, a mixture of print, in person and internet sources were preferred, with face-to-face contact offering the opportunity to ask questions and print/internet providing reference material.

Accessing formal support services would be easier for families affected by disability if there was more flexibility and better communication and understanding of needs. Other recommendations of things that would help these families included direct payments, services meeting a range of support services, and respite services. The study also identified concerns in previous literature from families about the “‘gap’ that exists between children and families’ services and adult services” in supporting the family; that “practitioners often report a lack of confidence and experience in supporting disabled parents”; and that the focus tends to be on parental ‘incapacity’ or ‘risk’ rather than support. It was also found that “for disabled parents, other disabled parents are key sources of information and advice”.

One of the pieces of research cited throughout the ‘Parenting and Support’ topic report is research conducted by Children in Scotland for NHS Health Scotland - *Exploration of the information support needs of parents* (2012).

The aim of this qualitative research project was to explore the information support experiences, needs and preferences of selected groups of parents with young children (aged 8 and under), especially very young children, living in Scotland. The scope of the work included how parents obtain information and support in relation to both parenting, in general, and child health issues, in particular. There were three specific targeted groups: fathers, young parents (aged 24 and under) and parents with literacy issues.

The three overarching themes that emerged from this research were:

- Parent information/support is undermined when parents feel marginalised

  This perception of being ‘discounted’ or treated differently/negatively was reported as having a significant impact by most parents. It affected the amount/quality of information support they received and parents’ willingness to seek, believe or use various sources of parenting/child health information and support.

- ‘Trust’ shapes how information is sought, received and used

  Where sources of information support were felt to be trustworthy, parents were far more likely to seek, and act upon, the information or advice that was made available to them. Parents had different views regarding whom they felt they could trust and why. All three groups made sharp distinctions between ‘trust’ in relation to medical information and support (particularly when this was immediately required to assess the significance of and to deal with a child's illness or injury), and 'trust' in relation to information/support received in relation to broader parenting and longer-term child development issues.

- Parents respond most positively to personalised information and support

  Parents voiced a strong preference for individualised solutions to parenting and child health issues. Most commented that a 'one-size-fits-all' approach could not meet their information/support needs. Although parents recognised the universality of many issues, they repeatedly expressed their need to understand how general information about a range of issues applied to their own child and their own specific circumstances.

  Parents also indicated that information and support should be ongoing and cumulative. If one idea or suggestion did not work for them, then they wanted help and information that would build upon what they had already tried.

  More impersonal sources of information and support, including written materials, the media and the Internet, were discussed as being potentially valuable, but almost always as secondary/complementary adjuncts to the establishment of good relationships with trusted practitioners/professionals.

Key points on current information and support included:

- Parents wanted more detailed, but also more understandable (Plain English) information about the specific illnesses, injuries and medical conditions affecting their children. This information was much more likely to be believed if given to parents by a respected medical practitioner.

- Parents appreciated and preferred a two-way conversation about their child's health, development, wellbeing and parenting issues. In particular, parents wanted to be able to ask questions and to explore what they as parents could do to help their child.

- The usual sources of personalised information and support, e.g. health visitors, social workers, GP surgery staff and Early Years educators/carers were not automatically accorded trust and respect by these parents. Instead, parents expressed widely differing opinions about their experiences with such professionals and about the value/credibility of the information/advice provided by them.

- Parents expressed their clear belief about the value of peer support/social networks, but these were rarely described as the primary source of child health, medical or parenting information.

- Among the more impersonal sources of information and support, parents tended to rate most highly: NHS 24; certain commercial products/producers and websites; and publications carrying either the NHS or the Scottish Government 'brand'.

In terms of future information and support, parents expressed the following views:

- Using the Internet to search for relevant information and advice was familiar to and valued by parents (even amongst those with literacy issues). However, scepticism was expressed about the credibility of unfamiliar sources, i.e. those that lacked a known and respected ‘brand’. Websites could not (yet) provide the bespoke, contextualised information and support that was most wanted by participating parents.

- Social media (such as Facebook) and newer technologies (such as mobile phone applications) were largely perceived as being unimportant as primary sources of child health information or parenting support.

- There was a limited, but generally positive expression of interest (when prompted) in educational DVDs as a medium for showing valuable child health information and graphically demonstrating good parenting practices.

There were similarities across the three specific groups of parents but there was also diversity within and between groups in terms of preferences. This emphasised the importance of *not* treating parents and subgroups of parents as a homogenous group, and instead recognising and responding to the individual characteristics and circumstances presented by individual parents and children. For example, the fathers group valued gender-specific information and support that is explicitly directed to improving the knowledge and engagement of fathers.

Engagement with our membership and others on information and advice around SDS

For Scotland's Disabled Children

Children in Scotland recently undertook a survey of parents of disabled children in Scotland as part of the 'for Scotland's Disabled Children Parent Participation Project'. This asked parents about their involvement with disability groups and organisations – a key source of information and support. 72% of respondents were involved with a group. The most common nature of involvement was receiving regular communication, attending meetings and receiving direct support. A substantial minority of parents of disabled children did not have any direct contact with any groups or organisations.

Most of the parents and carers who told us how they had heard about the organisations with which they were involved had done so through personal contact. This included word of mouth (often other parents) and through internet search. A smaller number had been directed to the organisation through contact with an agency such as a school or a health professional. Some respondents had set up a group themselves in the absence of any existing provision.

Enquire

Children in Scotland manages Enquire, the Scottish advice Service for Additional Support for Learning. Enquire provides parents/carers, practitioners and children and young people about additional support for learning. Enquire provides a telephone helpline and has a website for both parents and practitioners and for children and young people. Enquire also produces a variety of publications relating to ASL. Enquire's most recent annual report provided information on how people get in touch with them. Most people contact Enquire by telephone (73%), 17% get in touch by email and 5% make contact via the website. Helpline calls are typically lengthy with the average time dealing with an enquiry being 66 minutes. They are most commonly contacted by parents.

Growing up in Scotland

Growing up in Scotland (GUS) is the longitudinal research study tracking the lives of thousands of children and their families from birth through to the teenage years and beyond. GUS provides new information to help the Scottish Government and others develop policies and services for children and their families so that all children in Scotland have 'the best start in life'. Commissioned in 2003 and currently looking at three cohorts of children and families in Scotland the study asks about a wide range of issues including information and support.

Parents in the study have expressed a preference for receiving information or advice about parenting in person – and this was a particularly strong preference for parents in the most deprived areas and those with lower levels of education. Certain groups, such as younger parents, and parents with lower education and income levels, found it more difficult to ask for formal help. When compared with older mothers, younger mothers tended to prefer receiving information about parenting in person from family or friends. The Sweep 5 report in 2011 noted: "It is clear that policymakers and service providers cannot rely on parents who do not engage with formal services having high levels of informal support to replace this because, particularly when their children are very young, this is not always the case."

The most common sources of information or help on health issues were GPs and Health Visitors with almost all consulting at least one person or service for information and advice about their child's health in the last year (Research findings 4, 2007). Parents living in less deprived areas were more likely to have sought information and to have sought it from a greater number of sources than respondents who lived in more deprived areas. Lone parents and young mothers were less likely to have used other formal resources, such as books, telephone helplines or the internet and were more likely instead to seek advice from informal sources particularly their own parents. Other friends and family were also popular sources of information.

Findings for Sweep 1 published in 2008, demonstrated that: "Most families with young children are involved in often complex informal support networks. Almost all parents have access to, and make considerable use of, an informal network variously composed of friends, family and other parents for support, information and advice on a range of parenting concerns. However, there exists a small group of parents who are unsure of asking for help or advice both formally and informally, many of whom either draw heavily on a limited informal network or receive little or no informal support at all."

In a sweep 2 report from the same year, it was revealed that: "Most parents are not wary of the impact or connotations of receiving parenting advice or support from professionals and believe that enough support of this kind is already provided. However, a significant minority believed that receipt of formal parenting support carried certain negative associations."

"Service contact is higher among younger mothers, lone parents, lower income families - in services where contact is service-led and targeted; that is, where the impetus is on the service provider to maintain contact. Those services where the responsibility lies with the user - i.e. the parent - to make contact and seek advice see lower use from the same sub-groups". (Sweep 2 report, chapter 8).

A 2013 Growing up in Scotland study found that:

- Parents of disabled children used a higher number of sources of information on their child's behaviour at ages 2 and 3 compared with parents of non-disabled children.

- The most common source of advice used on the child's health was the family doctor – this applied to both parents of disabled children and parents of non-disabled children.

- For behavioural advice the most common source of information used by parents of disabled children at age 2 was a Health Visitor, with 22% of parents using this source. However, at age 3 a higher proportion used their own parents or other families for advice.

- There was no difference in the proportion of parents of disabled children and parents of non-disabled children who were not at all satisfied with the information available to them as a parent, with 3% of both groups reporting this. However, a higher proportion of parents with disabled children reported being not at all satisfied with the support services available to them in their role as a parent compared with parents of non-disabled children.

It Always Comes Down to Money (2013) – K Stalker et al.

This recent report for Scotland's Commissioner for Children and Young People looked at recent changes in service provision to disabled children, young people and their families in Scotland. The voluntary organisations providing various types of support to families reported changes to their services in recent years – including limiting services received and not being able to provide the same level of support as in previous years. Some organisations expressed concerns that current and future Self-Directed Support (SDS) funding might lead to reduced services and smaller budgets.

The researchers also consulted with parents who, when asked about SDS, expressed some concerns about the responsibilities, particularly those that come with option 1 - direct payments. Stalker et al found that: "There was wide awareness across the groups that they would be asked to consider SDS in the near future. Some parents viewed it as 'too complicated for me' or had thought they were not eligible for it, suggesting a need for better information, including the range of options available under SDS".

Parents were asked about information provision, of which there were: "Frequent references across groups to poor provision of information about services. Many parents found out information by word of mouth from other parents, or through their own efforts searching the internet or making numerous phone calls."

Some of the focus groups felt that: "Partly due to scarce resources, service providers had deliberately withheld information - about direct payments, short breaks and housing adaptations - in order to deter families from applying for or securing support." This finding underlines the importance of independent information and support – separate to that provided by providers".

Misinformation was also identified by parents as an issue to overcome in information provision.

In its conclusion the report recommends that:

- "In relation to Self-Directed Support, local authorities should ensure disabled young people and their families have access to information about its potential benefits and the underlying principles of choice, control, flexibility and inclusion. Families also need practical assistance with the organisation and administration associated with SDS. When it is fully implemented in 2014, local authorities should perceive and promote SDS as a means to develop children and young people's independence and social inclusion rather than as a way to save money."

And

- “Public bodies should be more active in disseminating information about services for disabled children and young people, taking time to explain how the information may apply to particular children. Materials should be available in a range of accessible formats for children and young people.”

Raising awareness of the range of support available to children and families

In June 2013 Children in Scotland held a joint event with the CCPS Providers and Personalisation Programme to bring together current or future provider organisations to discuss current issues surrounding SDS. This event gave both organisations a chance to talk about the work they would be doing, provide an update from the Scottish Government and hear about other pieces of SDS-related work taking place in Scotland.

Providers were able to talk with their peers about the specific issues they were facing with regards to SDS implementation, discuss barriers for children, young people and families and share practice on delivering personalised support.

Among the wide range of issues discussed on the day a number of points with regard to information and support were raised, including:

- There is a lack of information for parents and families about the opportunities that are available at local level.

- Children will need support and information to understand their options under SDS. Capacity to understand and make choices will depend upon the age and maturity of the child.

- There is a need for more information sharing between providers of best practice examples and what is working.

- Good practice guides should be developed and shared.

- There is a need for information and data on what users want in terms of support both nationally and locally.

Following this event CCPS and Children in Scotland produced a short, joint briefing that summarised the event and findings. It was published on both organisation’s websites. This included the following top tips relating to SDS and Children:

- Ensure that children and young people (and other recipients of support) are at the centre of the SDS process. Providing real choice means that the young person’s voice is heard, shared and acted upon.

- Find children, young people and parents who are willing to be SDS Champions and tell positive stories of why SDS works for them. Share good practice examples with other families and support providers.

- Balance risk management and child protection issues with enabling choice. This may include additional education for professionals on risk management.

- Think about existing and potential service models and how to personalise support. Some ‘group activities’ may need to provide more personalised support e.g. after school clubs, respite services, and play schemes. SDS brings an opportunity to design services around the child and the family, to develop new and different services, and to be creative and ‘think outside the box’.

- Young people and families should have access to independent advocacy, advice and information about the full range of options and support available to them under SDS.

- Ensure parents/carers/guardians have full involvement in assessments and decision-making around support planning whilst also involving the child or young person.

- Assessments and support plans should be co-produced and outcomes-focussed.

Other work in this initial period included engaging with the Children in Scotland membership and others to provide responses from the children’s sector to the Scottish Government’s consultations on regulations and guidance to accompany the SDS Act.

Conclusions from Stage 1 and next steps for Stage 2

From the Stage 1 work undertaken so far - exploring current availability of independent (and non-independent) sources of information and support for children, young people and their families; reviewing the literature on families preferences for accessing advice support; and engagement with our membership and others on information and support around Self-Directed Support (SDS) – we have come to the following conclusions:

- There is a demand for more information in relation to SDS and children, young people and families. This demand comes from across our membership and the wider children's sector.

- There is not currently one place that professionals from across Scotland would turn to for information and support around SDS, although several local services such as the Lothian Centre for Inclusive Living and the Glasgow Centre for Inclusive Living are cited as useful.

- Families respond positively to personalised information and support, with each person considered individually rather than as part of a group. Trust to deliver this information can be built through personal connections such as telephone (rather than email/internet) contact, or where possible face-to-face.

- There is a need for information, data and best practice-sharing at both the national and local level.

- There is not currently 'too much' information and support around SDS and there is a need for children and families to learn more about SDS, an issue that many are currently unsure of.

There is, therefore, a need to work with children, young people and their families to produce recommendations around the future delivery of independent information and support around SDS.

At this stage, before consultation and engagement, we anticipate this could potentially take the form of, but is not limited to, the following:

1. Establishing a national SDS information and support service/resource – or adding this responsibility to an existing similar national service.
2. Building the capacity of existing local and national information and support services working with children, young people and families across Scotland.
3. Building the capacity of existing professionals in universal services such as education and health to offer information and support on SDS.

We will be undertaking the following work from late 2013 - early 2015 to inform these final recommendations:

- Consultation and engagement with parents on SDS information and support needs
- Consultation and engagement with children and young people on information and support needs
- Profiling existing information and support services
- Consultation with professionals on SDS information and support requirements
- Ongoing communication and awareness raising across the children's sector.

APPENDIX 1:
List of organisations contacted

List 1 - Organisations potentially providing Independent Support and Advice on disability and SDS

Aberdeenshire SDS Consortium
Action fort Sick Children
Afasic Scotland
Alliance
ARC Scotland
Ayrshire Independent Living Network (AILN)
Bobath Scotland
Borders Disability Forum
Borders Independent Advocacy Service
Butterfly Trust
C-change
Carers Scotland
Central Advocacy Partners
Centre for Inclusive Living Perth and Kinross (CILPK)
CHIP+
Direct Inclusive Collaborative Enterprise (DICE) CIC
Direct Payment Support Service Dundee
Downs Syndrome Scotland
Dumfries and Galloway SDS Consortium
East Dunbartonshire Direct Payments Support Service
Encompass
Enquire
Epilepsy Connections
Equal Say Advocacy
Family Fund
Fife Self Directed Support Consortium
Fife Sensory Impairment Services
Forth Valley Direct Payment Support Service
Glasgow Centre for Inclusive Living
Glasgow Disability Alliance
Grampian Opportunities
Hayfield Support Services with Deaf People
Headway UK (Scotland)
Independent Living Project Orkney
Keys to Inclusion
Kindred
LEAD
Lothian Autistic Society
Lothian Centre for Inclusive Living
Mindroom
National Deaf Children’s Society

PAMIS
Parent to Parent
Partners in Advocacy
PLUS Perth and Kinross
Scottish Borders SDS Consortium
Scottish Consortium for Learning Disability
Scottish Huntington’s Association
Scottish Independent Advocacy Alliance
SDEF
SDS Forum East Renfrewshire
Self Directed Support Scotland
Share Scotland
South Lanarkshire Self Directed Support Network
Tagsa Uibhist
The Family Advice and Information Resource
The Richmond Fellowship Scotland

List 2 - Organisations potentially providing information and support on disability and SDS - provider or potential provider organisations (Not independent)

Aberlour
Action for Children Scotland
Barnardo’s
Camphill Scotland
Capability Scotland
Carers Trust
Carr Gomm
Children 1st
Contact a Family
Cornerstone
CrossReach
Enable
HRM Homecare Services
HSC Futures
Includem
Inclusion Scotland
Kibble
Penumbra
Quarriers
Scottish Personal Assistants Employers Network
Sense Scotland
The Action Group
The Mungo Foundation
The Thistle Foundation
Y People

Local carers Centres

Connecting Carers
Dundee Carers Centre
East Lothian Carers Centre
Glasgow East End Community Carers Centre
Greater Pollok Carers Centre
North Argyll Carers Centre
PKAVS Carers Centre
PRT Angus Carers Centre
PRT Borders Carers Centre
PRT Carers Centre (Falkirk and Clacks)
PRT Carers of West Dunbartonshire
PRT Carers of West Lothian
PRT Dumfries and Galloway Carers Centre
PRT East Ayrshire Carers Centre
PRT East Renfrewshire Carers Centre
PRT Fife Carers Centre
PRT Glasgow South East Carers Centre
PRT Helensburgh and Lomond Carers Centre
PRT Lanarkshire Carers Centre
PRT North Ayrshire Carers Centre
PRT Orkney Carers Centre
PRT Renfrewshire Carers Centre
PRT South Ayrshire Carers Centre
PRT Vocal Edinburgh Carers Centre
PRT Voluntary Services Aberdeen YC Activity Centre
Stirling Carers Centre
VSA Aboyne Carers Support
VSA Carers Centre Aberdeen
VSA Fraserburgh Carers Centre
VSA Oldmeldrum Carers Support
VSA Peterhead Carers Support
VSA Stonehaven Carers Support
West Glasgow Carers Centre

List 3 - Organisations providing general information and support to children, young people and families in Scotland

Breathing Space
Care for the Family
Childline
Child Poverty Action Group
Citizens Advice Scotland
Cl@n Childlaw

Families Need Fathers
Home Start Scotland
Mentor UK
One Parent Families Scotland
Parent Network Scotland
Parenting Across Scotland
Relationships Scotland
Samaritans in Scotland
Scotland’s Commissioner for Children and Young People
Scottish Child Law Centre
Who Cares?
Young Scot

Citizen’s Advice Bureaux

Aberdeen Citizens Advice Bureau
Airdrie CAB
Annan CAB
Arbroath CAB
Argyll and Bute CAB
Banff and Buchan CAB
Barra CAB
Bellshill CAB
CA Leith
CA Pilton
CA Portobello
CAB West Lothian
Caithness CAB
Castle Douglas CAB
Central Borders CAB
Citizens Advice and Rights Fife
Clackmannanshire CAB
Clydesdale CAB
Coatbridge CAB
Cumbernauld CAB
DAGCAS
Dalkeith CAB
Denny and Dunipace CAB
Drumchapel CAB
Dundee CAB
East Ayrshire CAB
East Dunbartonshire CAB
East Kilbride CAB
East Renfrewshire CAB
East Sutherland CAB
Easterhouse CAB
Falkirk CAB

Forfar CAB
Glasgow CAB
Grangemouth and Boness CAB
Haddington CAB
Hamilton CAB
Harris CAB
Inverness, Badenoch and Strathspey CAB
Kincardine and Mearns CAB
Lewis CAB
Lochaber CAB
Maryhill and Possilpark CAB
Montrose CAB
Moray CAB
Motherwell and Wishaw CAB
Musselburgh and District CAB
Nairn CAB
North and West Sutherland CAB
North Ayrshire Citizens Advice Service
Orkney CAB
Parkhead CAB
Peebles CAB
Perth CAB
Renfrewshire CAB
Ross and Cromarty CAS
Roxburgh and Berwickshire CAB
Rutherglen and Cambuslang CAB
Saltcoats CAB
Shetland CAB
Skye and Lochalsh CAB
Stirling District CAB
Stranraer CAB
Turriff and District CAB
Uist CAB
West Dunbartonshire CAB
Westhill and District CAB

List 4 – Local Coordinators

View the full list of local coordinators at:

http://www.scld.org.uk/local-area-co-ordination/what-local-area-co-ordination

List 5 - Local Authority leads for SDS

Supplied by SDSS.

APPENDIX 2:
Copies of the five surveys sent out to the five lists

LIST 1

Self-Directed Support: Access to independent support and advice

Children in Scotland has been funded to help implement the Scottish Government's commitment to the provision of independent information and support for children and young people on Self-Directed Support. As part of the initial stages of this work we are reviewing the ***current availability of independent support and advice for children, young people and their families*** *and have identified your organisation as a* ***potential source of independent support, information and advice to children, young people and families in Scotland.*** *We would very much appreciate you taking 10-15 minutes to complete this short survey which can also be accessed online at:*

http://www.surveymonkey.com/s/K2PJNQN

The survey can be completed online or saved and sent by email to scollier@childreninscotland.org.uk It would be appreciated if they could be returned by ***Friday 24th May****. If you have any questions please contact Sara Collier, 0131 222 2412, scollier@childreninscotland.org.uk at Children in Scotland.*

This short survey seeks to find out what support and advice you provide to children, young people and families.

1. Personal/Organisational information

Please note your answers will not be attributed directly to you or your organisation.

Name
Organisation
Contact email
Contact phone number

2. Do you provide information and support to:

Children and Young People ☐
Parents/carers ☐
Professionals ☐
Other

3. Are you a national or local organisation?
National (UK) ☐
National (Scotland) ☐
Local☐ Which area?
Other

4. **On which topics does your organisation give information and support?**

Self-Directed Support ☐
Disabilities ☐
Medical/health related information/specific condition ☐
Employment ☐
Welfare and benefits ☐
Housing ☐
Education ☐
Other and comments

5. What format do you provide information and support in?

Telephone ☐
Website ☐
Via Email ☐
Via social media (twitter, facebook etc) ☐
Face to face ☐
Other

6. Do you provide information in alternative formats to meet language and communication needs (eg different languages)?
Yes ☐
No ☐
Comment

7. Do you run any support groups or networks specifically for:

Children and Young People ☐
Parents/carers ☐
Professionals ☐
Other and comments

8. Do you provide support and advice directly to children and young people?
Yes ☐
No ☐

9. Do you provide any other services for children, young people and families?

10. Are you asked about or do you provide information/advice about Self-Directed Support to children, young people and their families:

Never ☐
Occasionally ☐
Frequently ☐
Other and comments

11. If children, young people and/or their families asked your organisation about Self-Directed Support are there other organisations you would direct or signpost them to for more information?

12. As an organisation providing information and advice do you need more information on Self-Directed Support and children and young people?

Yes ☐
No ☐

What information do you need?

13. Does your organisation have plans to do any work around/learn more about SDS before the Self-Directed Support Act (Scotland) is enacted in 2014?

14. Any other comments?

15. Would you like to add your details to a mailing list to receive more information from Children in Scotland about our work on Self-Directed Support?
Yes ☐
No ☐

Thank you for completing this survey - we very much appreciate it. The findings will be written up in the coming months and used to help us with further stages of work to develop recommendations for future delivery of information and support to ensure effective implementation of Self-Directed support in Scotland.

LIST 2

Self-Directed Support: Access to independent support and advice

Children in Scotland has been funded to help implement the Scottish Government's commitment to the provision of independent information and support for children and young people on Self-Directed Support. As part of the initial stages of this work we are reviewing the current availability of independent support and advice for children, young people and their families and have identified your organisation as a ***potential source of support, information and advice to children, young people and families in Scotland, or current/ future provider of Self-Directed Support.*** *We would very much appreciate* *you taking 10-15 minutes to complete this short survey which can also be accessed online at:*

http://www.surveymonkey.com/s/KT5LJWJ

The survey can be completed online or saved and sent by email to scollier@childreninscotland.org.uk It would be appreciated if they could be returned by ***Friday 24th May****. If you have any questions please contact Sara Collier, 0131 222 2412, scollier@childreninscotland.org.uk at Children in Scotland.*

This short survey seeks to find out what support and advice you provide to children, young people and families.

1. Personal/Organisational information

Please note your answers will not be attributed directly to you or your organisation.

Name
Organisation
Contact email
Contact phone number

2. Are you a national or local organisation?
National (UK) ☐
National (Scotland) ☐
Local ☐ Which area?
Other

3. What services does your organisation currently provide?

Childcare ☐
Education ☐
Residential care ☐
Day care ☐
Health care ☐
Family support ☐
Campaigning/policy/research ☐
Information and advice ☐
Training ☐
Other

4. Do you currently provide Self-Directed Support or personalisation services?
Yes ☐
No ☐
Please give details

5. If so, do you currently provide Self-Directed Support services for:

Children and young people ☐

Adults ☐
Comment

6. If not, does your organisation plan to offer Self-Directed Support or personalisation services in future to:
Children and young people ☐
Adults ☐
Comment

7. Are you asked about or do you provide information/advice about Self-Directed Support to children, young people and their families:

Never ☐
Occasionally ☐
Frequently ☐

Other and more details – eg what are you most commonly asked about/given information and advice on in relation to SDS?

8. If children, young people and/or their families asked your organisation about Self-Directed Support are there other organisations you would direct or signpost them to for more information?

9. As an organisation do you need more information on Self-Directed Support and children and young people?

Yes ☐
No ☐

Comment – what information do you need?

10. Does your organisation have plans to do any work around/learn more about SDS before the Self-Directed Support Act (Scotland) is enacted in 2014?

11. Any other comments?

12. Would you like to add your details to a mailing list to receive more information from Children in Scotland about our work on Self-Directed Support?
Yes ☐
No ☐

Thank you for completing this survey - we very much appreciate it. The findings will be written up in the coming months and used to help us with further stages of work to develop *recommendations for future delivery of information and support to ensure effective implementation of Self-Directed support in Scotland.*

LIST 3

Self-Directed Support: Access to independent support and advice

Children in Scotland has been funded to help implement the Scottish Government's commitment to the provision of independent information and support for children and young people on Self-Directed Support. As part of the initial stages of this work we are reviewing the current availability of independent support and advice for children, young people and their families and have identified your organisation as ***a potential source of information and advice to children, young people and families in Scotland****. We would very much appreciate you taking 5-10 minutes to complete this short survey which can also be accessed online at:*

http://www.surveymonkey.com/s/K3MG5HJ

The survey can be completed online or saved and sent by email to scollier@childreninscotland.org.uk It would be appreciated if they could be returned by ***Friday 24th May****. If you have any questions please contact Sara Collier, 0131 222 2412, scollier@childreninscotland.org.uk at Children in Scotland.*

More information on Self-Directed Support in Scotland can be found on this website: http://www.selfdirectedsupportscotland.org.uk

This short survey seeks to find out what information and support you provide to children, young people and families.

1. Personal/Organisational information

Please note your answers will not be attributed directly to you or your organisation.

Name
Organisation
Contact email
Contact phone number

2. Do you provide information and support to:

Children and young people ☐
Parents/carers ☐
Professionals ☐
Other

3. Are you a national or local organisation?
National (UK) ☐
National (Scotland) ☐
Local☐ Which area?
Other

4. On which topics does your organisation give information and support about?

5. What format do you provide information and support in?

Telephone ☐
Website ☐
Via Email ☐
Via social media (twitter, facebook etc) ☐
Face to face ☐
Other

6. Do you provide information in alternative formats to meet language and communication needs (eg different languages)?

7. Do you run any support groups or networks specifically for:

Children and young people ☐
Parents/carers ☐
Professionals ☐
Other and comments

8. Do you provide any other services for children, young people and families?

9. Are you asked about or do you provide information/advice about Self-Directed Support to children, young people and their families:

Never ☐
Occasionally ☐
Frequently ☐
Other and comments

10. If children, young people and/or their families asked your organisation about Self-Directed Support are there other organisations you would direct or signpost them to for more information?

11. As an organisation providing information and advice do you need more information on Self-Directed Support and children and young people?

Yes ☐
No ☐

Comment – what information do you need?

12. Any other comments?

13. Would you like to add your details to a mailing list to receive more information from Children in Scotland about our work on Self-Directed Support?
Yes ☐
No ☐

Thank you for completing this survey - we very much appreciate it. The findings will be written up in the coming months and used to help us with further stages of work to develop recommendations for future delivery of information and support to ensure effective implementation of Self-Directed support in Scotland.

LIST 4

Self-Directed Support: Access to independent support and advice

Children in Scotland has been funded to help implement the Scottish Government's commitment to the provision of independent information and support for children and young people on Self-Directed Support. As part of the initial stages of this work we are reviewing the current availability ***of independent support and advice for children, young people and their families*** *and have identified you as a* ***Local Area Co-ordinator in Scotland****. We would very much appreciate you taking 10 minutes to complete this short survey which can also be accessed online at:*

http://www.surveymonkey.com/s/K5HC8CR

The survey can be completed online or saved and sent by email to *scollier@childreninscotland.org.uk* *It would be appreciated if they could be returned by*

Friday 24th May*. If you have any questions please contact Sara Collier, 0131 222 2412, scollier@childreninscotland.org.uk at Children in Scotland.*

This short survey seeks to find out what information and support you provide to children, young people and families.

1. Personal/Organisational information

Please note your answers will not be attributed directly to you or your organisation.

Name
Organisation
Contact email
Contact phone number

2. Do you provide information and support to:

Children and Young people ☐
Parents/carers ☐
Professionals ☐
Other

3. **On which topics does your organisation give information and support?**

4. What format do you provide information and support in?

Telephone ☐
Website ☐
Via Email ☐
Via social media (twitter, facebook etc) ☐
Face to face ☐
Other

5. Do you run any support groups or networks specifically for:

Children and young people ☐
Parents/carers ☐
Professionals ☐
Other and comments

6. Do you provide information in alternative formats to meet language and communication needs (eg different languages)?

7. Do you provide any other services for children, young people and families?

8. Are you asked about or do you provide information/advice about Self-Directed Support to children, young people and their families:

Never ☐
Occasionally ☐
Frequently ☐

Other and more details – eg what are you most commonly asked about/given information and advice on in relation to SDS?

9. If children, young people and/or their families asked your organisation about Self-Directed Support are there other organisations you would direct or signpost them to for more information?

10. Do you need more information on Self-Directed Support and children and young people?

Yes ☐
No ☐

Comment – what information do you need?

11. Does your organisation have plans to do any work around/learn more about SDS before the Self-Directed Support Act (Scotland) is enacted in 2014?

12. Any other comments?

13. Would you like to add your details to a mailing list to receive more information from Children in Scotland about our work on Self-Directed Support?
Yes ☐
No ☐

Thank you for completing this survey - we very much appreciate it. The findings will be written up in the coming months and used to help us with further stages of work to develop recommendations for future delivery of information and support to ensure effective implementation of Self-Directed support in Scotland.

LIST 5

Self-Directed Support: Access to independent support and advice

Children in Scotland has been funded to help implement the Scottish Government's commitment to the provision of independent information and support for children and young people on Self-Directed Support. As part of the initial stages of this work we are reviewing the ***current availability of independent support and advice for children, young people and their families*** *and have identified you as a* ***Local Authority lead for Self-Directed Support.*** *We would very much appreciate you taking 5-10 minutes to complete this short survey which can also be accessed online at:*

http://www.surveymonkey.com/s/8LKCRTM

The survey can be completed online or saved and sent by email to scollier@childreninscotland.org.uk It would be appreciated if they could be returned by ***Friday 24th May****. If you have any questions please contact Sara Collier, 0131 222 2412, scollier@childreninscotland.org.uk at Children in Scotland.*

This short survey seeks to find out what information and support you provide to children, young people and families.

1. Personal/Organisational information

Please note your answers will not be attributed directly to you or your organisation.

Name
Organisation
Contact email
Contact phone number

2. Do you provide information and support on Self-Directed Support to:

Children and young people ☐
Parents/carers ☐
Professionals ☐
Other

3. What information and support does your local authority provide directly to children, young people and families on Self-Directed Support?

4. What format do you provide information and support in?

Telephone ☐
Website ☐
Via Email ☐

Via social media (twitter, facebook etc) ☐
Face to face ☐
Other

5. Is information and support provided directly by Local Authority staff or do you fund another organisation to provide this?

6. Do you sgnpost or direct children, young people and families to other organisations or individuals to provide information and advice? If so, who?

7. Do you run any support groups or networks specifically for:

Children and young people ☐
Parents/carers ☐
Professionals ☐
Other and comments

8. Do you provide information in alternative formats to meet language and communication needs (eg different languages)?

9. Do you provide any other services relating to Self-Directed Support for children, young people and families?

10. Are you asked about or do you provide information/advice about Self-Directed Support to children, young people and their families:

Never ☐
Occasionally ☐
Frequently ☐

Other and more details – eg what are you most commonly asked about/give information and advice on in relation to SDS?

11. Do you need more information on Self-Directed Support and children and young people?

Yes ☐
No ☐

Comment – what information do you need?

12. Any other comments?

13. Would you like to add your details to a mailing list to receive more information from Children in Scotland about our work on Self-Directed Support?
Yes ☐
No ☐

Thank you for completing this survey - we very much appreciate it. The findings will be written up in the coming months and used to help us with further stages of work to develop recommendations for future delivery of information and support to ensure effective implementation of Self-Directed support in Scotland.

Children in Scotland
Princes House
5 Shandwick Place
Edinburgh
EH2 4RG

November, 2013