



By My Side Research Report:

# Summary, Findings, Conclusions and Recommendations

People's experiences of using Independent SDS  
Information and Support services across Scotland

2024



## Key Contents

Introduction and background .....	3
Research Conclusions .....	5
Research Recommendations .....	11
Briefing Reports .....	13

This research was undertaken between March – April 2024  
Self Directed Support Scotland

# Introduction and background

*In 2023, Self Directed Support Scotland were commissioned by the Scottish Government to undertake research looking at people's experiences of using Independent SDS Information and Support services across Scotland.*

## Independent Support Organisations (ISOs)

These organisations help people to access the social care support that they need on a day to day basis, and include:

- Independent SDS Information and Support services (eg SiRD funded<sup>1</sup>)
- Advocacy organisations
- Carers' Centres
- Brokerage organisations
- Peer Support Groups.

## The aims of the research were:

- To understand people's experience of trying to access Independent Support
- To understand what 'good quality' support looks like
- To understand what support people want and value from ISOs
- To understand the impact of Independent Support
- To identify any gaps in the provision of Independent Support
- To make recommendations relating to how the quality of Independent Support can be maintained and improved across Scotland.

The aim of this research was to gain a better understanding of people's experiences, filling a gap in current data and complementing the reporting on the delivery of independent support by Support in the Right Direction funded organisations. The ultimate aim of the research is to support the strategic planning and delivery of future Independent Support for SDS.

## What we did

In collaboration with a Project Advisory Group, we developed a research survey and disseminated this across key stakeholder groups between March - April 2024.

---

1 SiRD is short for Support in the Right Direction, the Scottish Government funding stream for Independent SDS Information and Support services across Scotland

## Who responded to the survey

While we received a good response to the survey given the short time frame, there remains gaps in the data from specific geographic areas and from certain groups of people.

There are particular data gaps from:

- People who live in rural and remote areas of Scotland
- People who experience problematic substance use
- Autistic people
- People from minority ethnic communities
- People under the age of 18

The majority of responses were from people aged between 18 – 64, who were predominately white, female and identified as having a disability or health condition. Most respondents identified as having either a physical disability, a mental health condition or a learning disability. A significant number of unpaid carers also completed surveys, for themselves or the person they care for.

# Research Conclusions

This provides a summary of the main conclusions. The full list appears in the Full Research Report.

## **Conclusion 6: People need support at all stages of the SDS journey**

People need support at the beginning of the SDS process. They require clear information, help to understand what SDS is and how the social care system works locally, as well as needing support with 'key' areas, such as the assessment of needs and choices around the 4 Options of SDS.

## **Conclusion 3: People accessed multiple ISOs support during their social care journey**

A number of respondents accessed support from multiple ISOs in the previous 12 months. This could indicate a higher level of need for support for some people, or it could highlight the boundaries and roles that different Independent Support Organisations have (eg Independent Advocacy, carers services). This could also potentially indicate a lack of 'end-to-end' support being available from any one specific organisation. Future research is required to explore the reasons for this and any implications there might be for people trying to access the support they need.

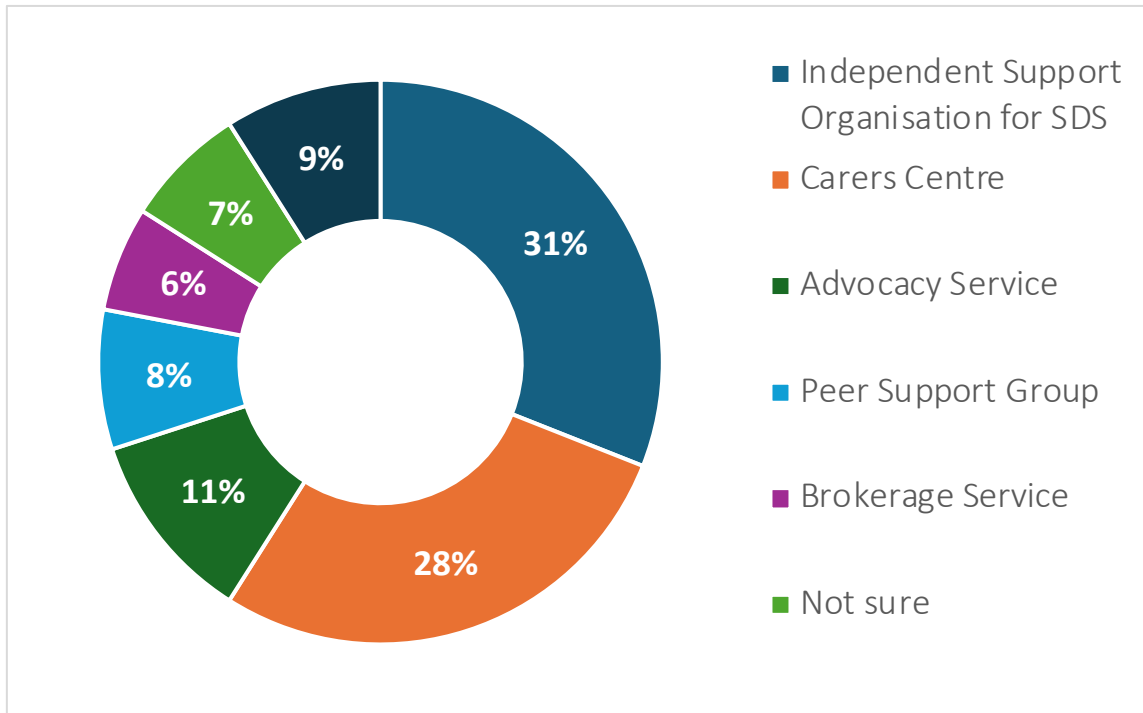
## **Conclusion 7: People needed to access a variety of Independent support to address a variety of issues they face**

People who approached ISOs with requests for support also came with a whole range of other issues and concerns, that ISOs need to be aware of. These often related to issues not directly related to people's health and social care needs.

ISOs need to be aware of other forms of support that would be available to people and how they can support them to access that support.

You can see the range of Independent Support that people accessed in Chart 10 below.

**Chart 10: The types of organisations or groups that people had support from**



**Conclusion 5: Local Authorities are the main source of information on ISO services**

People accessed information about ISOs from a wide variety of different sources. The vast majority of people responding to this Survey were made aware of ISO by their Local Authority and specifically by a Social Worker.

Other significant sources of information included other organisations and friends and family. Very few people found details through searching on the internet or social media and even fewer were made aware of ISO by their GP or someone in the NHS.

**Conclusion 8: ISOs are accessible, provide high quality support and make a positive difference to people being able to access social care support**

The responses indicate a high level of accessibility, availability and quality of Independent Support, when it comes to people being able to uphold their rights, exercise real choice over their social care support and to sort out any problems they might face with SDS.

Whilst these responses overall are very positive, we cannot say if they relate equally across different groups of people and different types of Independent Support across Scotland. This may require further research to clarify.

**Conclusion 9: ISO support is ‘essential’ to enable people to access the support they need**

86% of respondents stated that they found Independent Support to be ‘Essential’ or ‘Very helpful’. This indicates that Independent Support is not only valued by people who access it, but that it is central to their ability to access and make use of SDS.

We also know from the responses to the demographic questions, that we have not learnt about the experiences of certain marginalised groups.

If this finding is equally valid for other groups of people, this highlights the need for Independent Support to be available to anyone who is looking to access social care support. This has particular implications for the prioritisation and allocation of resources and how the variety of Independent Support can be sustained and developed at a local level.

### **Conclusion 10: People face a range of barriers to accessing Independent Support**

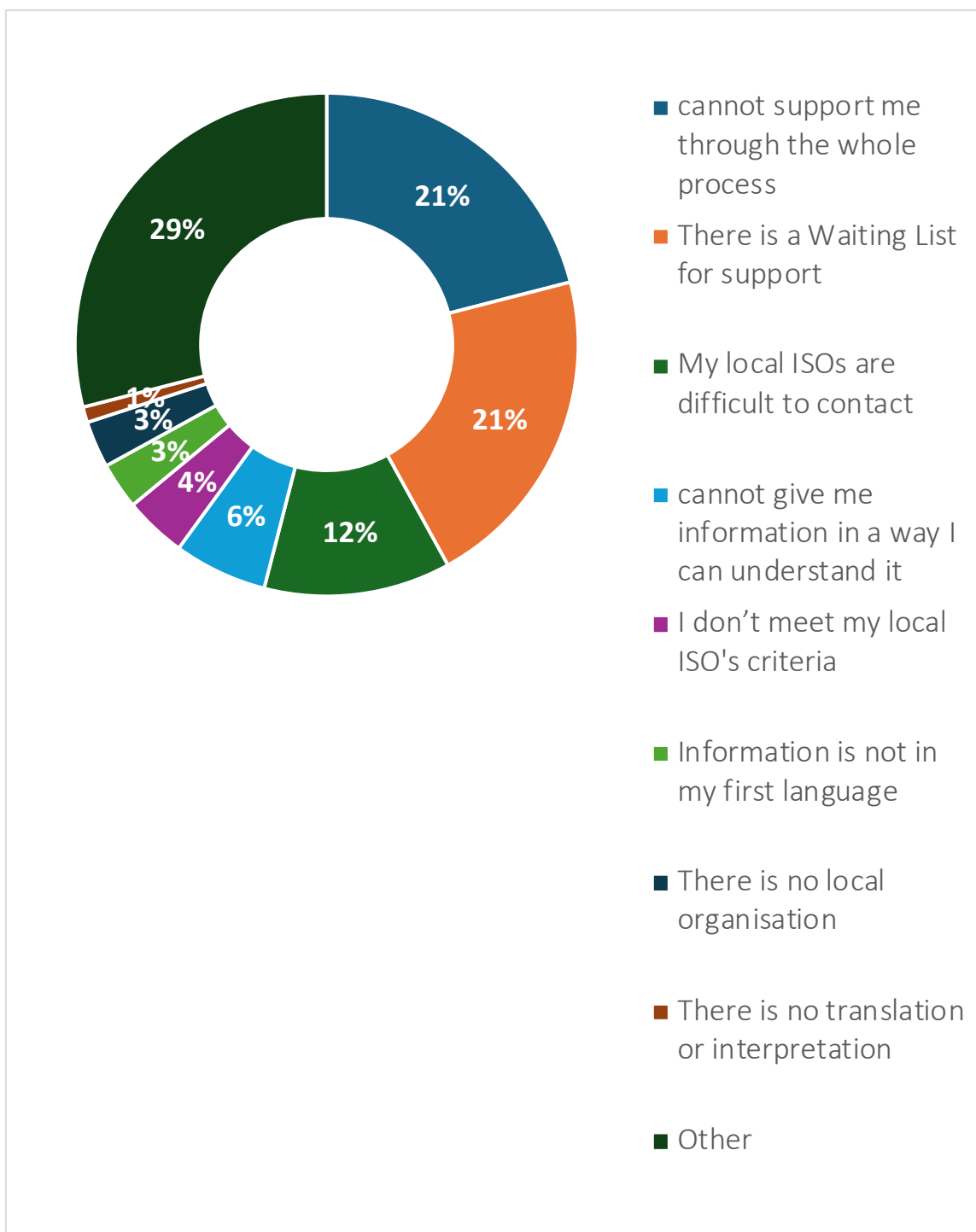
For some people, there are difficulties in accessing the Independent Support that they need to enable them to access and make use of SDS. Respondents identified some clear, specific areas of difficulty, relating to:

- the awareness of Independent Support that is available to them
- the breadth of the service that ISOs can provide
- the availability of ISO support
- the ability of ISOs to meet people's access needs
- the variation in ISO services across Scotland
- the lack of information on ISOs support from other key stakeholders

Responses also highlighted some of the challenges that ISOs face when delivering support. A number of different ISOs have introduced waiting lists for their service. This indicates that at times, the level of need for their support is greater than their capacity to meet that need. This then raises the question of funding for ISO support and whether this is sufficient. One effect of having a Waiting List is how quickly people can access the support that they need, particularly at times of crisis.

Respondents also highlighted their access needs around information, communication, translation and interpretation not always being met by some ISOs. Chart 20 identifies the difficulties that people faced when trying to access ISO support (see below)

Chart 20: The difficulties people faced when trying to access local information and support about social care/ SDS



**Conclusion 11: Independent Support would be improved by being better supported by the Local Authority or NHS**

People identified a number of factors that could improve Independent Support, with the most common being that ISOs are better supported by their local Council or NHS. Other factors focused on the information ISOs produce, being better promoted and being easier to find.

Most responses related to the impact of ISO support, such as influencing Local Authorities decisions, being able to stand up for people's rights and to be able to support people for as long as they need it.



You can see people's responses in Chart 22 below.

Chart 22: What would improve Independent Support



**Conclusion 14:** It would be easier for people to access ISOs support if they had clearer information on ISOs and were told about them by their Local Authority or NHS

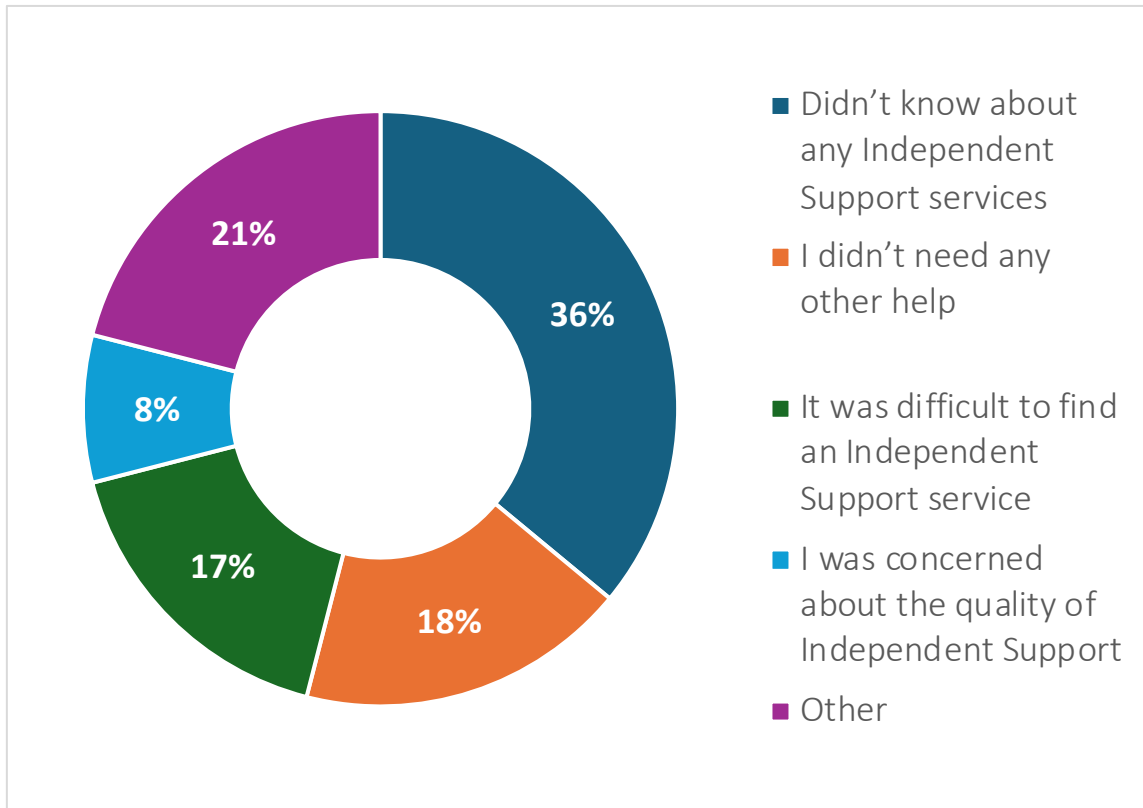
The importance of having clearer information on Independent Support and an easier way to find ISOs were highlighted, as well as the need for the Local Authority and NHS to tell people about the ISO support available to them.

**Conclusion 12:** A lack of awareness of ISOs led to people not accessing ISO support in the last 12 months

Most people who didn't access ISO support in the last 12 months, told us they didn't do this because they weren't aware of this support or it was difficult to find. A further group of people told us that they didn't need any other help during the last 12 months.

You can see people's responses in Chart 23 below.

Chart 23: Reasons why people have not used Independent Support in the last 12 months



**Conclusion 13: People still needed support even when they didn't have contact with an ISO in the last 12 months**

Those people who didn't access ISO support in the last 12 months told us about a range of things that they still needed support with during this time.

Some people were looking for support with starting the process of accessing social care, including getting an assessment of their needs. Other people were looking to understand what SDS is and how it works, or were looking for support with their existing support arrangements, such as with Support Planning, to recruit or manage a Personal Assistant or to change their support in some way.

# Research Recommendations

## Recommendation 4: Accessible information is available on ISO services, their availability and scope

The research showed one of the main barriers that people faced when trying to access Independent Support was a lack of accessible information. ISOs need to ensure they understand the information needs of the people who need their support. Where it's not available, they need to produce clear, accessible information for all, including in a range of formats and languages.

## Recommendation 5: Promoting ISO services with key local partners

The findings tell us that people did not always receive information about local ISOs services from key stakeholders, such as the Local Authority, NHS or Social Work Department. ISOs should identify key local partners and work with them to improve their understanding of the support ISOs provide. ISOs and Local Authorities should work together to consider how to ensure that key members of the Local Authority workforce, including Social Work professionals and call centre staff, understand what Independent Support is, what is available locally and how to signpost or refer people for support.

## Recommendation 6: Developing referral pathways to ISOs

The research showed that most people learned about local ISO services from their Local Authority or Social Work Department. This was mainly through being signposted rather than being referred.

Referral pathways provide an opportunity for people who need support the most, to access that support at the earliest opportunity. This can happen prior to any assessment of need. Developing referral pathways involves learning, relationship building and joint working, which is beneficial to all parties. ISOs, Local Authorities and other stakeholders should work together to develop effective referral pathways for people needing to access ISOs support.

## Recommendation 7: Identifying and addressing gaps in ISO support

Any gaps in Independent Support need to be identified, recorded and acted upon at a local level. This requires mapping the extent of ISO support across the country, including equality of access for marginalised groups. Where accessing ISO support is a statutory right, this needs to be identified with the relevant regulatory bodies, as well as organisations that have a role in planning, funding and overseeing the delivery of ISOs support, such as Health and Social Care Partnerships (HSCPs) and Integration Joint Boards (IJBs). Any national and local plans that relate to the provision of social care support, both for supported people and their carers, should include reference to accessing Independent Support.

### **Recommendation 8: People need to be supported to access ISOs services for early help and support**

There is a need to ensure that early help and support from ISOs is available to all people in all areas. This means ensuring that ISOs are funded to provide pre-assessment support and involves all local stakeholders being aware of the support that ISOs provide and to actively signpost and refer people to them. This also requires an increase in the level of awareness of ISOs services and to provide relevant information and training to the workforce of key stakeholders.

### **Recommendation 9: People need access to 'end-to-end' support for as long as they need it**

There is a need for 'end-to-end' support to be available in all areas to all those who need it. It would be important for people to understand what currently exists and what gaps there might be. A mapping exercise to understand the true picture of the extent of ISO support is needed. Any gaps in 'end-to-end' provision could be identified, recorded and a plan produced to address this at a local level, with relevant stakeholders.

### **Recommendation 10: There is a need to ensure equality of access to Independent Support for all who need it**

To ensure that access to Independent Support is available to all who need it, there needs to be a clear understanding of the barriers that prevent people from accessing ISO support, as well as any specific access needs that different groups of people have. This is especially the case for people from marginalised groups. ISOs need to identify the access needs of people in their community and plan to address those needs in practise.

### **Recommendation 11: ISOs contribute evidence to support SDS improvement**

The research indicated that some respondents linked the effectiveness of ISOs support to their ability to influence Local Authority decisions around SDS implementation. This highlights the challenging role that ISOs have in supporting people to access support from Local Authorities, whilst looking to improve local SDS implementation as well as needing the support of Local Authorities to be more effective in their role. Local Authorities and ISOs should explore ways to ensure that ISOs can provide evidence to help address local issues in SDS implementation.

### **Recommendation 2: To undertake follow up research in Local Authority areas with few responses**

Some Local Authority areas received none or only 1 survey response. This highlights a significant gap in our knowledge. To understand people's experiences in those areas, further research is needed. This could involve:

- Using the same Survey and involving key local stakeholders to be involved in the planning and delivery of the research
- Undertaking Focus Group discussions and/or interviews in each area

### Recommendation 3: To research the need for multiple ISO support

The research has highlighted that people looked for support from multiple organisations. We don't know if this is because people need to access a diverse range of specialist support, in areas which differ from social care support. Or there might be issues relating to the boundaries on ISOs support and whether they can support people on an 'end-to-end' basis. Follow up research is needed to explore the reasons that people access multiple ISOs and whether this has implications for the provision of ISO support in the future.

## Briefing Reports

The key findings and recommendations from the By My Side research project are presented in two of Briefing reports for specific stakeholders. You can access the reports here:

- Independent Support Organisations (ISOs)
- Funders, Commissioners and Strategic Planners of Independent Support Organisations (ISOs)

### How to get in touch:

If you would like to discuss any aspect of the research or Report, contact SDS Scotland at [info@sdscotland.org.uk](mailto:info@sdscotland.org.uk)

## Self Directed Support Scotland

Phone: 0131 475 2623

Email: [info@sdsscotland.org.uk](mailto:info@sdsscotland.org.uk)

X: [@SDSScot](https://twitter.com/SDSScot)

Website: [www.sdsscotland.org.uk](http://www.sdsscotland.org.uk)

Address: Norton Park, 57 Albion Road, Edinburgh, EH7 5QY

SDSS is supported by grants from the Scottish Government.

SDSS is a company registered by guarantee No SC371469  
Charity No SC039587.

Please contact us to  
request this publication  
in a different format.

