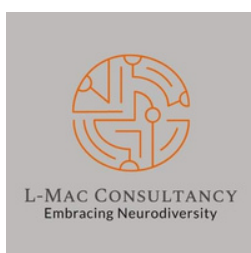


2022/23

# Autism and Self-directed Support (SDS)

A report commissioned by Self-Directed  
Support Scotland to examine barriers  
autistic people face in accessing SDS



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# Introduction

## **Donald Macleod, Chief Executive Officer Self-Directed Support Scotland (SDSS)**

Self-Directed Support Scotland is the Scottish Government's delivery partner for SDS related policy. As such, we receive many enquiries from people about accessing SDS. The largest number of enquiries come from autistic people, struggling with access to SDS, with issues related to general information to assessment, eligibility and implementation. It has been clear to us through these enquiries, and through feedback from our members, that autistic people are not benefitting from social care support as they could be, in achieving their identified outcomes.

This report was commissioned from Lynsey Stewart of L-mac consultancy as an initial step in understanding access related issues, as well as barriers, lastly identifying some potential solutions through recommendations for improvement. This has been achieved through discussion with a focussed range of key partners working in SDS and Autism.

The current context in which this report is issued is a critical time for social care planning, with the evaluation of The Scottish Strategy for Autism highlighting the need for partnership working with autistic people in order to achieve systemic change across services and sectors, so that locally, autistic people can engage with services to live productive lives. Nationally, following a review of the SDS Statutory Guidance, the National Care Service Bill has been published to improve outcomes for people accessing care and support. In the interim period, the Self-Directed Support National Improvement Plan is being developed.

This report will help inform our future work in the context of the SDS Improvement Plan, ensuring that the needs of autistic people in relation to SDS are understood and addressed.





The recommendations also provide a starting point for further development, so that SDSS and our partners can work to improve access to SDS for autistic people.

# Scope of the study

This was a small scoping exercise to identify the key challenges that autistic people face when accessing Self-directed Support (SDS).

The information was gathered through one-to-one discussions with a range of stakeholders including autistic people, family members, third sector organisations, and Social Work Scotland.

We asked about:

-  **People's general experiences with SDS**
-  **The barriers to accessing SDS**
-  **How those barriers specifically affected autistic people**
-  **What needs to change to improve access to SDS for autistic people**

# The barriers

People who took part in the study identified several barriers to accessing SDS, which have been grouped under five headings.

These barriers are those that relate specifically to autistic people, rather than general barriers to accessing SDS.

## Fair Access to SDS

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The focus on physical and learning disabilities in SDS eligibility criteria and assessment processes is not appropriate for autistic people, as their support needs are often very different. The differences were reflected in people's experiences of:

- Eligibility criteria
  - It was felt these are not responsive to specific needs of autistic people
  - As a result, autistic people may interpret criteria as not being relevant to them and so were not accessing support until at the point of crisis
  - Eligibility criteria also often rely on a formal diagnosis and do not consider self-identity.
- Assessing autistic people
  - Autistic people identified different patterns of support needs that do not follow a standard pattern, and felt current assessment processes did not allow for this
  - Individuals' communication differences resulted in their needs not being understood
  - It was felt that assessors had a lack of autism knowledge and understanding
  - Current assessment processes are aimed at identifying outcomes which are often behaviourist in nature, which is not appropriate for autistic people
  - Autistic people's understanding of their own support needs may differ and require specific ways of communicating to unpick.

- Autistic people also identified travel as a significant barrier due to communication differences, sensory overwhelm and changing emotional needs, but felt that this was not recognised within SDS eligibility criteria or assessment.

## **Information and resources**

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People reported a need for accurate information both about autism and autistic experience, and about how to successfully access SDS.

Examples given were:

- Guidance on how best to assess autistic people for SDS, taking into consideration the different ways autistic people may access support
- Information on the different ways autistic people might use SDS: non-traditional methods of support
- Information on the specific communication needs of autistic people and guidance on good communication skills
- Guidance on what good quality SDS looks like for autistic people – both for staff and for autistic people
- Information on community based assets that are responsive to the needs of autistic people
- Guidance for autistic people accessing SDS, that is specific to their needs and style of communication.

## **Meeting needs**

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People we interviewed also identified a lack of support options for autistic people, especially:

- support for autistic people with multiple support needs who may be supported out of area
- Personal Assistants who are knowledgeable about autism.

## Quality and capacity building

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In general, people reported a lack of knowledge of autism and a lack of understanding of the experiences of autistic people. People also reported that there was a lack of support and information for autistic people and their families to allow them to utilise SDS to its full potential. Examples were:

- Lack of autism knowledge and understanding for:
  - assessors
  - Personal Assistants (PAs)
  - supporting organisations
  - organisations providing Option 2
- Lack of understanding of the different ways in which autistic people might access SDS
- Lack of support and training for autistic people/their families in how to use SDS to its full potential
- Lack of support and training for autistic people using Option 1, for example recruiting and managing staff.

Autistic people are often more likely to have support needs that do not follow a standardised support pattern.

This is sometimes referred to as a "spiky profile".

This means that there are often a number of factors affecting an autistic person's support needs including the environment, health, sensory experiences, anxiety and levels of burnout.

Standardised methods of assessment and support provision often do not take this into account, resulting in autistic people's needs not being met.

Anyone assessing for SDS or providing support should have a good understanding of the range of different ways autistic people might communicate, and, wherever possible, this needs to be autistic led.

# Recommendations

This report suggests some initial recommendations to address the issues and barriers identified above.

These recommendations are not exhaustive but should be seen as a starting point for a wider piece of work.

Any work arising from these recommendations should be developed in partnership with the autistic community.

The report authors also feel it may be more appropriate, timely and sustainable to widen these recommendations beyond autism, to neurodiversity in a broader context.

All recommendations should be viewed within a Human Rights context.

## Fair Access to SDS

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- Due to the differences and challenges that autistic people experience, it is recommended that the forthcoming SDS Improvement Plan specifically considers the needs of autistic people. The Plan should include reference to the support requirements of autistic people and give guidance on how these should be met.
- The Guidelines for assessing adults with autism for self directed support (SDS), published by Autism Self Direct should be updated and promoted.
- Eligibility criteria should be reviewed to be more responsive to the needs of autistic people. This to apply across the lifespan, with key points being highlighted around transitions.



## Quality and capacity building

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- Training should be developed with autistic people to increase knowledge and understanding of autism. Training should include examples of the different ways autistic people might use SDS to meet their outcomes. Training to be available to:
  - assessors
  - Personal Assistants
  - supporting organisations
  - organisations providing Option 2
- There should be dedicated online information for autistic people around SDS, with examples of how autistic people have used SDS, and signposting to resources and information for further help. This could be hosted on SDSS website.
- Training should be developed and made available for autistic people to support them to use all SDS options to their full potential.

## Information and resources

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- The ongoing review of the [Self-directed Support Framework of Standards](#) should pro-actively seek perspectives from autistic people to ensure the standards are meeting their needs.
- There is a need to develop a database of community-based supports that are appropriate for autistic people and responsive to their needs, with a focus on peer support and autistic-led groups.
- Guidance for autistic people in how to fill out the SDS application form and to put the criteria into the context of autism should be developed and promoted.

## Meeting needs

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- Local SDS improvement plans should include a specific action point on autism, and SDS local strategy committees should include autism as a standing point on meeting agendas.
- There is a need for wider consultation to take place to develop work to improve access to SDS for Autistic people. Rather than this being a barriers-focused consultation, it should focus on solutions, ideas and examples of things that work.

# Conclusion

This report is the beginning. It forms the starting point for building a programme of work to support autistic people to fully access all that SDS has to offer.

## Highlight 1

All work in relation to autism should be carried out in partnership with the autistic community

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## Highlight 2

There needs to be a much better understanding of the different ways autistic people may need to, or want to, access support

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## Highlight 3

Autistic people have the right to good quality, appropriate support and being autistic should not be a barrier to this

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