

DOWN SYNDROME INTERNATIONAL

England & Wales · Charity number 1091843

Details

Status	Registered
Legal form	Charitable company
Company number	04327941
Registered	2002-05-01
Register	View on the Charity Commission register

Contact

Address	Langdon Down Centre 2a Langdon Park Teddington Middlesex TW11 9PS
Phone	01395493108
Email	contact@ds-int.org
Website	www.ds-int.org

Activities

Objects: 1) TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF THOSE WITH DOWN SYNDROME THROUGH THE PROVISION OF SUPPORT AND RESOURCES TO PEOPLE WITH DOWN SYNDROME, THEIR FAMILIES AND CARERS, AND THE PROFESSIONALS WHO WORK WITH THEM WITH SPECIFIC FOCUS ON DEVELOPING COUNTRIES; AND2) TO UNDERTAKE ANY OTHER CHARITABLE ACTIVITIES IN CONNECTION WITH DOWN SYNDROME AND OTHER LEARNING DISABILITIES AS THE TRUSTEES SHALL DETERMINE

Activities: Providing support networks and assistance to people with Down syndrome and those who live and work with them throughout the world. Committed to ensuring quality of life and human rights for all people with Down syndrome worldwide.

Classification

- **How:** Provides Human Resources, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, Disability, Economic/community Development/employment
- **Who:** People With Disabilities

Geography

- **Area of benefit:** NOT DEFINED. IN PRACTICE WORLDWIDE
- Albania
- Argentina
- Bangladesh
- Brazil
- Indonesia
- Kenya
- Nigeria
- Rwanda
- South Africa
- Uganda
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£389,077	£372,241	-	-
2024-03-31	£422,957	£397,585	-	-
2023-03-31	£316,812	£402,758	-	-
2022-03-31	£413,569	£359,482	-	-
2021-03-31	£411,852	£382,291	-	-

Trustees

Name	Role	Appointed
Ana Lucia Arellano Barba		2019-08-01
Angus Graham		2024-12-03
BRIDGET SNEDDEN		2006-08-22
CAROL BOYS		2009-08-18
Dr RHONDA FARAGHER		2009-08-18
JESSAMY TANG		2012-08-13
Janet Charchuk		2024-12-03
VANESSA DOS SANTOS		2004-04-15

Accounts

DOWN SYNDROME INTERNATIONAL (DSi)



REPORT OF TRUSTEES (AND DIRECTORS) AND FINANCIAL STATEMENTS

for the period from 1 April 2024 to 31 March 2025



**Report of Trustees and Financial Statements -
March 2025**

Reference and administrative information

Company number	04327941
Country of incorporation	United Kingdom
Charity number	1091843
Country of registration	England and Wales

Registered Office

Down Syndrome International
Langdon Down Centre
2A Langdon Park
Teddington
Middlesex
TW11 9PS
United Kingdom

Operational Address

Down Syndrome International
7/9 Chapel Street
Exmouth
Devon
EX8 1HR
United Kingdom

Trustees

The trustees are the members of the DSi board.

They are also the company directors.

The trustees who served during this year were:

B Snedden	(President)
R Faragher	(Vice President)
JP Clarke	(Treasurer, Retired Dec 2024)
A Graham	(Appointed Dec 24, Treasurer)
V dos Santos	
P Robertson	(Retired Dec 2024)
C Boys	
J Tang	
A L Arellano	
D Warkcup	(Retired December 2024)
J Charchuk	(Served all year, Appointed Dec 2024)

Principal Staff

A Boys (Executive Director)
(Company Secretary)

Principal Bankers

HSBC
16 King Street
Covent Garden
London
WC2E 8JF

Solicitors

Russell Cooke
2 Putney Hill
London
SW15 6AB

Introduction

In this document, the trustees of DSi are sharing a report and financial statements for the year ending 31 March 2025.

These statements cover the last 12 months, starting from 1 April 2024.

The information in the “Reference and administrative information” section above is part of this report.

These financial statements follow:

- the rules required by the law (known as statutory requirements).
- the rules of DSi (our articles of association).
- a set of recommended accounting rules for charities (the Statement of Recommended Practice – Accounting and Reporting by Charities: SORP FRS 102).

For a list of our member organisations, please refer to Annex 1.

Because our organisation earned more than £25,000 in the year ending 31 March 2025, we had to get an independent examination of our financial statements.

Objectives and activities

Charity objects

DSi has charitable “objects” set out in our official document (our articles of association). The objects are:

- To promote and protect the physical and mental health of those with Down syndrome through the provision of support and resources to people with Down syndrome, their families and carers, and the professionals who work with them with specific focus on developing countries.
- To undertake any other charitable activities in connection with Down syndrome and other learning disabilities as the trustees shall determine.

These objects inform the Charity Commission of England and Wales what we are trying to achieve and what kinds of activities we do.

The Charity Commission is appointed by the UK government to check we are doing work charities should do and that we are doing it in the right way.

Our vision, purpose, strategy and activities

DSi launched a new strategy in October 2023 after a comprehensive review of the charity and our work, including consultations with all key stakeholders.

To develop our new strategy, we first established:

- **who we are** – we are the global network of people with Down syndrome and their families.
- **our purpose** - together, we speak up for the human rights of all people with Down syndrome around the world.
- **our vision** - a better world where all people with Down syndrome are fully included in society.

We were then able to develop a 10-year strategy (2024-2034), outlining how we will deliver our purpose to realise our vision.

Critical to the success of our new strategy will be:

- sticking to the **principles** guiding our work;
- putting in place our **foundations** to enable DSi to thrive;
- delivering activities based on our **approaches**.

If we do this, we will achieve our **goal** – for people with Down syndrome and their families around the world to have a say in all laws, policies and other decisions that affect them.

Over time this will lead to:

- communities that respect and include people with Down syndrome;
- laws and policies that protect and promote the human rights of people with Down syndrome;
- systems and services that are accessible and include people with Down syndrome.

In the long term, we know this will realise our vision.

We made sure we followed guidelines from the Charity Commission (on public benefit) when developing our new strategy and we do the same when we make any strategic plans or decisions.

A more detailed explanation of our new strategy can be found on our website.

How our activities help people (how we deliver public benefit)

Our work is all about helping people with Down syndrome to have opportunities to live better lives. We speak up for their human rights so that they will have these opportunities.

We work with our network of member organisations to represent people with Down syndrome and their families, making sure that it is people with Down syndrome themselves who can speak up.

This report describes what we have achieved this year to help people. All our activities deliver public benefit and serve the purpose for which DSI was set up.

Who uses and benefits from our services?

DSi is a worldwide organisation with member organisations from more than 120 countries. We are an international organisation of persons with disabilities (OPD).

We work on national, regional, and global projects to improve the lives and the human rights of people with Down syndrome.

There are about 7 million people with Down syndrome worldwide. Since we opened our international office in 2009, we have seen a significant increase in demand for our services.

We review our strategy and activities every year. This report looks at what we have achieved and how our work has helped the people we aim to support. It also helps us stay focused on our purpose and our goals.



Achievements and performance

Our approaches

All our work this year was guided by our 10-year strategy. This strategy is based on 5 key "approaches", which are the ways we make change happen.

Our 5 approaches are:

- **Developing and sharing evidence**, stories and examples of inclusion of people with Down syndrome.
- **Empowering people with Down syndrome** and their families to speak up for their human rights.
- **Supporting Down syndrome organisations** to become stronger and more inclusive.
- **Building and leading partnerships** with important people, groups and organisations.
- **Coordinating advocacy** for the human rights of persons with Down syndrome.

We group our activities under three main pillars:

1. Knowledge, policy and practice

- We play a leading role globally in developing new policies, documents and other published information about issues that affect people with Down syndrome.
- We work with our member organisations and partners to make sure accurate information is available.
- We advise and help our member organisations and others when they need it.

2. Network development

- We make our member organisation network stronger by involving member organisations in all our work and improving communication.
- We develop and support networks, alliances and advocacy groups among our member organisations.
- We provided training to help our member organisations and those who represent them.

3. Global advocacy

- We run worldwide campaigns and events.
- We support local, regional and global activities that fight for the rights of people with Down syndrome.
- We take part in international meetings on disability and human rights to represent the global Down syndrome community.

Key issues

Most of our work involves one or more of these issues that affect a lot of people with Down syndrome:

- the right to an education
- the right to work
- the right to health
- being included in important decision making

The next part of this report summarises our project activities from April 2024 to March 2025 and shows how we have used our 5 approaches.

1. Knowledge, policy and practice

Listen Include Respect guidelines

The Listen Include Respect guidelines help organisations understand what they need to do to make sure people with intellectual disabilities can take part in their work and are included in decision making.

We developed the guidelines with Inclusion International and they are published on the website listenincluderespect.com in English, Spanish and Arabic.

This year, we published an Arabic version of the guidelines. We also made significant progress on the Chinese, Indonesian, and Portuguese versions.

Self-advocates took part in consultations to make sure that translations stay in plain language and are accessible for people with intellectual disabilities.

The consultation and technical work will continue next year so we can publish more alternative language versions of the guidelines.



We have been working in partnership on this project with Higher Council for the Rights of Persons with Disabilities (Government of Jordan – Arabic), Up for Down's China (Chinese), Instituto Alana and Federacao Brasileira das Associacoes Sindrome de Down (Portuguese) and Indonesia Down Syndrome Care Foundation (YAPESDI - Indonesian).

*Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Building and leading partnerships with important people, groups and organisations*

World Down Syndrome Congress (WDSC)

This was an important year for our global congress. We worked closely with our member organisation, Down Syndrome Australia, to deliver the **World Down Syndrome Congress in Brisbane, in July 2024**. The event was a big success, bringing together over 1,000 delegates. This event is a rare and vital in-person opportunity, bringing our network together to gain knowledge, experience and mutual understanding, establish important connections and support each other's work.



“Coming out of Congress, I felt inspired. I listened to all the people speaking and watched the videos because, like everyone, I want to be included. I want to feel like I am achieving something – like I matter.”

Kez Glenane, Down Syndrome Victoria Advisory Network Member

We also looked to the future and ran the process to select the host for the next congress. We were delighted to announce that our member in Argentina, Asociacion Sindrome de Down de la Republica Argentina (ASDRA), [will host the World Down Syndrome Congress in 2027.](#)

*Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Supporting
Down syndrome organisations to become stronger and more inclusive*

Global health equity consultation

People with disabilities around the world have worse health outcomes than other people. This is not fair. We want better health outcomes for everyone.

A significant focus for us this year was developing and sharing new evidence on health equity. We organised a major global consultation to learn about health equity for people with intellectual disabilities, working in partnership with Humanity & Inclusion. We gathered data through surveys and focus groups from over 750 individuals and 118 organisations.

We are now working with London School of Economics to analyse the data, and [we will publish a global report on health equity in July 2025.](#)

We will present preliminary findings to a small group of government, UN and other influential stakeholders at the Global Disability Summit in Berlin, Germany in April 2025.



The World Health Organization global report on health equity for people with disabilities was published in December 2022. That report explains the causes of bad health outcomes and what can be done to improve them.

Our new report is a natural follow up to the WHO report, with more of a focus specifically on people with intellectual disabilities.

The report findings will help the DSi network to advocate for policy change in their countries.

Listen Include Respect Services

This year, working in partnership with Inclusion International, **we delivered several paid consultations**. We supported organisations to prepare and publish resources, ensuring that the resources are accessible for people with intellectual disabilities.

We call these consultations “Listen Include Respect Services” and they use the methods from our global guidelines. The consultations include paid

self-advocate reference groups, providing advice to international organisations, to help them be more inclusive.

This year, we worked with:

- Global Disability Fund (previously UNPRPD) – to help write a guide on meaningful participation of marginalised people with disabilities [link to guide here](#)
- UNICEF (in their role coordinating [Disability Reference Group](#)) – to review a new resource they created about gender-based violence.
- International Disability and Development Consortium (IDDC) – to review their website and make it more accessible.



*Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Building and leading partnerships with important people, groups and organisations*

Advising on global initiatives and membership of IDA

Because we built strong partnerships, delivered successful projects and developed our excellent reputation, we were given opportunities to consult on other important global work this year.

DSi was part of the consultation group for the new [Global Disability Inclusion Report](#), which was published as a key output of the [2025 Global Disability Summit \(GDS\)](#). The preparation of this report was coordinated by UNICEF and International Disability Alliance (IDA).

We were part of an expert stakeholder group with World Health Organization on their new "[Health Equity for Persons with Disabilities: Guide for Action](#)".

We continued our work [as a full member of IDA](#). IDA and its members work together as a global alliance representing persons with disabilities from around the world.

We advocate for disability rights at the United Nations and in international development work.

Within IDA, as members, DSi ensures that people with Down syndrome and their families are heard and advocate for inclusive projects and programmes.



Relevant approaches: *Developing and sharing evidence of inclusion
*Building and leading partnerships with important people, groups and organisations
*Coordinating advocacy for the human rights of persons with Down syndrome

Providing resources and information on Down syndrome

One important job of DSi is to ensure people with Down syndrome and their families have the information they need to remove the barriers to being full and active participants in society.

We work every year to provide information and support and show people where help is available from our member organisations and others in countries around the world.

This project is partly funded by National Lottery Community Fund.

This year, we published our "[Self-Advocacy Group Guide](#)", a key resource for supporting our member organisations to set up and run self-advocacy groups. We also published our "[About Down syndrome](#)" pack in Spanish.



*Relevant approaches: *Developing and sharing evidence of inclusion
Supporting Down syndrome organisations to become stronger and more inclusive

2. Network development

Listen Include Respect training with members

In the United Kingdom, we continued our project supporting people with Down syndrome to work as Listen Include Respect consultants for the Down's Syndrome Association.

Having completed their training, the consultants helped to develop a new tool for organisations to measure how inclusive they are. The team also presented their work at the World Down Syndrome Congress in Brisbane.

In early 2025, they facilitated training for a UK Integrated Care Board, which was well received. Participants commented how the practical approaches to inclusion will help them change the way they work.

This project is funded by the Down's Syndrome Association.

INCLUSIVE PARTICIPATION

WHAT IS INCLUSIVE PARTICIPATION?

Inclusive participation is about everyone being able to take part in the work and activities of an organisation and is something that is at the heart of what the DSA seeks to do. It means everyone's voice is listened to and that decisions are made with people rather than for them.

We include people who have Down's syndrome in all aspects of our work and they tell us what is important to them.

DSA staff working in our Information and Training Team think carefully about how we can best include people who have Down's syndrome of all abilities, even those people who might find expressing their ideas and opinions more difficult. We think creatively about how our activities that involve people who have Down's syndrome can be as accessible as possible.

The Down's Syndrome Association is here to amplify the voices of people who have Down's syndrome by working together.



Down's Syndrome Association
A Registered Charity No. 1047814

DOWN'S SYNDROME ASSOCIATION

"Be my microphone not my voice"
Dave Hingsburger

In early 2025, we also created a new 'Train the Trainer' course on Listen Include Respect, with Inclusion International. We then delivered the first

ever course of its kind in Toronto, Canada, hosted by Community Living Toronto, with organisations from across Canada attending.

We want to see all members of DSi and Inclusion International use the methods of Listen Include Respect in their own organisations and to encourage others they work with, to do the same. This might be other disability organisations, public bodies, governments or companies.

*Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Supporting
Down syndrome organisations to become stronger and more inclusive*

New DSi network groups

To help our members connect and work together, we formed two new network groups this year:

- DSi Self-Advocacy Network Group
- DSi Health Equity Network Group

This work is central to our approach of supporting our member organisations to become stronger and more connected.



Both groups are co-chaired by members and provide a space to share experiences, support each other, and work together on new projects.

The Self-Advocacy Network Group includes a person with Down syndrome and another organisation representative from each member. They will focus on developing shared tools and resources to support others to establish and run self-advocacy groups.

The Health Equity Network Group includes a representative from member organisations across the world. They will focus on understanding health equity in different countries and what our members are doing to deliver better outcomes.

*Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Supporting Down syndrome organisations to become stronger and more inclusive
Coordinating advocacy for the human rights of persons with Down syndrome

Including people with Down syndrome

We are committed to ensuring that people with Down syndrome are included in all of the work of DSi and our network.

DSi will only realise our vision if we do this. We want people with Down syndrome to be working and having a significant influence at all levels of our organisation. This year we have made excellent progress, in the DSi office, on the DSi board and in the membership network.

- Including people with Down syndrome – DSi staff and board

In September 2023, we recruited a permanent staff member with Down syndrome, Emma Bishop, as Inclusion and Advocacy Officer. Emma is an

advocate for the rights of people with disabilities, who has spoken at the UN Conference of State Parties (COSP) on disability.

Emma provides valuable insights for our work and will speak at the Global Disability Summit in Berlin in April 2025.

The Clare Milne Trust funds Emma's salary.

In December 2023, Janet Charchuk, joined the DSi board of trustees. She is the first person with Down syndrome to join the board.

This year, Janet has worked with the board, supporting all aspects of DSi's new strategy and helping us make key decisions.

Janet was chosen to be a co-chair of the Civil Society Forum at the Global Disability Summit in Berlin, in April 2025.



More broadly, the DSi staff team has been working on a number of initiatives, across all departments, to make sure all of our work involves

people with Down syndrome at every stage, so that we know we are working on the right things and that it is accessible.

- Including people with Down syndrome – membership network

We have a committee of people with Down syndrome called the DSI Ambassadors. They represent our member organisations in their countries.

Our Ambassadors have been instrumental in shaping our initiatives and advocating for change at international events, including speaking on our behalf at the United Nations.

The Ambassador Committee shows that an organisation is strongest when its leaders are the very people it is helping.



This year, we have made some changes to the committee. We are transitioning to a new, more formal structure that will allow for both consistent leadership and fresh perspectives.

In the future, our Ambassadors will serve for 3 year terms. This new system will be staggered, so there will always be a mix of experienced and

new Ambassadors on the committee. This ensures a dynamic group while also creating new opportunities for people to join and contribute.

We are also introducing a mentorship system. As ambassadors finish their terms, they will guide new members through their first year, passing on their knowledge and experience.

*Relevant approaches: *Developing and sharing evidence of inclusion
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syndrome*

Delivering our new strategy

In October 2023 we published our new 10-year strategy for the organisation. A strategy is a plan for how DSi and our network will make the world better.

Since its publication, all of our work has been guided by its principles and approaches, as we strive to achieve our goal.

Working in solidarity and coordination with our global network is the only way we can hope to deliver our goal. We remain fully committed to developing our global network.

A breakdown of the key parts of our strategy can be found on pages 4-5 of this report.

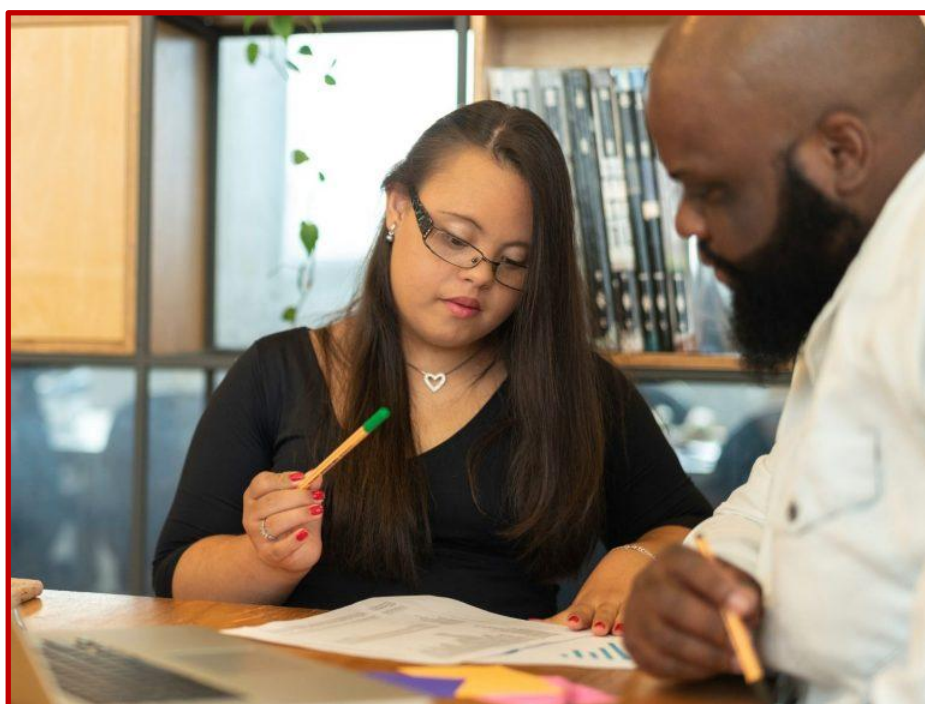
3. Global advocacy

Listen Include Respect advocacy

We continued our advocacy, for organisations to adopt the Listen Include Respect (LIR) guidelines, to include people with intellectual disabilities in their work. Self-advocates promoted the guidelines when speaking at various global events, including [Conference of State Parties \(COSP\)](#) in New York in June 2024. We have an LIR exhibition stand and key meetings planned for [Global Disability Summit](#) in Berlin, in April 2025.

When we do our “Listen Include Respect Services” work (see page 12), we make sure we talk to our project partners about what they can do, beyond the service they have asked us for help with.

Both DSi and Inclusion International are committed to applying LIR principles in all our projects. We know our members are too. Our networks also speak to partners we work with on every project, about the importance of ensuring people with intellectual disabilities are included.



Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Supporting
Down syndrome organisations to become stronger and more inclusive
*Building and leading partnerships with important people, groups and
organisations *Coordinating advocacy for the human rights of persons with
Down syndrome

Conference of State Parties (COSP) in New York

We attended the Conference of State Parties (COSP) in June 2024. The event takes place every year at the UN Headquarters in New York. It is a conference about the UN Convention on the Rights of Persons with Disabilities (CRPD) attended by many important stakeholders.

Our Programme Director, Nathan Rowe, presented a statement to the Civil Society Forum on the impact of conflict on people with Down syndrome and their families.

Michael Cox, a self-advocate with Down Syndrome Australia, spoke about the rights of persons with disabilities to decent work and sustainable livelihoods.



We also gave a presentation to UN Missions about care and support.

COSP is an excellent opportunity for our network to advocate together and connect with influential decision makers.

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Down syndrome*

World Down Syndrome Day 2025

- **WDSD and 2025 theme**

On 21st of March every year, we bring the global Down syndrome community together for World Down Syndrome Day (WDSD).

We run the WDSD website and the WDSD social media pages. We also promote a theme annually. In 2025, this was “[Improve Our Support Systems](#)”. The theme was decided following consultations with our members and ambassadors. We worked with the international community to deliver awareness and advocacy messages.

This year we wanted the world to know that, just like everyone, people with Down syndrome need support to live and be included in the community. Families also need support, as they are often supporting their family member with Down syndrome. We have the right to support that meets our needs and gives us choice, control and dignity. Governments must ensure there is a support system, so people with disabilities are included in the community.



We also partnered with CoorDown on their 2025 video “No Decision Without Us”.

We ran the Lots of Socks campaign too. We asked people worldwide to wear interesting socks on 21st March, to get people talking about WDSD.

We partnered with National Down Syndrome Society (United States) and Down’s Syndrome Association (UK) again this year to assist this global effort.

- **Our WDSD conferences**

The [14th World Down Syndrome Day Conference](#) took place at the United Nations in New York, on Friday 21st March 2025.

This year, we focused on our theme “Improve Our Support Systems”. Self-advocates and other experts spoke up about support systems and what needs improvement.

We called on leaders to make changes so people with Down syndrome and other disabilities are included in the community.

The event was attended by people with Down syndrome, families, organisation and government representatives, and many stakeholders working in the area of care and support.

People with Down syndrome were involved in planning and speaking at the event. We had a diverse range of speakers from around the world.



As well as New York, in 2025, [we were able to return to United Nations in Geneva](#), to mark World Down Syndrome Day.

On 20 March, advocates joined a day of general discussion on the rights of persons with disabilities to participate in political and public life. The event was organised by the UN Office of the High Commissioner for Human Rights (OHCHR), on behalf of the UN Committee on the Rights of Persons with Disabilities.

On 21 March, attendees enjoyed a tour of the Palais des Nations followed by a special celebration organised by the United Nations Office at Geneva (UNOG), in collaboration with DSi, European Down Syndrome Association (EDSA) and Association Romande Trisomie 21 (ART 21).

Advocates later joined the afternoon session of the UN Committee on the Rights of Persons with Disabilities and took part in conversations about ways to improve support systems for individuals with Down syndrome and their families.



This project is funded by the International Disability Alliance.

Relevant approaches: *Developing and sharing evidence of inclusion
*Empowering people with Down syndrome and their families *Building and leading partnerships with important people, groups and organisations
*Coordinating advocacy for the human rights of persons with Down syndrome

Global Disability Summit

During this year, we prepared for the upcoming Global Disability Summit (GDS), taking place in Berlin, Germany from 1st-3rd April 2025.

The GDS is an event attended by thousands of advocates and decision-makers, that asks countries to do more to include people with disabilities.

Before the GDS, WHO, IDA, Global Disability Fund and International Disability and Development Consortium co-hosted an event on Health equity for persons with disabilities.

This event aimed to plan clear actions to make health systems more inclusive and promote health equity for people with disabilities.

Pearl, our Ambassador for Switzerland, spoke at the meeting about her experience of the healthcare system and the work we are doing to achieve health equity for people with Down syndrome and intellectual disabilities.



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Coordinating advocacy for the human rights of persons with Down syndrome

Joining global alliances

To help us advocate for the rights of people with Down syndrome, we joined three new important groups this year:

Global Alliance for Care

This is a community that works together to advocate for care as a right. We worked with them and UN OHCHR to push for care and support systems that enable people with Down syndrome to be included in the community.

Partnership for Maternal, Newborn and Child Health (PMNCH)

This is the world's largest global alliance for the health and well-being of women, children, and adolescents. It is hosted by the World Health Organization.

Disability Reference Group (DRG)

The DRG brings together OPDs, NGOs, UN entities, academia, donors and others to strengthen inclusion of persons with disabilities in humanitarian action, and ensure no one is left behind in situations of risk and humanitarian emergencies.



Relevant approaches: *Developing and sharing evidence of inclusion
*Building and leading partnerships with important people, groups and organisations

Raising funds

To keep DSi running well and helping those who need us, we need money.

We have 2 types of income:

- **Restricted income** – this is money we receive that must be allocated to specific projects. We agree detailed budgets with the organisations who provide this money.
- **Unrestricted income** – this is money we receive that we can spend on projects if we need to. But we can also spend it on other things that help keep DSi running. Or we can save it (as reserves) to keep DSi financially stable.

Restricted income - April 24 to March 25

This year restricted income went down.

Last year we received significant funding from International Disability Alliance (IDA) for the Listen Include Respect - IDA Bridge Consultation. That project has now finished. This year we continued to receive funding from IDA for the World Down Syndrome Day Conference and Global Advocacy project, but the total amount from IDA was lower than the previous year. We also received continued funding from the Down's Syndrome Association (DSA) for Inclusive Organisations Training and Programme Team Funding.

The money we received this year for projects did not include enough to cover all of what it costs us to pay staff to manage the projects. So, we had to use some of our unrestricted income for this. We used some funds that we had designated in the previous year to support the DSi network. We also designated new unrestricted income to projects such as the World Down Syndrome Day Partnership and World Down Syndrome Congress Consultancy.

If we can find new restricted funding for projects, this will mean more unrestricted money is available to spend on other important things we need to do.

Importantly, this will also help us to save some money as reserves, to keep DSi financially stable.

Unrestricted income - April 24 to March 25

This year unrestricted income went up.

As mentioned in the previous section, currently we need to use some of our unrestricted funds to pay for our projects. We label this as designated funds, and it is in addition to the income listed below.

Income from general donations (gifts) went up. Of this, income from trusts and foundations went up significantly. This was primarily due to a new 4-year legacy grant from Joffe Charitable Trust (£50,000 per year for 4 years, 2025-2028). Income from membership fees also went up. Donations from individual people and companies went down.

We generate income from trading (merchandise sales). This year, sales increased slightly due to an improved marketing strategy.

We also receive gifts in kind (donated services). This is where people or organisations provide us with free things, but because those things have a value, we include them as income (and also as expenditure). This year gifts in kind went down to £13,796 (2023-24: £37,119). This is because we received a smaller in-kind grant for Google Ads.

We did not receive any income from fundraising events this year (2023-24: £25,258).

We also received unrestricted income of £17,308 from Listen Include Respect consultancy services, we provided to various government, multilateral and international development donors.

Financial review

Income

In the 12 months starting from 1 April 2024 (2024-25), DSi's total income was £389,077. This was less than in the 12 months from 1 April 2023 (2023-24), when it was £422,957.

Restricted income went down in 2024-25 following completion of the Listen Include Respect - IDA Bridge Consultation.

We received money again from IDA for our World Down Syndrome Day Conference in New York and, in addition this year, for our global advocacy work, including Global Disability Summit.

We received money from member organisation the Down's Syndrome Association (DSA) to continue delivering training in the UK on inclusive organisations. We also received money from DSA to fund our programme team.

Unrestricted income increased slightly. Although individual donations and gifts in kind were lower and we did not hold a fundraising event like last year, this was offset by the new grant from the Joffe Charitable Trust, income from Listen Include Respect Services and increased merchandise sales.

We also received money from member organisation National Down Syndrome Society (United States) to support our WDSD partnership.

Expenditure (costs)

In the 12 months starting from 1 April 2024 (2024-25), DSi's total costs were £372,241. This was less than in the 12 months from 1 April 2023 (2023-24), when it was £397,585.

Staff costs increased in line with inflation and to bring staff salaries up to market levels. Travel costs increased as the DSi board met in person for the first time since 2019.

Direct spending on project activities reduced. This was partly because we completed project work in 2023-24. But also, because most of our project work is delivered by our staff team, and the cost of doing the projects is included in the "Staff costs" rather than "Project activities".

Advertising, marketing and publicity costs reduced, because we received a smaller in-kind grant for Google Ads, and therefore had less to spend.

Otherwise, we saw similar levels of spending on other things, and we made some cost savings.

We have a stable base in terms of staff numbers and projects that we will do with our current staff. This has helped us keep costs consistent.

Overall

When we subtract our costs from our income, we arrive at an overall financial position for the year. This might be a surplus (if we had more income than costs) or a deficit (if we had more costs than income).

In the 12 months starting from 1 April 2024 (2024-25), we had a surplus of £16,836. This compares to the 12 months from 1 April 2023 (2023-24), when we had a surplus of £25,372.

We also have some money saved (total funds) that we carry over from previous years. We carried over £50,915 from 2023-24.

When we add this year's surplus to total funds we carried over from last year, this leaves us with total funds on 31 March 2025 of £67,751.

Some of our funds (£6,654) are restricted. If we subtract this from total funds, this leaves us with total unrestricted funds of £61,097.

We have a policy (reserves policy) which requires DSi to keep a certain amount of unrestricted funds saved (called "free reserves"). At the end of this year, we have less free reserves than we should have.

So, we need to develop strong financial and fundraising strategies to become more financially stable.

Reserves policy and going concern

We have a policy (reserves policy) which requires DSi to keep a certain amount of unrestricted funds saved (called “free reserves”).

The policy says that we should keep between 3 and 6 months of our annual costs in reserve.

Based on our 2024-25 costs (£372,241), 3 months reserves would be £93,060 and 6 months would be £186,121.

At this level the trustees agree that if our income dropped suddenly, we would still be able to continue doing our work.

The trustees also agree that if income did drop suddenly, we would think very carefully about how to replace that income or reduce our costs.

Our free reserves for 2024-25 are £61,097. This means we have approximately 2 months of costs in reserve. While this is still below the minimum of 3 months required by our policy, our reserves position is improving.

We do have something in our accounts called gifts in kind. This is where people or organisations provide us with free things, but because those things have a value, we include them both as income and costs. We would still be able to do our work without these things.

This year the gifts in kind were £13,796. This makes DSi’s costs look a bit bigger than they really are. If you take this out of our costs, this shows we have slightly more costs in reserve.

DSi also has an overdraft agreement with creditor the Down’s Syndrome Association (DSA). DSA pays staff for DSi and DSi repays DSA every quarter. DSA allows an overdraft facility to DSi, up to a maximum of £35,000, to help DSi if we cannot repay DSA when it asks for the quarterly repayment.

During 2024/25 we repaid DSA for our staff costs on a monthly basis.

Risk Management

We look carefully at risks to DSi. We have a policy for risk and also a risk management plan.

We decide which risks are most important and we take any action we can to reduce the risks that could have a negative impact on DSi. Some of the most important risk areas are:

Funding: We don't have money saved (reserves). A sudden loss of funding could mean we run out money and have to stop what we do. So, we focus on trying to get new funding and long-term funding from different people and organisations.

Leadership: It is important we have good leaders to take us forward and keep everyone at DSi happy. Our leaders will change as time passes. We need to make sure when that happens, our new leaders will be just as good. So, we plan for what will happen when leadership changes.

Staff: It is important that our staff feel happy to work for us and believe that they are important to DSi's success. So, we treat them well, we ask them how they are doing, we ask them what they think about DSi and we listen to what they tell us.

Project activities: We need to do our project work well. We need to do what we say we will do. Our projects need to be completed on time and at the same cost we agreed. We also need to make a big impact. So, we make sure we check how we are doing, we ask others how we are doing and we always try to do things better.

Operational systems: We have a small staff team and we have a lot of different things we need to do to keep DSi running well and following the law. So, we use software and we have systems to help us do all of these things in the right way, as quickly and as cheaply as we can.

Reputation: It is really important that everyone we work with believes DSi is a good organisation and trusts us. So, we make sure all of our work is relevant to people and makes an impact. We also make sure we are run really well. We listen to what people tell us and we always try to make good decisions.

Plans for next year

Activities we have planned for next year starting 1 April 2025 include:

Knowledge, policy and practice

- We will complete and publish Chinese, Indonesian and Portuguese translations of the Listen Include Respect Guidelines.
- We will work with ASDRA, our member in Argentina, on the initial stages of planning for the 2027 World Down Syndrome Congress. We will also ask our members to submit bids for the 2030 WDSC.
- We will launch our major global report on health equity, in English, and then in other languages. We will continue to work closely with our partner Humanity & Inclusion on next steps and will connect with high level stakeholders about our report, including the Global Action on Disability Network (GLAD) network, a group of global disability movement donors and key stakeholders.
- We will review the long-term strategy for the Listen Include Respect Services work we do, with our partner Inclusion International.
- We will continue our work as a member of the International Disability Alliance (IDA), making sure the voices of people with Down syndrome and their families are represented internationally.
- We will review the issue of work and employment for people with Down syndrome, to understand the barriers people face when trying to get a job.

Network development

- We will support the UK Listen Include Respect team to provide consultancy services in the final year of this project.
- Our new Self-Advocacy Network Group, co-chaired by our members in New Zealand and South Africa, will carry out a "mapping exercise" to find self-advocacy groups across our global network.
- Our new Health Equity Network Group will continue to meet online, co-chaired by our members from Georgia and United States. They will focus on some specific health areas. They will also create an online library of resources.
- We will welcome 8 new self-advocates to our DSi Ambassadors Committee, representing our member organisations. We will provide them with induction training to help them represent our global network, with outgoing Ambassadors providing mentor support.
- Our staff team will go to China to deliver training on self-advocacy, with our member organisation Up for Downs China.
- We will select five member organisations from Africa to take part in a pilot training on health equity advocacy, based on a training curriculum we will develop using our global report on health equity. This is a new project funded by Government of Finland.

Global Advocacy

- Self-advocates will continue to advocate for inclusive organisations when speaking at events, by promoting the use of the Listen Include Respect guidelines. We will be at the 2025 Global Disability Summit.

- We will organise activities for World Down Syndrome Day 2026. This will include deciding on a theme and an advocacy campaign, organising our UN conferences in New York and Geneva, running the website and social media pages and running the Lots of Socks awareness campaign.
- Staff, board members and member organisations will be at the 2025 Global Disability Summit, working on various projects and activities and networking to develop partnerships. DSi board member Janet Charchuk will co-chair the event's Civil Society Forum.
- We will be starting a new project supporting IDA and WHO, running webinars and producing advocacy materials to help people understand health equity.
- As part of the foundation committee, we will attend the inaugural meeting of the WHO Disability Health Equity Initiative in Geneva. We will co-chair one its four workstreams, which aims to build leadership on health equity among persons with disabilities.

Raising funds

- We will try to find more funds for our projects from different types of organisations that make project grants. So that we do not have to use money we want to keep in reserves.
- We will try to increase the funds we get from donations, events and sales so that we can save more and improve our reserves position.
- We will look for new ways to raise money and grow our organisation. But make sure we are financially safe, so we can keep doing what we do.

Structure, governance, and management

DSi is a company (a charitable company limited by guarantee) and is also a registered charity.

We registered as a company on 23 November 2001, and as a charity on 1 May 2002.

DSi was started by a legal document called our Articles of Association.

This document provides information about what our purpose is, what we need to do and what we cannot do.

We also have a Code of Governance. This guidance document helps our trustees know what their responsibilities are and how we all need to behave.

The Code of Governance also has a guide on how trustees come on to the board and how they leave the board.

All of the trustees are volunteers and receive no benefits from DSi.

Any expenses trustees reclaim from the charity are minimal and can be seen in note 7 of the accounts.



Members and trustees

Charity members and other members

Our legal document (Articles of Association) says that we have members (known as the “charity members”) who have a vote at all important meetings, like the annual general meeting.

The “charity members” are all individual people, and they are different from our member organisations.

The charity members are also the trustees. When you become a trustee of DSi you also become a charity member. When you are no longer a trustee, you are no longer a charity member.

We are also able to have other types of members, but our legal document is clear that these members are not charity members and so they do not have a vote at important meetings.

We have 2 other types of members at the moment:

- Representative members – for organisations only.
- Affiliate members – for organisations only.

A list of our representative and affiliate members can be found on our website here ds-int.org/network-member-organisations.

Appointment of trustees

The board of trustees manages the business of the charity.

We currently have 8 trustees.

All trustees are elected by the charity members and we can have between 5 and 21 trustees.

Each time we have an annual general meeting (AGM), one third of the trustees must retire. To make it fair this happens on a rotation basis. So, each trustee gets 3 years before they retire.

When trustees retire, they have the option to seek re-election. If they do this, then the other trustees decide by vote if they will re-elect each person.

The trustees can also vote to bring in new trustees at other times of year for a specific reason. If they do this, the new trustee will be in their post until the next AGM. Then they can seek election at the AGM.

Recruitment of trustees

A policy on how to recruit trustees can be found in our Code of Governance.

The trustees must be open and honest in any search for new people.

Trustees must be aware of the legal rules on who can and cannot be a trustee.

Trustees should consider whether any candidates might have “conflicts of interest”. This is something that might cause a trustee to act in a way that is not in DSI's best interests.

The trustees should look for people with the right skills to join, especially if there are skills that the current board does not have. But this is not the only thing to consider.

As a priority, we should ask our representative member organisations first if they have candidates to consider. Then we should ask our affiliate member organisations. After this we can look wider.

The trustees need to make sure that:

- 55% of the board are people with Down syndrome or family members.
- There is a maximum of 2 people from any country.

- There is at least 1 person from Europe, North America, South America, Africa, Asia and Australia (continent).
- At least 25% of the board are from “developing economies” (defined by International Monetary Fund’s World Economic Outlook Report, April 2015).

Induction of new trustees

All trustees must understand the charity’s purpose and aims and their duties and responsibilities.

They are then able to explain this to new trustees.

The trustees must make sure that they, rather than staff, have overall responsibility for inducing new trustees.

The board should provide all new trustees with induction material, such as governing documents, annual reports, meeting minutes, strategy and management documents.

This allows new trustees to understand their charitable purposes, financial position and current issues.



Related parties and connected organisations

DSi works with many Down syndrome, disability and international development organisations worldwide.

We have a close working relationship with the Down's Syndrome Association (DSA) in United Kingdom. We share a registered office with DSA in Teddington. We also share resources, and we have a funding agreement.

We receive membership organisation fees, and we work on projects with many member organisations throughout the world. A list of our member organisations can be found on our website here ds-int.org/network-member-organisations.

At the regional level, we support the work of European Down Syndrome Association, African Down Syndrome Network, Federación Iberoamericana de Síndrome de Down (Latin America) and Asia Pacific Down Syndrome Federation.

DSi is in special consultative status with the Economic and Social Council of the United Nations (UN).

DSi is a member of International Disability Alliance (IDA)

We also work with Inclusion International on projects.

Remuneration (pay) policy

We pay our staff fairly to get the best people for the job while using our money wisely.

We decide on what to pay people by looking at what other people in similar charity roles get (on average) and we set our salaries at the same level.

All DSi staff get a pay rise every year based on changes to the cost of living where they live. In the UK (where most of our staff live) this is usually a 3% increase.

DSi will go ahead with these pay rises unless we cannot for financial reasons.

Any changes to this method of giving pay rises must be agreed by the trustees.

Some staff may get a higher pay rise if there are reasons for it. This must be agreed by the trustees.

Pay rises start from the start of the financial year, which is 1 April.

The trustees evaluate the executive director's performance and determine the executive director's annual salary.

They assess the executive director's performance against established targets. Additionally, they consider the compensation necessary to retain the most qualified candidate for the position.

Fundraising

We make sure all the fundraising we do follows the rules and regulations charities must follow.

We always talk to our supporters in a fair and honest way.

We protect people who support us by keeping their information secure. We do not put pressure on people to give us money. We ask people if we can contact them.

We do all of our own fundraising. No one has ever complained about us.

The trustees reviewing fundraising activities regularly.



Statement of responsibilities of the trustees

The trustees (who are also the company directors of DSi) are responsible for writing this trustees' annual report and the financial statements.

The trustees ensure we have complied with the law and accounting standards in the UK (United Kingdom Generally Accepted Accounting Practice) when writing this report.

Company law requires the trustees to write financial statements for each financial year which:

- give a true and fair view of DSi's financial position.
- provide details of the money coming in and how that money was spent, over the year (accounting period).

When writing this report, the trustees have to:

- choose good accounting methods and use them in all of the report.
- use the methods in the charity accounting standards (SORP).
- make sensible decisions.
- say whether we have used UK accounting standards and give details where we have not.
- write the financial statements based on the idea that DSi will continue to operate, unless we are not going to.

The trustees have to keep good accounting records that:

- can show accurately our financial position at any time.
- can show we comply with the Companies Act 2006.

The trustees must also safeguard DSi's financial assets. So, they must try to prevent financial crimes such as fraud and other bad behaviour.

To the best of the trustees' knowledge:

- there is no audit information that our auditor does not know about.
- we have taken all steps we need to make sure we know about all audit information and the auditor does too.

The trustees are responsible for keeping all company and financial information on our website up to date and true.

Laws in the United Kingdom on financial statements might be different to laws in other countries.

Members of the charity (charity members) guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up.

The total number of such guarantees on 31 March 2025 was 8 (2024: 10).

The trustees are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.



Independent examiner

DSi as a company has taken advantage of the small companies' exemption in preparing the report above.

The following person was appointed to carry out an independent examination of these accounts:

Mr Luke Burns
Fellow Member of the Association of Chartered Certified Accountants (ACCA)
65 Bulmershe Road, Reading, RG1 5RH, UK.

Trustee approval

The trustees' annual report has been approved by the trustees on 9 December 2025 and signed on their behalf by:



Bridget Snedden ONZM
President
Board of Trustees



Section A

Independent Examiner's Report

**Report to the
trustees/directors/
members of**

Down Syndrome International

**On accounts for the year
ended**

31 March 2025

Charity no.:

1091843

Company no.:

04327941

Set out on pages

I report to the charity trustees on my examination of the accounts of the Company for the year ended **31/03/2025**.

**Responsibilities and
basis of report**

As the charity's trustees of the Company (who are also the directors of the company for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ("the 2011 Act"). In carrying out my examination, I have followed the Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act).

**Independent
examiner's statement**

The company's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Association of Chartered Certified Accountants (ACCA).

I have completed my examination. I confirm that no material matters have come to my attention which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the Companies Act 2006; or
- the accounts do not accord with such records; or
- the accounts do not comply with relevant accounting requirements under section 396 of the Companies Act 2006 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:



Date:

21/11/25

Name:

Mr Luke Burns

Relevant professional qualification(s) or body (if any):

Fellow of the Association of Chartered Certified Accountants (ACCA)

Address:

1 Century Drive

Reading

RG7 1PE

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

No material matters to note

Consolidated statement of financial activities (incorporating income and expenditure account)					
For the year ended 31 March 2025					
	Note	Unrestricted funds £	Restricted funds £	2024/25 total funds £	2023/24 total funds £
Income from:					
Donations and legacies	2	135,721	-	135,721	118,447
Charitable activities					
1. Knowledge, Policy and Practice	3	24,033	25,000	49,033	92,804
2. Network Development	3	-	59,500	59,500	58,100
3. Global Advocacy	3	22,127	44,981	67,108	53,790
Other trading activities	4	77,715	-	77,715	99,816
Total income		259,596	129,481	389,077	422,957
Expenditure on:					
Raising funds	5	103,872	-	103,872	139,766
Charitable activities					
1. Knowledge, Policy and Practice	5	65,143	27,943	93,086	92,486
2. Network Development	5	21,051	59,500	80,551	74,483
3. Global Advocacy	5	53,824	40,908	94,732	90,850
Total expenditure		243,891	128,350	372,241	397,585
Net income/(expenditure) for the year		15,705	1,131	16,836	25,372
Net movement in funds		15,705	1,131	16,836	25,372
Reconciliation of funds:					
Total funds brought forward		45,392	5,523	50,915	25,543
Total funds carried forward		61,097	6,654	67,751	50,915
All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 11 to the financial statements.					

Balance sheet			
As at 31 March 2025			
	Note	2024/25 £	2023/24 £
Fixed assets:			
Tangible assets		-	-
Investments		-	-
Total fixed assets:		-	-
Current assets:			
Stock			
Debtors		34,506	29,829
Accrued Gift Aid		1,041	1,048
Other current debtors		-	5,291
Prepaid items		12,971	
Cash at bank and in hand		64,613	43,432
Total current assets:		113,130	79,600
Liabilities:			
Creditors: amounts falling due within one year		47,076	25,258
Accrued expenses		(1,697)	3,427
Net current assets (liabilities):		45,379	50,915
Total net assets (liabilities):		67,751	50,915
Funds:	11		
Restricted income funds		6,654	5,523
Unrestricted income funds		61,097	45,392
Total funds:		67,751	50,915

- The company was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small companies.
- The member organisations have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.
- The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.
- These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies regime and in accordance with FRS102 SORP.

Approved by the trustees on 9 December 2025 and signed on their behalf by*:



Bridget Snedden ONZM – President, Board of Trustees

* This is also the signature of a director authenticating accounts being sent to Companies House.

Consolidated statement of cash flows			
For the year ended 31 March 2025			
	Note	2024/25 £	2023/24 £
Cash flows from operating activities:			
Net cash used in operating activities		30,364	(13,525)
Cash flows from investing activities:		-	-
Net cash used in investing activities		-	-
Change in cash and cash equivalents in the year		30,364	(13,525)
Cash and cash equivalents at the beginning of the year		47,220	60,745
Cash and cash equivalents at the end of the year		77,584	47,220

Down Syndrome International
Notes to the financial statements
For the year ended 31 March 2025

1. Accounting policies

a) Statutory information

Down Syndrome International is a charitable company limited by guarantee and is incorporated in England. The registered office address is Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS. The principal place of business is 7/9 Chapel Street, Exmouth, Devon, EX8 1HR.

b) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015 - 2nd edition effective 1 January 2019) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (August 2014) and the Companies Act 2006.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

c) Public benefit entity

The charitable company meets the definition of a public benefit entity under FRS 102.

d) Going concern

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

There are no key judgements that the charitable company has made which have a significant effect on the accounts.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

e) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received, and the amount can be measured reliably and is not deferred.

Income generated from the supply of goods or services is included in the statement of financial activities in the period in which the supply is made.

Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when received.

Revenue grants are credited to the statement of financial activities when received or receivable whichever is earlier.

Where unconditional entitlement to grants receivable is dependent upon fulfilment of conditions within the charity's control, the incoming resources are recognised when there is sufficient evidence that conditions will be met. Where there is uncertainty as to whether the charity can meet such conditions, the incoming resource is deferred.

Member organisation income is included in full in the statement of financial activities when received.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably, and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

f) Donations of gifts, services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item or received the service, any conditions associated with the donation have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), volunteer time is not recognised so refer to the trustees' annual report for more information about their contribution.

On receipt, donated gifts, professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

g) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

h) Fund accounting

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

i) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required, and the amount of the obligation can be measured reliably.

Expenditure is classified under the following activity headings:

- Costs of raising funds relate to the costs incurred by the charitable company in inducing third parties to make voluntary contributions to it, as well as the cost of any activities with a fundraising purpose.
- Expenditure on charitable activities includes the costs of delivering services and campaigning undertaken to further the purposes of the charity and their associated support costs.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

j) Allocation of support costs

Resources expended are allocated to the particular activity where the cost relates directly to that activity. However, the cost of overall direction and administration of each activity, comprising the salary and overhead costs of the central function, is apportioned on the following basis which are an estimate, based on staff time, of the amount attributable to each activity.

Where information about the aims, objectives and projects of the charity is provided to potential beneficiaries, the costs associated with this publicity are allocated to charitable expenditure.

Support and governance costs are re-allocated to each of the activities on the following basis, which is an estimate, based on staff time, of the amount attributable to each activity:

• Cost of Raising Funds	10%
• Knowledge, Policy and Practice	30%
• Network Development	30%
• Global Advocacy	30%

Governance costs are the costs associated with the governance arrangements of the charity. These costs are associated with constitutional and statutory requirements and include any costs associated with the strategic management of the charity's activities.

k) Operating leases

Rental charges are charged on a straight-line basis over the term of the lease.

l) Tangible fixed assets

Items of equipment are capitalised where the purchase price exceeds £1,000. Depreciation costs are allocated to activities on the basis of the use of the related assets in those activities. Assets are reviewed for impairment if circumstances indicate their carrying value may exceed their net realisable value and value in use.

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

• Leasehold improvements	5 years
• Fixtures and fittings	5 years
• Computer equipment	3 years

m) Listed investments

Investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the balance sheet date using the closing quoted market price. Any change in fair value will be recognised in the statement of financial activities and any excess of fair value over the historic cost of the investments will be shown as a fair value reserve in the balance sheet. Investment gains and losses, whether realised or unrealised, are combined and shown in the heading "Net gains/(losses) on investments" in the statement of financial activities. The charity does not acquire put options, derivatives or other complex financial instruments. Investments in subsidiaries are at cost.

n) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks. Donated items of stock, held for distribution or resale, are recognised at fair value which is the amount the charity would have been willing to pay for the items on the open market.

o) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

p) Short term deposits

Short term deposits include cash balances that are invested in accounts with a maturity date of between 3 and 12 months.

q) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account. Cash balances exclude any funds held on behalf of service users.

r) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

s) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

t) Pensions

Payments to the stakeholder pension scheme are charged as an expense as they fall due.

2. Income from donations and legacies				
For the year ended 31 March 2025				
	Unrestricted funds £	Restricted funds £	2024/25 total funds £	2023/24 total funds £
Gifts	121,925	-	121,925	81,328
Legacies	-	-	-	-
Donated services	13,796	-	13,796	37,119
Total income from donations and legacies	135,721	-	135,721	118,447

3. Income from charitable activities				
For the year ended 31 March 2025				
	Unrestricted funds £	Restricted funds £	2024/25 total funds £	2023/24 total funds £
International Disability Alliance (Listen Include Respect - IDA Bridge Consultation)	-	-	-	42,844
Government, Multilateral and Development Donors* (Listen Include Respect - Services)	17,308	-	17,308	1,975
Down's Syndrome Association UK (Programme Team Funding)	-	25,000	25,000	25,000
National Lottery Community Fund (Supporting DSi Network)	-	-	-	20,000
Down Syndrome Australia (World Down Syndrome Congress Consultancy)	6,725	-	6,725	2,985
Sub-total for Knowledge, Policy and Practice	24,033	25,000	49,033	92,804
The Clare Milne Trust (Inclusive Organisations - DSi Staff Member with Down Syndrome)	-	-	-	7,100
Down's Syndrome Association UK (Programme Team Funding)	-	25,000	25,000	25,000
Down's Syndrome Association UK (Inclusive Organisations Training)	-	34,500	34,500	26,000
Sub-total for Network Development	-	59,500	59,500	58,100
Down's Syndrome Association UK (Programme Team Funding)	-	25,000	25,000	25,000
National Down Syndrome Society United States (World Down Syndrome Day Partnership)	20,000	-	20,000	16,000
International Disability Alliance (World Down Syndrome Day Conference)	-	-	-	12,000
International Disability Alliance (World Down Syndrome Day Conference + Global Advocacy)	-	19,981	19,981	-
Instituto Alano (World Down Syndrome Day Conference)	1,400	-	1,400	-
Permanent Mission of Japan to UN (World Down Syndrome Day Conference)	727	-	727	790
Sub-total for Global Advocacy	22,127	44,981	67,108	53,790
Total income from charitable activities	46,160	129,481	175,641	204,694

*UN DESA, Government of Jordan, UNICEF, Global Disability Fund, Community Living Toronto, IDDC, BMZ

4. Income from other trading activities				
For the year ended 31 March 2025				
	Unrestricted funds £	Restricted funds £	2024/25 total funds £	2023/24 total funds £
Fundraising events	-	-	-	25,258
Trading	77,715	-	77,715	74,558
Total income from other trading activities	77,715	-	77,715	99,816

5. Analysis of expenditure		Charitable activities						
For the year ended 31 March 2025								
	Cost of Raising Funds £	Knowledge, Policy and Practice £	Network Development £	Global Advocacy £	Governance Costs £	Support Costs £	2024/25 Total £	2023/24 Total £
Staff costs (Note 7)	53,722	49,081	49,081	49,081	24,827	14,551	240,342	227,249
Fundraising Costs	42,491	-	-	-	-	-	42,491	44,011
Advertising, marketing and publicity	-	4,533	4,533	4,533	-	-	13,600	41,489
Spending on projects and activities	-	16,350	3,816	17,996	-	-	38,161	50,158
Office running costs and equipment	-	-	-	-	-	11,309	11,309	12,112
Consultants and professional fees	-	-	-	-	119	550	669	1,534
Rent, insurance and maintenance	-	-	-	-	-	12,595	12,595	11,616
Travel, meetings and conferences	-	142	142	142	6,643	-	7,070	1,867
Management, communications, finance, data and storage operational Systems	-	-	-	-	-	6,004	6,004	7,548
Sub-total	96,212	70,106	57,572	71,753	31,589	45,008	372,241	397,585
Support costs	4,501	13,503	13,503	13,503		45,008		
Governance costs	3,159	9,477	9,477	9,477	31,589			
Total expenditure	103,872	93,086	80,551	94,732			372,241	

6. Grant making		
For the year ended 31 March 2025		
	2024/25 total funds £	2023/24 total funds £
	-	-
	-	-
	-	-
Total grant making	-	-

7. Analysis of staff costs, trustee remuneration/expenses and cost of key management personnel		
For the year ended 31 March 2025		
	2024/25 total funds £	2023/24 total funds £
Salaries and wages	206,911	196,369
Social security costs	19,594	18,191
Employer's contribution to defined pension schemes	11,867	10,694
Total staff costs	238,372	225,254

1 employee earned more than £60,000 during the year (2023/24: 1). The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £140,339.36 (2023/24: £134,991.45).

The charity trustees were neither paid nor received any other benefits from employment with the charity in the year (2023/24: £nil). No charity trustee received payment for professional or other services supplied to the charity (2023/24: £nil).

Trustees' expenses represent the payment or reimbursement of travel, accommodation and subsistence costs totalling £8,056 (2023/24: £1,185) incurred by 7 persons (2023/24: 3) relating to participation in project activities and governance meetings.

8. Staff numbers - average numbers of employees (head count based on number of staff employed) during the year		
For the year ended 31 March 2025		
	2024/25 No.	2023/24 No.
Raising funds	1	1
Charitable activities	3	3
Support	3	3
Governance	1	1
Total staff numbers	8	8

9. Related party transactions

There are no donations from or to related parties which are outside the normal course of business.

Membership fee transactions have taken place during the year with many member organisations of Down Syndrome International. Organisation Membership requires a fee and in exchange basic support and advice is provided, member organisations participate as partners or stakeholders in our activities, and we promote our member organisations' work. The maximum annual fee charged for Organisation Membership is £300.

Some DSi member organisations purchase merchandise from our shop related to World Down Syndrome Day for sale or distribution in their own countries. DSi also makes grants to certain member organisations, as set out in note 6 of these notes to the accounts.

The Down's Syndrome Association (DSA) is a member of DSi. DSi uses office space at DSA's headquarters. The Chief Executive of DSA, Carol Boys, is a trustee of Down Syndrome International. DSi's Executive Director, Andrew Boys, is Carol's son. DSA is the payroll agency for DSi.

General donations and restricted grants are given by DSA to DSi to support our work. Donations for certain events and activities organised together are shared equally.

DSA made the following payments to DSi during the year:		
For the year ended 31 March 2025		
	2024/25 total funds £	2023/24 total funds £
Donations and grants	30,000	40,000
Membership fee	300	300
Income to fund Inclusive Participation Training UK	34,500	26,000
Income to fund Programme Team	75,000	75,000
Merchandise	14,550	15,498
Total	154,350	156,798

DSi made the following payments to DSA during the year:		
For the year ended 31 March 2025		
	2024/25 total funds £	2023/24 total funds £
Merchandise	-	1,090
Total	-	1,090

DSi received £28,125 funds (2023/24: £20,960) from 3 (2023/24: 3) other member organisations in 2024/25 - £6,725 (2023/24: £2,985) from Down Syndrome Australia, £20,000 (2023/24: £16,000) from National Down Syndrome Society and £1,400 (2023/24: £1,975) from Instituto Alana.

DSi received grants of £19,981 (2023/24: £54,844) from International Disability Alliance (IDA) in 2024/25 for the World Down Syndrome Day Conference and Global Advocacy project. DSi is a member of IDA.

10. Taxation

The charity is exempt from corporation tax. All its income is charitable and is applied for charitable purposes.

11. Movement in funds (current year)					
For the year ended 31 March 2025					
	At the start of the year £	Incoming resources and gains £	Outgoing resources and funds £	Transfers £	At the end of the year £
Restricted funds:					
Programme Team Funding	-	75,000	75,000	-	-
Inclusive Organisations Training	-	34,500	34,500	-	-
Inclusive Organisations - DSi Staff Member with Down Syndrome	5,523	-	2,943	-	2,580
World Down Syndrome Day Conference and Global Advocacy	-	19,981	15,908		4,074
Total restricted funds	5,523	129,481	128,350	-	6,654
Unrestricted funds:					
Designated funds:					
Supporting DSi Network	10,000	-	10,000	-	-
World Down Syndrome Day Partnership	-	20,000	20,000	-	-
World Down Syndrome Congress Consultancy	-	6,725	6,725	-	-
Total designated funds	10,000	26,725	36,725	-	-
General funds	35,392	232,871	207,166	-	61,097
Total unrestricted funds	45,392	259,596	243,891	-	61,097
Total funds	50,915	389,077	372,241	-	67,751

Purpose of restricted funds

Programme Team Funding

Funding for the salaries of our programme team, to enable much of our work on crucial projects and the development and delivery of our strategy.

Inclusive Organisations Training

Working with the Down's Syndrome Association (DSA) to train self-advocates with Down syndrome in the UK to become consultants on inclusive organisations.

Inclusive Organisations - DSI Staff Member with Down Syndrome

Funding to support the employment of a permanent staff member with Down syndrome, Emma Bishop, as Inclusion and Advocacy Officer. Emma is an advocate for the rights of people with disabilities.

World Down Syndrome Day Conference and Global Advocacy

Funding from International Disability Alliance (IDA) to support the WDSD Conference in New York and our global advocacy work.

Purpose of designated funds

Supporting DSI Network

Developing and signposting to resources and information to help people with Down syndrome and their families get support. Putting people in contact with our member organisations to get the support they need at the local level.

World Down Syndrome Day Partnership

Working with National Down Syndrome Society and the Down's Syndrome Association to bring WDSD to public attention. Running WDSD website and social media pages and running the Lots of Socks campaign.

World Down Syndrome Congress Consultancy

Working with Down Syndrome Australia to help plan and deliver the World Down Syndrome Congress, which took place in Brisbane in July 2024.

12. Legal status of the charity

The charity is a company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £10.

Accounts

DOWN SYNDROME INTERNATIONAL (DSi)



REPORT OF TRUSTEES (AND DIRECTORS) AND FINANCIAL STATEMENTS

for the period from 1 April 2023 to 31 March 2024

Reference and administrative information

Company number	04327941
Country of incorporation	United Kingdom
Charity number	1091843
Country of registration	England and Wales

Registered Office

Down Syndrome International
Langdon Down Centre
2A Langdon Park
Teddington
Middlesex
TW11 9PS
United Kingdom

Operational Address

Down Syndrome International
7/9 Chapel Street
Exmouth
Devon
EX8 1HR
United Kingdom

Trustees

The trustees are the members of the DSi board.

They are also the company directors.

The trustees who served during this year were:

B Snedden	(President)
R Faragher	(Vice President)
JP Clarke	(Treasurer)
V dos Santos	
P Robertson	
C Boys	
J Tang	
A L Arellano	
D Warkcup	
J Charchuk	(Co-opted December 2023)

Principal Staff

A Boys (Executive Director)
 (Company Secretary)

Principal Bankers

HSBC
16 King Street
Covent Garden
London
WC2E 8JF

Solicitors

Russell Cooke
2 Putney Hill
London
SW15 6AB

Introduction

In this document, the trustees of DSi are sharing a report and financial statements for the year ending 31 March 2024.

These statements cover the last 12 months, starting from 1 April 2023.

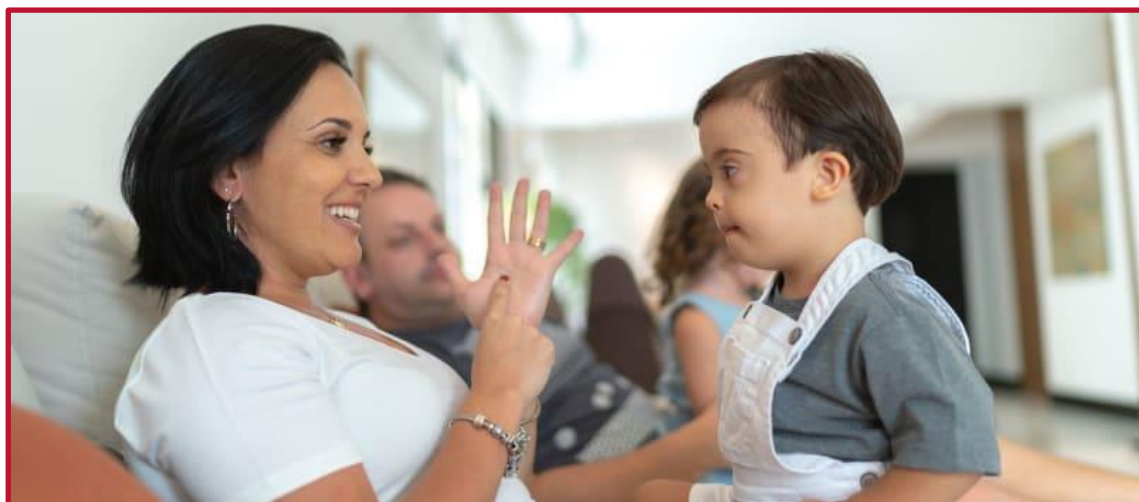
The information in the “Reference and administrative information” section above, is part of this report.

These financial statements follow:

- the rules required by the law (known as statutory requirements).
- the rules of DSi (our articles of association).
- a set of recommended accounting rules for charities (the Statement of Recommended Practice – Accounting and Reporting by Charities: SORP FRS 102).

For a list of our member organisations, please refer to Annex 1.

Because our organisation earned more than £25,000 in the year ending 31 March 2024, we had to get an independent examination of our financial statements.



Objectives and activities

Charity objects

DSi has charity “objects” which are written in our official document (our articles of association). The objects are:

- To promote and protect the physical and mental health of those with Down syndrome through the provision of support and resources to people with Down syndrome, their families and carers, and the professionals who work with them with specific focus on developing countries.
- To undertake any other charitable activities in connection with Down syndrome and other learning disabilities as the trustees shall determine.

These objects tell the Charity Commission of England and Wales what we are trying to achieve and what kinds of activities we do.

The Charity Commission is appointed by the UK government to check we are doing work charities should do and that we are doing it in the right way.

Our vision, purpose, strategy and activities

DSi launched a new strategy in October 2023 after a comprehensive review of the charity and our work, including consultations with all key stakeholders.

To develop our new strategy, we first established:

- **who we are** – we are the global network of people with Down syndrome and their families.
- **our purpose** - together, we speak up for the human rights of all people with Down syndrome around the world.
- **our vision** - a better world where all people with Down syndrome are fully included in society.

We were then able to develop a 10-year strategy (2024-2034), setting out how we can channel our purpose so we can realise our vision.

Critical to the success of our new strategy will be:

- sticking to the **principles** guiding our work;
- putting in place our **foundations** to enable DSi to thrive;
- delivering activities based on our **approaches**.

If we do this, we will achieve our **goal** – for people with Down syndrome and their families around the world to have a say in all laws, policies and other decisions that affect them.

Over time this will lead to:

- communities that respect and include people with Down syndrome;
- laws and policies that protect and promote the human rights of people with Down syndrome;
- systems and services that are accessible and include people with Down syndrome.

In the long term, we know this will realise our vision.

We made sure we followed guidelines from the Charity Commission (on public benefit) when developing our new strategy and we do the same when we make any strategic plans or decisions.

A more detailed explanation of our new strategy can be found on our website.

How our activities help people (how we deliver public benefit)

Our work is all about helping people with Down syndrome to have opportunities to live better lives. We speak up for their human rights so that they will have these opportunities.

We work with our network of member organisations to represent people with Down syndrome and their families, making sure that it is people with Down syndrome themselves who can speak up.

This report describes what we have achieved this year to help people. All our activities deliver public benefit and happen for the purpose DSi was set up.

Who uses and benefits from our services?

DSi is a worldwide organisation with member organisations from more than 120 countries. We are an international organisation of persons with disabilities (OPD).

We work on national, regional, and global projects to improve the lives and the human rights of people with Down syndrome.

There are about 7 million people with Down syndrome worldwide. Since we opened our international office in 2009, we have seen a big increase in demand for our services.

We review our strategy and activities every year. This report looks at what we have achieved and how our work has helped the people we aim to support. It also helps us make sure we stay focused on our purpose and our goals.



Achievements and performance

Our approaches

Following the launch of our new strategy in October 2023, as of April 2024, all of the work we do will be based on 5 approaches:

1. Developing and sharing evidence, stories and examples of inclusion of people with Down syndrome.
2. Empowering people with Down syndrome and their families to speak up for their human rights.
3. Supporting Down syndrome organisations to become stronger and more inclusive.
4. Building and leading partnerships with important people, groups and organisations.
5. Coordinating advocacy for the human rights of persons with Down syndrome.

These new approaches match up broadly to our previous approaches, which are as follows:

1. Policy and practice, information, support and advice

- We play a leading role globally working on new policies, documents and other published information about issues that affect people with Down syndrome.
- We work with our member organisations and partners to make sure accurate information is available.
- We give advice and help to member organisations and others when they need it.

2. Network development and training

- We make our member organisation network stronger by involving member organisations in all our work and improving communication.

- We develop and support networks, alliances and advocacy groups among our member organisations.
- We provided training to help our member organisations and those who represent them.

3. Advocacy and campaigning

- We run worldwide campaigns and events.
- We support local, regional and global activities that fight for the rights of people with Down syndrome.
- We take part in international meetings on disability and human rights to represent the global Down syndrome community.

Key issues

Most of our work involves one or more of these issues that affect a lot of people with Down syndrome:

- the right to an education
- the right to work
- the right to health
- being included in important decision making

The next part of this report will summarise all of our project activities from April 2023 to March 2024.

We will explain our project work using our previous approaches. We will review the best way to explain our work using our new approaches for our next report in March 2025.

1. Policy and practice, information, support and advice

Translating the Listen Include Respect guidelines

The Listen Include Respect guidelines help organisations understand what they need to do to make sure people with intellectual disabilities can take part in their work and are included in decision making.

We developed the guidelines with Inclusion International and they were published last year on the website listenincluderespect.com in English and Spanish.

This year we started work to translate the guidelines into Arabic, Chinese, Indonesian and Portuguese.

Self-advocates took part in consultations to make sure that the translations stay in plain language and are accessible for people with intellectual disabilities.

The consultation work and technical work will continue next year so that we can publish alternative language versions of the guidelines via the website in late 2024.



We have been working in partnership on this project with Higher Council for the Rights of Persons with Disabilities (Government of Jordan – Arabic), Up for Down's China (Chinese), Instituto Alana and Federacao Brasileira das Associacoes Sindrome de Down (Portuguese) and Indonesia Down Syndrome Care Foundation (YAPESDI - Indonesian).

World Down Syndrome Congress (WDSC)

We have been working with Down Syndrome Australia to help plan the next World Down Syndrome Congress, taking place in Brisbane in July 2024.

The Congress is an event where people and organisations come together to share experiences and best practices.

The Congress happens every few years and we support them to make sure it goes well.



Working as a member of the International Disability Alliance

We continued our work as a full member of the International Disability Alliance (IDA). IDA and its members work together as a global alliance representing persons with disabilities from around the world.

We advocate for disability rights at the United Nations and in international development work.

Within IDA we make sure the voices of people with Down syndrome and their families are heard and push for inclusive projects and programmes.

Consultation for BRIDGE CRPD-SDGs Training

We worked with Inclusion International and International Disability Alliance (IDA) to run a consultation on how to make the BRIDGE CRPD-SDGs training more accessible for people with intellectual disabilities.

BRIDGE CRPD-SDGs is a training programme developed and run by IDA and International Disability and Development Consortium (IDDC). It helps advocates with disabilities speak up for their rights.



We ran a survey and a workshop in Kenya in December 2023, with people with intellectual disabilities who had taken part in the BRIDGE CRPD-SDGs training. Then we submitted an accessible report in March 2024, with recommendations for actions to make the training more accessible.

The project was funded by International Disability Alliance (IDA).

Providing resources and information on Down syndrome

One important job of DSi is to make sure people with Down syndrome and their families have the information they need to help with challenges.

People with Down syndrome can have problems with getting good healthcare, doing well in school, getting a job and in other areas of life. The COVID-19 pandemic made many challenges even harder.

We work every year to provide information and support and show people where help is available from our member organisations and others in countries around the world.

This project is partly funded by National Lottery Community Fund.

World Down Syndrome Awards

In 2023, we developed and ran the first “World Down Syndrome Awards”. The World Down Syndrome Awards are given to projects, achievements, or practices that make the lives of people with Down syndrome better – based on the principles of inclusion and human rights.

The first winners were announced in September 2023 and then formally presented with awards at the World Down Syndrome Day Conference in New York in March 2024.

The following projects received an award:

- Students for Inclusion, University of Malaga (Spain).
- "INployable", Canadian Down Syndrome Society (Canada).

- La Casa de Carlota (Spain).
- "Make Your Voice Heard!", Trisomie 21 (France).
- Down Syndrome Advisory Network, Down Syndrome Australia (Australia).



Launch of health equity project and consultation

In late 2023 we developed a new project, working with Humanity & Inclusion, to learn about health equity for people with Down syndrome and intellectual disabilities.

People with disabilities around the world have worse health outcomes than other people. This is not fair. We want better health outcomes for everyone.

The World Health Organization wrote a global report on health equity for people with disabilities, published in December 2022. The report explains what causes bad health outcomes and what can be done to improve outcomes.

Our project will include:

- Raising awareness around the world on the right to health equity.
- Gathering evidence about the health equity of people with Down syndrome around the world.
- Advocating for changes in policy and legislation to promote health equity.



The project was launched at the 13th World Down Syndrome Day Conference at the United Nations in New York in March 2024.

Self-advocates from around the world spoke up about their experience of health equity. Supporters, government and UN officials and NGO representatives also shared knowledge, experience, and good practice.

During the event we launched a global consultation on health equity, including a survey and focus groups. The results will be shared in a report that the DSi network will use to advocate for policy change in their countries.

2. Network development and training

UK Listen Include Respect project

Throughout 2023-24, we continued to work with the Down's Syndrome Association (UK) to train self-advocates with Down syndrome, to become consultants on inclusive organisations.

As of March 2024, the consultants have completed most of their training and will go on to work as consultants for the Down's Syndrome Association. They will consult with UK government departments, as well as international disability and development NGOs. They will train staff to include people with intellectual disabilities in policy making and government consultations.

This training will help the UK government create more inclusive policies that positively impact important areas of people's lives - like education, health, employment, social care and more.

This project is funded by the Down's Syndrome Association.



Including people with Down syndrome

We are committed to ensuring that people with Down syndrome are included in all of the work of DSi and our network.

DSi will only realise our vision if we do this. We want people with Down syndrome to be working and having a big influence at all levels of our organisation. This year we have made excellent progress, in the DSi office, on the DSi board and in the membership network.

- **Including people with Down syndrome – office and board**

Last year, we conducted a review of how inclusive DSi is and we made an action plan of everything we need to do to be more inclusive.

In September 2023, we recruited a permanent staff member with Down syndrome, Emma Bishop, as Programme Officer. Emma is an advocate for the rights of people with disabilities, who has spoken at the UN Conference of State Parties (COSP) on disability.

Emma's salary is funded by the Clare Milne Trust.



In December 2023, Janet Charchuk, who has worked on the DSi Ambassadors committee for a number of years, joined the DSi board of trustees. She is the first person with Down syndrome to join the board.

She helped us review how the meetings are planned and delivered, so they are inclusive for people with Down syndrome.

Janet is now working with the board to support all aspects of DSi's new strategy.



In addition to the appointments of Emma and Janet, our team has been working on a number of initiatives, across all departments, to make sure all of our work involves people with Down syndrome at all stages, so that we know we are working on the right things and that it is accessible.

- **Including people with Down syndrome – membership network**

We have a committee of people with Down syndrome called the DSi Ambassadors. They represent our member organisations in their countries.

There are currently ambassadors from 19 countries.

We meet monthly with the ambassadors to discuss important topics and work on projects.

Some examples from this year included:

- Helping plan the World Down Syndrome Awards.
- Reviewing our new strategy.
- Giving feedback on a new website.
- Recording videos and sharing stories.



Throughout 2023-24, DSi Ambassadors Stuart Campbell from Scotland and Janet Charchuk from Canada (now a board member), participated in the DSi board programme strategy working group.

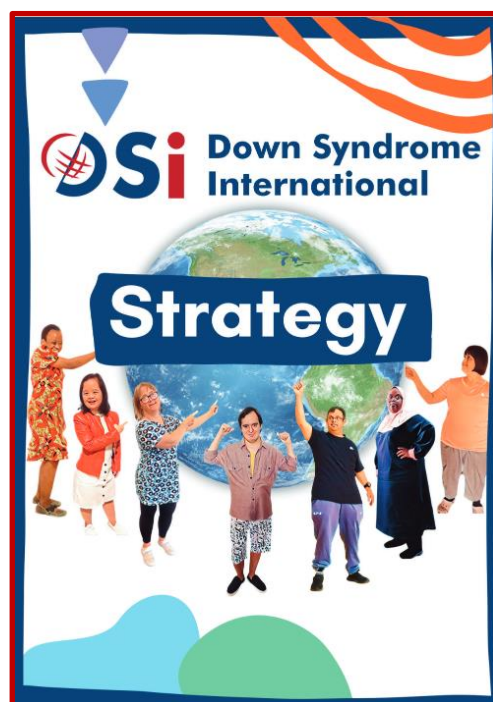
The DSi Ambassadors committee is just one example of the work we do with our network, to ensure inclusion of people with Down syndrome. They play a central role in all of our projects and our new strategy published in October 2023. We will ensure this continues for the next 10 years.

Publishing our new strategy

In October 2023 we published our new 10-year strategy for the organisation. A strategy is a plan for how DSi and our network will make the world better.

To create the strategy we involved:

- our board and our staff;
- people with Down syndrome from the DSi Ambassadors;
- our member organisations;
- organisations we work with such as project partners, donors and other organisations in the disability movement.



The strategy includes:

- **Who we are**
- Our **purpose** – a good way of explaining why we are doing our work.
- The **principles** that guide our work.
- The **foundations** we are putting in place to help us do our work.
- The **approaches** we will use to make change happen.
- Our **goal** for what we want to achieve in 10 years. So that we can contribute to our vision.
- Our **vision** of how we want the world to be in the future.

The strategy is published on our website in Easy Read and videos formats. More information can also be found on pages 4-5 of this report.

Other DSi network activities

- **Advocacy and human rights research with members**

We carried out research with member organisations to understand their current advocacy and human rights work. We will use this information to plan future advocacy work together as a network, and how we can support members with advocacy work in their countries.

- **Webinar for members on UN resolution on easy-to-understand communication**

We ran a joint webinar with Inclusion International to talk to members about how to use the United Nations Resolution on Easy-to-Understand Communication in their advocacy. The Resolution was passed by the UN General Assembly in 2022.

- **High support needs meeting with members**

We met with member organisations to discuss how our network can better work with people who have higher support needs. We recognise that more work is needed on this topic to ensure that all people with Down syndrome are included in the work of our network.

- **Celebrated 30 years of DSi**

During awareness month in October 2023, we celebrated 30 years since DSi was founded.

In 1993, 3 women from different parts of the world joined together to form Down Syndrome International - with a mission to make the world more inclusive for people with Down syndrome.

Today, we are thousands of people with Down syndrome, their families and representative organisations from every part of the world.

To celebrate, we shared stories about Down Syndrome International and our network.



3. Advocacy and campaigning

Listen Include Respect advocacy

We continued our advocacy for organisations to use the Listen Include Respect Guidelines to include people with intellectual disabilities in their work. Some highlights were:

- Briefing UN disability focal points in the Asia-Pacific region.
- Presenting to different UN agencies as part of a UNPRPD regional workshop.
- Briefing Light for the World staff.
- Participating in Learning Disability England conference.



Conference of State Parties (COSP) in New York

We attended the Conference of State Parties (COSP) in June 2023. The event takes place every year at the UN Headquarters in New York. It is a conference about the UN Convention on the Rights of Persons with Disabilities (CRPD) attended by many important stakeholders.

We joined member organisations from Australia, Brazil, United Kingdom and United States who attended.

Self-advocates representing DSi spoke in many events.

With Inclusion International, we organised a side event on easy-to-understand communication, that was well attended.

It was a great opportunity for our member organisations to advocate together and get to know each other better.



World Down Syndrome Day 2024

- **Bringing WDSO to public attention and 2024 theme**

On 21st of March every year, we bring the global Down syndrome community together for World Down Syndrome Day (WDSO).

We run the WDSO website and the WDSO social media pages. We also promote a theme annually. In 2024, this was “End the Stereotypes”. The theme was decided by consultations with our members and ambassadors.

We worked with the international community to deliver awareness and advocacy messages focused on how stereotypes have a negative impact on the lives of people with Down syndrome and how this must change. We also partnered with CoorDown on their 2024 video “Assume that I can”.

We run the Lots of Socks campaign too. We ask people worldwide to wear interesting socks on 21st March, to get people talking about WDSO.



This year we partnered with National Down Syndrome Society (United States) and Down's Syndrome Association (UK) to assist this global effort.

- **Our WDSO conferences**

The 13th World Down Syndrome Day Conference, took place over two days in New York.

This year, rather than focus on the WDSO theme (see page 24), we used our event to launch our campaign and project on health equity (see pages 13-14).

The event was attended by people with Down syndrome, families, organisation and government representatives and many health stakeholders.

People with Down syndrome were involved in planning and speaking at the event. We had a diverse range of speakers from around the world.

On the first day, we had group discussions about the issue of health equity at a meeting venue in New York. On the second day, at United Nations Headquarters, speakers shared their experiences and ideas for improving health outcomes for people with Down syndrome.



As well as the WDSO Conference in New York, we took part in some other advocacy events at this time, including:

- A presentation about Down syndrome to staff from EnableIn, LinkedIn's employee resource group for people with disabilities.
- Virtual presentations about the right to health equity as part of World Down Syndrome Day events by DSI members in Nigeria and Trinidad and Tobago.

Unfortunately, we were not able to hold an event at United Nations in Geneva this year. We will look to return next year.

Other advocacy opportunities

- **WHO Guide for Action**

We were part of the World Health Organization's External Consultation Group on the Disability Guide for Action. This group gave feedback on the guide, which will be used to support governments to improve health equity for persons with disabilities.

- **OHCHR – care and support work**

We took part in consultations by the UN Office of the High Commissioner on Human Rights (OHCHR) around care and support. This is part of work to push for a disability rights-based approach to care and support.

Our new Programme Officer, Emma Bishop, was interviewed by the UN to celebrate the first International Day of Care and Support.

- **GIZ Living Inclusion Network event**

We presented about including people with intellectual disabilities at a Living Inclusion Network event. The Living Inclusion Network is run by GIZ, the government international development agency of Germany.

- **ICCA Conference**

We went to the International Congress and Convention Association, Middle East Summit in Muscat, Oman.

Chaica, a DSI Ambassador, ran an hour-long workshop with our programme team on why inclusive conferences are important and how to plan them.



Raising funds

To keep DSi running well and helping those who need us, we need money.

We have 2 types of income:

- **Restricted income** – this is money we receive that we have to spend on projects. We agree detailed budgets with the organisations who provide this money.
- **Unrestricted income** – this is money we receive that we can spend on anything, as long as it is for DSi. So, we can spend this on projects if we need to. But we can also spend it on other things that help keep DSi running. Or we can save it (as reserves) to keep DSi financially stable.

Restricted income - April 23 to March 24

This year restricted income went up.

This was because we received a number of grants for new or continuing projects – including Listen Include Respect - IDA Bridge Consultation, Inclusive Organisations Training, Programme Team Funding and World Down Syndrome Day Conference.

By the end of last year, we had spent all the project money we had in the bank. This year we received new project funds and we spent the majority of those funds during the year.

The money we received this year for projects did not include enough to cover all of what it costs us to pay staff to manage the projects. So, we had to use some of our unrestricted income for this – which we designated to projects such as Supporting DSi Network and World Down Syndrome Day.

To meet the growing demand for our work, we need to find more money for projects. This will pay for us to do all of projects, including paying staff to manage them.

We are carefully planning how we can find more money in our financial and fundraising strategies.

Unrestricted income - April 23 to March 24

This year unrestricted income also went up.

Unrestricted income from donations from people and companies went down, as did gifts in kind. But combined income from trusts and foundations, member donors and membership fees went up. Sales of merchandise went up. Income from fundraising events went up significantly.

We are confident that these things will continue to deliver income in future years.

As mentioned in the previous section, currently we need to use some of our unrestricted funds to pay for our projects, which we label as designated funds.

If we can find new restricted funding for projects, this will mean more unrestricted money is available to spend on other important things we need to do.

Importantly this will also help us to save some money as reserves, to keep DSi financially stable.



Financial review

Income

In the 12 months starting from 1 April 2023 (2023-24), DSi's total income was £422,957. This was a lot more than in the 12 months from 1 April 2022 (2022-23), when it was £316,812.

Restricted income went up a lot in 2023-24 compared to 2022-23.

In 2022-23 we already had some of the money in the bank that we needed for projects, plus we did not receive money to use for the following year. But in 2023-24, we received new funds for various projects.

We received money from International Disability Alliance (IDA) to do a consultation on their BRIDGE CRPD-SDGs training.

We also received money from IDA for our World Down Syndrome Day Conference at the United Nations in New York.

We received money from our member organisation the Down's Syndrome Association (DSA) to continue delivering training in the UK on inclusive organisations.

We also received money from DSA to fund our programme team.

Unrestricted income in 2023-24 also went up compared to 2022-23.

Although unrestricted income from donations from people and companies went down, as did gifts in kind, all other types of unrestricted income increased.

Expenditure (costs)

In the 12 months starting from 1 April 2023 (2023-24), DSi's total costs were £397,585. This was slightly less than in the 12 months from 1 April 2022 (2022-23), when it was £402,758.

Staff costs, cost of merchandise and office operational costs increased by varying, but small, amounts. Fundraising/marketing remained at a similar level. Project costs/grant making reduced.

We now have a stable base in terms of our staff numbers and a maximum number of projects that we will sign up to each year, with our current staff. This has helped us keep costs consistent.

Overall

When we subtract our costs from our income, we achieve an overall financial position for the year. This might be a surplus (if we had more income than costs) or a deficit (if we had more costs than income).

In the 12 months starting from 1 April 2023 (2023-24), we had a surplus of £25,372. This compares to the 12 months from 1 April 2022 (2022-23), when we had a deficit of £85,946.

We also have some money saved (total funds) that we carry over from previous years. We carried over £25,543 from 2022-23.

When we add this year's surplus to total funds we carried over from last year, this leaves us with total funds on 31 March 2024 of £50,915.

Some of our funds (£5,523) are restricted. If we subtract this from total funds, this leaves us with total unrestricted funds of £45,392.

We have a policy (reserves policy) which requires DSi to keep a certain amount of unrestricted funds saved (called "free reserves"). At the end of this year, we have less free reserves than we should have.

So, we really need to manage our finances carefully and we need very good financial and fundraising strategies to help us become more financially stable.

Reserves policy and going concern

We have a policy (reserves policy) which requires DSi to keep a certain amount of unrestricted funds saved (called “free reserves”).

The policy says that we should keep between 3 and 6 months of our annual costs in reserve.

Based on our 2023-24 costs (£397,585), 3 months reserves would be £99,396 and 6 months would be £198,792.

At this level the trustees agree that if our income dropped suddenly, we would still be able to continue doing our work.

The trustees also agree that if income did drop suddenly, we would think very carefully about how to replace that income or reduce our costs.

Our free reserves for 2023-24 are £45,392. This means we have just over 1 month of costs in reserve, compared to the minimum of 3 months required by our policy.

We do have something in our accounts called gifts in kind. This is where people or organisations provide us with free things, but because those things have a value, we include them both as income and costs. We would still be able to do our work without these things.

This year the gifts in kind were £37,119. This makes DSi’s costs look a bit bigger than they really are. If you take this out of our costs, this shows we have slightly more costs in reserve. But still only 1.5 months of costs, significantly less than the 3 months minimum required.

DSi also has an overdraft agreement with creditor the Down’s Syndrome Association (DSA). DSA pays staff for DSi and DSi repays DSA every quarter. DSA allows an overdraft facility to DSi, up to a maximum of £35,000, to help DSi if we cannot repay DSA when it asks for the quarterly repayment.

Starting in 2024/25 we have agreed with DSA that we will repay staff costs on a monthly basis.

Risk Management

We look carefully at risks to DSi. We have a policy for risk and also a risk management plan.

We decide which risks are most important and we take any action we can to reduce the risks that could have a negative impact on DSi. Some of the most important risk areas are:

Funding: We don't have money saved (reserves). A sudden loss of funding could mean we run out money and have to stop what we do. So, we focus on trying to get new funding and long-term funding from different people and organisations.

Leadership: It is important we have good leaders to take us forward and keep everyone at DSi happy. Our leaders will change as time passes. We need to make sure when that happens, our new leaders will be just as good. So, we plan for what will happen when leadership changes.

Staff: It is important that our staff feel happy to work for us and believe that they are important to DSi's success. So, we treat them well, we ask them how they are doing, we ask them what they think about DSi and we listen to what they tell us.

Project activities: We need to do our project work well. We need to do what we say we will do. Our projects need to be completed on time and at the same cost we agreed. We also need to make a big impact. So, we make sure we check how we are doing, we ask others how we are doing and we always try to do things better.

Operational systems: We have a small staff team and we have a lot of different things we need to do to keep DSi running well and following the law. So, we use software and we have systems to help us do all of these things in the right way, as quickly and as cheaply as we can.

Reputation: It is really important that everyone we work with believes DSi is a good organisation and trusts us. So, we make sure all of our work is relevant to people and makes an impact. We also make sure we are run really well. We listen to what people tell us and we always try to make good decisions.

Plans for the future

Activities we have planned for next year starting 1 April 2024 include:

Policy and practice, information, support and advice

- We will organise launch webinars for the Arabic, Chinese, Indonesian and Portuguese translations of the Listen Include Respect Guidelines.
- With Down Syndrome Australia, we will deliver the World Down Syndrome Congress in Brisbane. Board members, staff and Ambassadors will participate in the conference in July 2024.
- We will continue our important work as a member of the International Disability Alliance, making sure the voices of people with Down syndrome and their families are represented internationally.
- We will run our global health equity consultation, including gathering data from surveys for individuals and organisations and focus group discussions. We will then analyse and publish the data, ready for our network to use it to advocate for health equity around the world.
- We will work with the UN Partnership on the Rights of Persons with Disabilities to produce a guidance note on meaningful participation of marginalised and under-represented persons with disabilities in UNPRPD programming.
- We will form reference groups of self-advocates to offer consultancy services. The first group will help develop an inclusive tool for sharing important global disability information for 'Fundacion Saraki'. The second group will review a UNICEF resource on gender-based violence.

Network development and training

- We will work with our Ambassadors and member organisations to restructure the Ambassador committee and open up opportunities for new self-advocates to join the team.
- The UK Listen Include Respect team will complete their training and begin providing consultancy services. They will also present at the World Down Syndrome Congress.
- We will develop a Listen Include Respect 'Train the Trainer' course. The first trial of this will be in person, in Canada.
- We will continue to develop our network of self-advocate groups. We will form a working group that will develop resources on starting and running self-advocacy groups.
- We will launch a new Health Equity Network Group for DSi member organisations. This group will be a space for members to share experiences, support each other and work together on projects and advocacy around health equity.

Advocacy and campaigning

- Self-advocates will continue to advocate for inclusive organisations when speaking at events, by promoting the use of the Listen Include Respect guidelines.
- In June 2024 we will attend the Conference of State Parties (COSP).
- We will organise activities for World Down Syndrome Day 2025. This will include deciding on a theme and an advocacy campaign,

organising our UN conferences in New York and Geneva, running the website and social media pages and running the Lots of Socks awareness campaign.

- We will continue our involvement with the UN Office of the High Commissioner for Human Rights (OHCHR), pushing for rights-based care and support systems that enable people with Down syndrome to be included in the community.

Raising funds

- We will try to find more funds for our projects from different types of organisations who make project grants. So that we do not have to use money we want to keep in reserves.
- We will try to increase funds we get from donations, events and sales so that we can save more and improve our reserves position.
- We will look for new ways to raise money and grow our organisation. But make we are financially safe so we can keep doing what we do.



Structure, governance, and management

DSi is a company (a charitable company limited by guarantee) and is also a registered charity.

We became a company on 23 November 2001 and we became a charity on 1 May 2002.

DSi was started by a legal document called our Articles of Association.

This document has information about what our purpose is, what we need to do and what we cannot do.

We also have a Code of Governance. This guidance document helps our trustees know what their responsibilities are and how we all need to behave.

The Code of Governance also has a guide on how trustees come on to the board and how they leave the board.

All of the trustees are volunteers and receive no benefits from DSi.

Any expenses trustees reclaim from the charity are very small and can be seen in note 7 of the accounts.



Members and trustees

Charity members and other members

Our legal document (Articles of Association) says that we have members (who we can call the “charity members”) who have a vote at all important meetings, like the annual general meeting.

The charity members are all individual people and they are different from our member organisations.

The charity members are also the trustees. When you become a trustee of DSi you also become a charity member. When you are no longer a trustee, you are no longer a charity member.

We are also able to have other types of members, but our legal document is clear that these members are not charity members and so they do not have a vote at important meetings.

We have 2 other types of members at the moment:

- Representative members – for organisations only.
- Affiliate members – for organisations only.

Appointment of trustees

The board of trustees manages the business of the charity.

We currently have 10 trustees.

All trustees are elected by the charity members and we can have between 5 and 21 trustees.

Each time we have an annual general meeting (AGM), one third of the trustees must retire. To make it fair this happens on a rotation system. So, each trustee gets 3 years before they retire.

When trustees retire, they have the option to seek re-election. If they do this, then the other trustees decide by vote if they will re-elect each person.

The trustees can also vote to bring in new trustees at other times of year for a specific reason. If they do this, the new trustee will be in their post until the next AGM. Then they can seek re-election alongside the other trustees who are retiring.

Recruitment of trustees

A policy on how to recruit trustees can be found in our Code of Governance.

The trustees must be open and honest in any search for new people.

Trustees must be aware of the legal rules on who can and cannot be a trustee.

Trustees should consider whether any candidates might have “conflicts of interest”. This is something that might make a trustee act in a certain way that is not in the best interests of DSi.

The trustees should look for people with the right skills to join, especially if there are skills that the current board does not have. But this is not the only thing to consider.

As a priority, we should ask our representative member organisations first if they have candidates to consider. Then we should ask our affiliate member organisations. After this we can look wider.

The trustees need to make sure that:

- 55% of the board are people with Down syndrome or family members.
- There is a maximum of 2 people from any country.
- There is at least 1 person from Europe, North America, South America, Africa, Asia and Australia (continent).

- At least 25% of the board are from “developing economies” (defined by International Monetary Fund’s World Economic Outlook Report, April 2015).

Induction of new trustees

All trustees must understand the charity’s purpose and aims and their duties and responsibilities.

They are then able to explain this to new trustees.

The trustees must make sure that they, rather than staff, have overall responsibility for inducing new trustees.

The board should provide all new trustees with induction material, such as governing documents, annual reports, meeting minutes, strategy and management documents.

This allows new trustees to understand their charitable purposes, financial position and current issues.



Related parties and connected organisations

DSi works with many Down syndrome, disability and international development organisations worldwide.

We have a close working relationship with the Down's Syndrome Association (DSA) in United Kingdom. We share a registered office with DSA in Teddington. We also share some resources and we have a funding agreement.

We receive membership organisation fees and we work on projects with many member organisations throughout the world. See Annex 1 for a list of our member organisations.

At the regional level, we support the work of European Down Syndrome Association, African Down Syndrome Network, Federación Iberoamericana de Síndrome de Down (Latin America) and Asia Pacific Down Syndrome Federation.

DSi is in special consultative status with the Economic and Social Council of the United Nations (UN).

DSi is a member of International Disability Alliance (IDA)

We also work with Inclusion International on projects.

Remuneration (pay) policy

We pay our staff fairly to get the best people for the job while using our money wisely.

We decide on what to pay people by looking at what other people in similar charity roles get (on average) and we set our salaries at the same level.

All DSi staff get a pay rise every year based on changes to the cost of living where they live. In the UK (where most of our staff live) this is normally a 3% increase.

DSi will go ahead with these pay rises unless we cannot for financial reasons.

Any changes to this method of giving pay rises must be agreed by the trustees.

Some staff may get a higher pay rise if there are reasons for it. This must be agreed by the trustees.

Pay rises start from the start of the financial year, which is 1 April.

The trustees look at how well the executive director is doing and decide what to pay that person specifically each year.

They will look at how the executive director is doing based on performance targets they have set for the person. They will also think about what they need to pay to keep the best person for the job.

Fundraising

We make sure all the fundraising we do follows the rules and regulations charities must follow.

We always talk to our supporters in a fair and honest way.

We protect people who support us by keeping their information secure. We do not put pressure on people to give us money. We ask people if we can contact them.

We do all of our own fundraising. No one has ever complained about us.

The trustees reviewing fundraising activities regularly.



Statement of responsibilities of the trustees

The trustees (who are also the company directors of DSi) are responsible for writing this trustees' annual report and the financial statements.

The trustees make sure we have followed the law and accounting standards in the UK (United Kingdom Generally Accepted Accounting Practice) when writing this report.

Company law requires the trustees to write financial statements for each financial year which:

- give a true and fair view of DSi's financial position.
- provide details of the money coming in and how that money was spent, over the year (accounting period).

When writing this report, the trustees have to:

- choose good accounting methods and use them in all of the report.
- use the methods in the charity accounting standards (SORP).
- make sensible decisions.
- say whether we have used UK accounting standards and give details where we have not.
- write the financial statements based on the idea that DSi will continue to operate, unless we are not going to.

The trustees have to keep good accounting records that:

- can show accurately our financial position at any time.
- can show we comply with the Companies Act 2006.

The trustees must also keep the financial assets of DSi safe. So, they must try to prevent financial crimes like fraud and other bad behaviour. To the best of the trustees' knowledge:

- there is no audit information that our auditor does not know about.
- we have taken all steps we need to make sure we know about all audit information and the auditor does too.

The trustees are responsible for keeping all company and financial information on our website up to date and true.

Laws in the United Kingdom on financial statements might be different to laws in other countries.

Members of the charity (charity members) guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up.

The total number of such guarantees on 31 March 2024 was 10 (2023: 9).

The trustees are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.



Independent examiner

DSi as a company has taken advantage of the small companies' exemption in preparing the report above.

The following person was appointed to carry out an independent examination of these accounts:

Mr Luke Burns
Fellow Member of the Association of Chartered Certified Accountants (ACCA)
65 Bulmershe Road, Reading, RG1 5RH, UK.

Trustee approval

The trustees' annual report has been approved by the trustees on 24 October 2024 and signed on their behalf by:



Bridget Snedden
President
Board of Trustees



Section A

Independent Examiner's Report

**Report to the
trustees/directors/
members of**

Down Syndrome International

**On accounts for the year
ended**

31 March 2024

Charity no.:

1091843

Company no.:

04327941

Set out on pages

I report to the charity trustees on my examination of the accounts of the Company for the year ended **31/03/2024**.

**Responsibilities and
basis of report**

As the charity's trustees of the Company (who are also the directors of the company for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ("the 2011 Act"). In carrying out my examination, I have followed the Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act).

**Independent
examiner's statement**

The company's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of Association of Chartered Certified Accountants (ACCA).

I have completed my examination. I confirm that no material matters have come to my attention which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the Companies Act 2006; or
- the accounts do not accord with such records; or
- the accounts do not comply with relevant accounting requirements under section 396 of the Companies Act 2006 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:  Date: 29/11/24

Name: Luke Burns

Relevant professional qualification(s) or body (if any): Fellow of the Association of Chartered Certified Accountants (ACCA)

Address: 65 Bulmershe Road
Reading
RG1 5RH

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

No material matters to note

Annex 1: Member organisations

Member organisations in Africa

Botswana

Representative Organisation

Down's Syndrome Association of Botswana

Cameroon

Representative Organisation

Aidrikings Foundation

Congo

Affiliate Organisation

Lenire Asbl

Eritrea

Affiliate Organisation

National Association of Intellectual/Developmental Disability in Eritrea (NAIDDE)

Eswatini

Affiliate Organisation

Down Syndrome Eswatini

Ethiopia

Affiliate Organisation

Ethiopian National Association on Intellectual Disabilities

Ghana

Representative Organisation

Robb Foundation

Affiliate Organisation

Inclusion Ghana

Kenya

Representative Organisation

Down Syndrome Society of Kenya

Liberia

Affiliate Organisation

My Heart's Appeal Inc

Libya

Representative Organisation

Libyan Down Syndrome Association

Madagascar

Representative Organisation

Down Syndrome Madagascar

Mauritius

Representative Organisation

Down Syndrome Association Mauritius

Morocco

Representative Organisation

Association Marocaine de Soutien et d'Aide aux Personnes Trisomiques (AMSAT)

Nigeria

Representative Organisation

Down Syndrome Foundation Nigeria

Affiliate Organisations

Larger Than I Developmental Foundation

Moyinoluwa Rainbow Foundation

Rwanda

Representative Organisation

Rwanda Down Syndrome Organisation (RDSO)

South Africa

Representative Organisation

Down Syndrome South Africa

Tanzania

Representative Organisation

Pearl of People with Down Syndrome Foundation

Affiliate Organisation

Elimisha

Morogoro Saving the Poor Organization

Togo

Representative Organisation

APAPE - Down Syndrome Togo

Tunisia

Affiliate Organisation

AMED (Association Mon Enfant Est Different)

Uganda

Representative Organisation

The Uganda Down Syndrome Association (TUDSA)

Affiliate Organisation

Inclusion Uganda

Angel's Center for Children with Special Needs

EmbraceKulture

Rowan's Down Syndrome Awareness Centre

Zimbabwe

Representative Organisation

Zimbabwe Down Syndrome Association

Member organisations in Asia Pacific

Australia

Representative Organisation

Down Syndrome Australia

Affiliate Organisation

e.motion 21

Bangladesh

Representative Organisation

Down Syndrome Society of Bangladesh

Affiliate Organisation

Bangladesh Down Syndrome Association

Bangladesh Protibandhi Kallyan
Somity

Bhutan

Affiliate Organisation

Ability Bhutan Society

China

Representative Organisation

Macau Down Syndrome Association

Up for Downs China

Affiliate Organisation

Shanghai Hope Star Public Welfare
Development Center

Hong Kong, S.A.R, China

Representative Organisation

Hong Kong Down Syndrome
Association

India

Representative Organisation

Down Syndrome Federation of India

Affiliate Organisation

ALAN T21 Welfare Trust

Indonesia

Representative Organisation

Indonesia Down Syndrome Care
Foundation (YAPESDI)

Affiliate Organisation

Ikatan Sindroma Down Indonesia
(ISDI)

Japan

Representative Organisation

Japan Down Syndrome Society
(JDS)

Affiliate Organisation

DSIJ

Malaysia

Affiliate Organisation

Kiwanis Down Syndrome
Foundation

Maldives

Representative Organisation

Beautiful Eyes Down Syndrome
Association

Mongolia

Representative Organisation

Down Syndrome Association
Mongolia (DSAM)

Myanmar

Representative Organisation

Myanmar Down Syndrome
Association

Nepal

Representative Organisation

Down's Syndrome Association of
Nepal (DSAN)

Down Syndrome Society Nepal

Affiliate Organisation

Down Syndrome Support Health
Association Nepal

New Zealand

Representative Organisation

New Zealand Down Syndrome
Association

Pakistan

Representative Organisation

Karachi Down Syndrome Program

Pakistan Down Syndrome
Association (PDSA)

Philippines

Affiliate Organisation

Down Syndrome Association of the
Philippines, Inc.

Singapore

Representative Organisation

Down Syndrome Association
Singapore

South Korea

Representative Organisation

Korea Down Syndrome Society

Sri Lanka

Representative Organisation

Jinendhi Resource Centre for Down
Syndrome

Affiliate Organisation

Jinendhi Resource Centre for Down
Syndrome

Kosala Dullewa Foundation for
Children with Special Needs

Soulink Lanka

Taiwan

Affiliate Organisation

Down Syndrome Foundation ROC

Vietnam

Affiliate Organisation

My Future

Member organisations in Central Asia

Armenia

Representative Organisation

Sun Children

Georgia

Representative Organisation

Georgian Down Syndrome
Association

Kazakhstan

Affiliate Organisation

Solnechnyi Mir

Kyrgyzstan

Representative Organisation

Public Fund of Parents of Children with Down syndrome "Sunterra"

Affiliate Organisation

Luch Dobra (The Ray of Kindness)

Russia

Representative Organisation

Downside Up

Affiliate Organisation

Regional public organization "Time of Changes"

Tajikistan

Representative Organisation

Nazari Digar

Affiliate Organisation

Public Organisation of Parents of Children with Down Syndrome "SiDa"

Public Organisation Open Hearts

Turkey

Representative Organisation

Down Turkiye Down Sendromu Dernegi

Ukraine

Representative Organisation

Ukrainian Charitable Organization "Down Syndrome"

Uzbekistan

Representative Organisation

Downside Sport Uzbekistan

Member organisations in Europe

Regional

Affiliate Organisation

European Down Syndrome Association (EDSA)

Albania

Representative Organisation

Down Syndrome Albania Foundation

Jonathan Center

Austria

Representative Organisation

Down-Syndrom Österreich

Belgium

Representative Organisation

Down Syndrome Foundation Belgium

Affiliate Organisation

APEM T21

Downsyndroom Vlaanderen

Inclusion ASBL

Bosnia & Herzegovina

Representative Organisation

Udruzenje Zivot Sa Down Sindromom

Bulgaria

Representative Organisations

Association of the Parents of
Children with Down Syndrome

Life with Down Syndrome

Croatia

Representative Organisation

Croatian Down Syndrome
Association

Cyprus

Representative Organisation

Pan Cyprian Down Syndrome
Association

Denmark

Representative Organisation

Landsforeningen Downs Syndrom

Estonia

Representative Organisation

Downi Sundroomi Uhing / Down
Syndrome Association Estonia

France

Representative Organisation

Trisomie 21 France

Germany

Representative Organisation

Deutsches Down-Syndrom
InfoCenter

Gibraltar

Representative Organisation

Down's Syndrome Support Group
Gibraltar (DSSGG)

Greece

Representative Organisation

Down Syndrome Association of
Greece

Hungary

Affiliate Organisation

Down Egyesület

Ireland

Representative Organisation

Down Syndrome Ireland

Affiliate Organisation

The Down Syndrome Centre
(Ireland)

Italy

Representative Organisation

Associazione Italiana Persone
Down

Affiliate Organisation

Coordinamento Nazionale
Associazioni delle Persone con
Sindrome de Down (CoorDown)

Kosova

Representative Organisation

Down Syndrome Kosova

Lithuania

Representative Organisation

Down Syndrome Lithuania

Macedonia

Affiliate Organisation

Trisomija 21 - Skopje

Malta

Representative Organisation

Down Syndrome Association Malta

Malta

Affiliate Organisation

Inspire

Netherlands

Affiliate Organisation

Stichting Down Syndroom (SDS)

Norway

Representative Organisation

Norsk Nettverk for Down Syndrom
(NNDS)

Poland

Affiliate Organisations

Ja Tez

Jeden Swiat

Legnickie Stowarzyszenie Rodzin i
Przyjaciol Dzieci z Zespolem Downa
Otworz Serce

Zakatek 21 Society of Parents and
Friends of Children with Down
Syndrome

Zespoldowna.info

Portugal

Affiliate Organisation

Pais21

Romania

Affiliate Organisation

Asociatia Down Bucuresti

Asociatia Ioana-Maria

European Centre for the Rights of
Children with Disabilities

Russia

Representative Organisation

Downside Up

Affiliate Organisation

Regional public organization "Time
of Changes"

Slovakia

Representative Organisation

Spolocnost' Downovho Syndromu
na Slovensku

Spain

Representative Organisation

Down Espana

Affiliate Organisation

ASNIMO

Sweden

Representative Organisation

Svenska Downforeningen

Switzerland

Representative Organisation

Insieme 21

Avventuno

Affiliate Organisation

Light for Sight Foundation

Turkey

Representative Organisation

Down Türkiye Down Sendromu
Derneği

Ukraine

Representative Organisation

Ukrainian Charitable Organization
"Down Syndrome"

United Kingdom

Representative Organisation

Down's Syndrome Association (UK)

Down's Syndrome Scotland

Affiliate Organisation

Cheshire Down's Syndrome Support
Group

Down Syndrome Extra 21

Down Syndrome Medical Interest
Group UK and Ireland (DSMIG-UK)

Down Syndrome Research
Foundation UK

Down's Heart Group

Sports Union for Athletes with Down
Syndrome (SU-DS)

Member organisations in Middle East

Bahrain

Affiliate Organisation

Maan Centre for Special Education

Iran

Representative Organisation

Aseman Nili Down Syndrome
Association

Affiliate Organisation

Down Syndrome Association of
Gilan

Iraq

Representative Organisation

Down Syndrome Association of Iraq
(Hiba Centre for Down Syndrome)

Israel

Representative Organisation

Yated Down Syndrome Parents
Association

Jordan

Representative Organisation

Jasmine Association for Children
with Down Syndrome

Lebanon

Representative Organisation

Lebanese Down Syndrome
Association

Affiliate Organisation

National Rehabilitation and
Development Center (NRDC)

Oman

Representative Organisation

Oman Down Syndrome Association

Palestinian Territory

Representative Organisation

Al-Raheem (Down Syndrome
Friends) Association

Affiliate Organisation

Right to Live Society

Qatar

Representative Organisation

HOPE Qatar Center for children with
special needs

Affiliate Organisation

Qatar Institute for Speech and
Hearing

Saudi Arabia

Affiliate Organisation

Werathah

Help Center

Gester

Sudan

Affiliate Organisation

Skill Up Training Center

Syria

Affiliate Organisation

White Hearts

United Arab Emirates

Representative Organisation

Emirates Down Syndrome
Association

Yemen

Representative Organisation

Yemeni Down Syndrome Society
(YDSS)

**Member organisations in North
America**

Bahamas

Representative Organisation

The Bahamas Down Syndrome
Association and Center

Bermuda

Representative Organisation

Bermuda Down Syndrome Support
Group

Canada

Representative Organisation

Canadian Down Syndrome Society

Affiliate Organisation

Down Syndrome Resource
Foundation

T21 Association Ouest Africaine

Dominican Republic

Representative Organisation

Asociacion Dominicana de
Sindrome de Down

Grenada

Representative Organisation

Grenada Down Syndrome
Association

Jamaica

Representative Organisation

Jamaica Down's Syndrome
Foundation

Trinidad and Tobago

Representative Organisation

Down Syndrome Family Network

United States

Representative Organisation

National Down Syndrome Society
(NDSS)

Affiliate Organisation

Alexander's Angels, Inc.

LuMind IDSC Foundation

National Down Syndrome Congress
(NDSC)

San Diego Down Syndrome
Organisation

Down Syndrome Affiliates in Action

Member organisations in South and Central America

Argentina

Representative Organisation

Asociacion Sindrome de Down de la
Republica Argentina (ASDRA)

Brazil

Representative Organisation

Federacao Brasileira das
Associacoes Sindrome de Down

Affiliate Organisation

Instituto Alana

MetaSocial Institute

Movimento Down

Chile

Representative Organisation

Fundacion down 21 Chile

Affiliate Organisation

Pro Inclusion Rayos de Sol

Colombia

Representative Organisation

Fundacion Sindrome de Down del Caribe (Fundown Caribe)

Costa Rica

Representative Organisation

Fundacion El Futuro es de Todos

El Salvador

Representative Organisation

Fundacion Club de Amigos Especiales a Distancia de El Salvador (FUNCAEDES)

Guatemala

Representative Organisation

Asociacion Guatemalteca para el Sindrome de Down

Affiliate Organisation

Fundacion Margarita Tejada Para Sindrome Down

Honduras

Representative Organisation

Integrar, Fundacion Sindrome de Down, Honduras

Affiliate Organisation

Centro de Educacion Activa

Mexico

Representative Organisation

Fundacion John Langdon Down

Affiliate Organisation

Comunidad Educativa Incluyente

Taller de Expresion y Desarrollo Integral A.C. (TEDI)

Trisomia 21 A.C.

Nicaragua

Affiliate Organisation

Fundacion 21 Sindrome de Down Nicaragua

Panama

Affiliate Organisation

Fundacion Down Panama

SD Padres en Accion

Paraguay

Affiliate Organisation

Asociacion de Padres de Personas con Sindrome de Down de Itapua

Fundacion Saraki

Peru

Representative Organisation

Sociedad Peruana de Sindrome Down (SPSD)

Affiliate Organisation

Asociacion Proyecto Yannick

Venezuela

Representative Organisation

Asociacion Venezolana para el Sindrome de Down (AVESID)

Consolidated statement of financial activities (incorporating income and expenditure account)

For the year ended 31 March 2024

	Note	Unrestricted funds £	Restricted funds £	2023/24 total £	2022/23 total £
Income from:					
Donations and legacies	2	118,447	-	118,447	169,520
Charitable activities					
1. Policy and practice, information, advice and support	3	22,985	69,819	92,804	21,522
2. Network development and training	3	-	58,100	58,100	38,098
3. Advocacy and campaigning	3	16,000	37,790	53,790	16,398
Other trading activities	4	99,816	-	99,816	71,273
Total income		257,248	165,709	422,957	316,812
Expenditure on:					
Raising funds	5	139,766	-	139,766	140,347
Charitable activities					
1. Policy and practice, information, advice and support	5	22,666	69,819	92,486	78,811
2. Network development and training	5	21,905	52,577	74,483	85,128
3. Advocacy and campaigning	5	53,060	37,790	90,850	98,473
Total expenditure		237,398	160,187	397,585	402,758
Net income/(expenditure) for the year		19,850	5,523	25,372	(85,946)
Net movement in funds		19,850	5,523	25,372	(85,946)
Reconciliation of funds:					
Total funds brought forward		25,543	-	25,543	111,489
Total funds carried forward		45,392	5,523	50,915	25,543

All the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 11.

Balance Sheet			
As of 31 March 2024			
	Note	2023/24 £	2022/23 £
Fixed assets:			
Tangible assets		-	-
Investments		-	-
Total fixed assets:		-	-
Current assets:			
Stock			
Debtors		29,829	16,836
Accrued Gift Aid		1,048	2,402
Other current debtors		5,291	6,279
Cash at bank and in hand		43,432	60,745
Total current assets:		79,600	86,261
Liabilities:			
Creditors: amounts falling due within one year		25,258	53,726
Accrued expenses		3,427	6,993
Net current assets (liabilities):		50,915	25,543
Total net assets (liabilities):		50,915	25,543
Funds:	11		
Restricted income funds		5,523	-
Unrestricted income funds		45,392	25,543
Total funds:		50,915	25,543

- The company was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small companies.
- The member organisations have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.
- The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.
- These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies regime and in accordance with FRS102 SORP.

Approved by the trustees on 3 December 2024 and signed on their behalf by*:



Bridget Snedden – President, Board of Trustees

* This is also the signature of a director authenticating accounts being sent to Companies House.

Consolidated statement of cash flows			
For the year ended 31 March 2024			
	Note	2023/24 £	2022/23 £
Cash flows from operating activities:			
Net cash used in operating activities		(13,525)	(633)
Cash flows from investing activities:		-	
Net cash used in investing activities		-	-
Change in cash and cash equivalents in the year		(13,525)	(633)
Cash and cash equivalents at the beginning of the year		60,745	61,377
Cash and cash equivalents at the end of the year		47,220	60,745

Down Syndrome International
Notes to the financial statements
For the year ended 31 March 2024

1. Accounting policies

a) Statutory information

Down Syndrome International is a charitable company limited by guarantee and is incorporated in England. The registered office address is Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS. The principal place of business is 7/9 Chapel Street, Exmouth, Devon, EX8 1HR.

b) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (August 2014) and the Companies Act 2006.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

c) Public benefit entity

The charitable company meets the definition of a public benefit entity under FRS 102.

d) Going concern

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

There are no key judgements that the charitable company has made which have a significant effect on the accounts.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

e) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Income generated from the supply of goods or services is included in the statement of financial activities in the period in which the supply is made.

Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when received.

Revenue grants are credited to the statement of financial activities when received or receivable whichever is earlier.

Where unconditional entitlement to grants receivable is dependent upon fulfilment of conditions within the charity's control, the incoming resources are recognised when there is sufficient evidence that conditions will be met. Where there is uncertainty as to whether the charity can meet such conditions, the incoming resource is deferred.

Member organisation income is included in full in the statement of financial activities when received.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

f) Donations of gifts, services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item or received the service, any conditions associated with the donation have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), volunteer time is not recognised so refer to the trustees' annual report for more information about their contribution.

On receipt, donated gifts, professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

g) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

h) Fund accounting

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

i) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Expenditure is classified under the following activity headings:

- Costs of raising funds relate to the costs incurred by the charitable company in inducing third parties to make voluntary contributions to it, as well as the cost of any activities with a fundraising purpose.
- Expenditure on charitable activities includes the costs of delivering services and campaigning undertaken to further the purposes of the charity and their associated support costs.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

j) Allocation of support costs

Resources expended are allocated to the particular activity where the cost relates directly to that activity. However, the cost of overall direction and administration of each activity, comprising the salary and overhead costs of the central function, is apportioned on the following basis which are an estimate, based on staff time, of the amount attributable to each activity.

Where information about the aims, objectives and projects of the charity is provided to potential beneficiaries, the costs associated with this publicity are allocated to charitable expenditure.

Support and governance costs are re-allocated to each of the activities on the following basis, which is an estimate, based on staff time, of the amount attributable to each activity:

• Cost of raising funds	10%
• Policy and practice, information, support and advice	30%
• Network development and training	30%
• Advocacy and campaigning	30%

Governance costs are the costs associated with the governance arrangements of the charity. These costs are associated with constitutional and statutory requirements and include any costs associated with the strategic management of the charity's activities.

k) Operating leases

Rental charges are charged on a straight-line basis over the term of the lease.

l) Tangible fixed assets

Items of equipment are capitalised where the purchase price exceeds £1,000. Depreciation costs are allocated to activities on the basis of the use of the related assets in those activities. Assets are reviewed for impairment if circumstances indicate their carrying value may exceed their net realisable value and value in use.

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

• Leasehold improvements	5 years
• Fixtures and fittings	5 years
• Computer equipment	3 years

m) Listed investments

Investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the balance sheet date using the closing quoted market price. Any change in fair value will be recognised in the statement of financial activities and any excess of fair value over the historic cost of the investments will be shown as a fair value reserve in the balance sheet. Investment gains and losses, whether realised or unrealised, are combined and shown in the heading "Net gains/(losses) on investments" in the statement of financial activities. The charity does not acquire put options, derivatives or other complex financial instruments. Investments in subsidiaries are at cost.

n) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks. Donated items of stock, held for distribution or resale, are recognised at fair value which is the amount the charity would have been willing to pay for the items on the open market.

o) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

p) Short term deposits

Short term deposits include cash balances that are invested in accounts with a maturity date of between 3 and 12 months.

q) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account. Cash balances exclude any funds held on behalf of service users.

r) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

s) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

t) Pensions

Payments to the stakeholder pension scheme are charged as an expense as they fall due.

2. Income from donations and legacies				
For the year ended 31 March 2024				
	Unrestricted funds £	Restricted funds £	2023/24 total funds £	2022/23 total funds £
Gifts	81,328	-	81,328	122,542
Legacies	-	-	-	-
Donated services	37,119	-	37,119	46,978
Total income from donations and legacies	118,447	-	118,447	169,520

3. Income from charitable activities				
For the year ended 31 March 2024				
	Unrestricted funds £	Restricted funds £	2023/24 total funds £	2022/23 total funds £
International Disability Alliance (Listen Include Respect - IDA Bridge Consultation)	0	42,844	42,844	0
Instituto Alana (Listen Include Respect - Translations)	0	1,975	1,975	0
Down's Syndrome Association UK (Programme Team Funding)	0	25,000	25,000	0
National Lottery Community Fund (Supporting DSI Network)	20,000	0	20,000	0
Down Syndrome Australia (World Down Syndrome Congress Consultancy)	2,985	0	2,985	0
SightSavers via Inclusion International (Inclusive Participation Guidelines)	0	0	0	20,000
International Disability Alliance (Programme Team Funding)	0	0	0	3,521
International Disability Alliance (Inclusive Participation Guidelines)	0	0	0	(1,998)
Sub-total for Policy and Practice, Information, Support and Advice	22,985	69,819	92,804	21,523
The Clare Milne Trust (Inclusive Organisations - DSI Staff Member with Down Syndrome)	0	7,100	7,100	0
Down's Syndrome Association UK (Programme Team Funding)	0	25,000	25,000	0
International Disability Alliance (Programme Team Funding)	0	0	0	3,521
Norwegian Agency for Development Cooperation via International Disability Alliance (NORAD Project)	0	0	0	11,577
W F Southall Trust (Rwanda Capacity Development)	0	0	0	3,000
Down's Syndrome Association UK (Inclusive Orgs Training)	0	26,000	26,000	20,000
Sub-total for Network Development and Training	0	58,100	58,100	38,098
Down's Syndrome Association UK (Programme Team Funding)	0	25,000	25,000	0
National Down Syndrome Society United States (World Down Syndrome Day Partnership)	16,000	0	16,000	0
International Disability Alliance (World Down Syndrome Day Conference)	0	12,000	12,000	0
International Disability Alliance (Programme Team Funding)	0	0	0	3,521
Norwegian Agency for Development Cooperation via International Disability Alliance (NORAD Project)	0	0	0	10,747
Instituto Alano (World Down Syndrome Day Conference)	0	0	0	1,350
Mission Japan to UN (World Down Syndrome Day Conference)	0	790	790	780
Sub-total for Advocacy and Campaigning	16,000	37,790	53,790	16,398
Total income from charitable activities	38,985	165,709	204,694	76,018

4. Income from other trading activities				
For the year ended 31 March 2024				
	Unrestricted funds £	Restricted funds £	2023/24 total funds £	2022/23 total funds £
Fundraising events	25,258	-	25,258	-
Trading	74,558	-	74,558	71,273
Total income from other trading activities	99,816	-	99,816	71,273

5. Analysis of expenditure		Charitable activities						
	Cost of Raising Funds £	Policy and Practice, Information, Support, Advice £	Network Development Training £	Advocacy Campaigning £	Governance Costs £	Support Costs £	2023/24 Total £	2022/23 Total £
Staff costs (Note 7)	51,189	44,610	46,187	44,610	24,783	15,869	227,249	225,361
Cost of operating online shop	42,452	-	-	-	-	-	42,452	36,408
Fundraising event and other fundraising costs	1,559	-	-	-	-	-	1,559	848
Advertising, marketing and publicity	37,101	1,463	1,463	1,463	-	-	41,489	52,630
Grant making for projects and activities	-	-	-	-	-	-	0	20,328
Spending on projects and activities	-	23,791	4,211	22,156	-	-	50,158	37,359
Office running costs and equipment	-	-	-	-	-	12,112	12,112	9,212
Consultants and professional fees	-	-	-	-	48	1,486	1,534	573
Rent, insurance and maintenance	-	-	-	-	-	11,616	11,616	10,071
Travel, meetings and conferences	-	227	227	227	1,185	-	1,867	2,881
Management, communications, finance, data and storage operational Systems	-	-	-	-	-	7,548	7,548	7,088
Sub-total	132,301	70,092	52,089	68,456	26,016	48,632	397,585	402,758
Support costs	4,863	14,590	14,590	14,590	-	48,632		
Governance costs	2,602	7,805	7,805	7,805	26,016			
Total expenditure	139,766	92,486	74,483	90,850			397,585	

6. Grant making		
For the year ended 31 March 2024		
	2023/24 total funds £	2022/23 total funds £
Rwanda Down Syndrome Organisation	-	2,455
Down Syndrome Society of Kenya	-	6,730
Down Syndrome Foundation Nigeria	-	6,310
Inclusion Uganda	-	4,833
Total grant making	-	20,328

7. Analysis of staff costs, trustee remuneration/expenses and cost of key management personnel		
For the year ended 31 March 2024		
	2023/24 total funds £	2022/23 total funds £
Salaries and wages	196,369	197,747
Social security costs	18,191	18,839
Employer's contribution to defined pension schemes	10,694	5,625
Total staff costs	225,254	222,210

1 employee earned more than £60,000 during the year (2022/23: 1). The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £134,991.45 (2022/23: £128,652.33).

The charity trustees were neither paid nor received any other benefits from employment with the charity in the year (2022/23: £nil). No charity trustee received payment for professional or other services supplied to the charity (2022/23: £nil).

Trustees' expenses represent the payment or reimbursement of travel, accommodation and subsistence costs totalling £1,184.66 (2022/23: £0) incurred by 3 persons (2022/23: 0) relating to participation in project activities and governance meetings.

8. Staff numbers - average numbers of employees (head count based on number of staff employed) during the year		
For the year ended 31 March 2024		
	2023/24 No.	2022/23 No.
Raising funds	1	1
Charitable activities	3	6
Support	3	3
Governance	1	1
Total staff numbers	8	11

9. Related party transactions

There are no donations from or to related parties which are outside the normal course of business.

Membership fee transactions have taken place during the year with many member organisations of Down Syndrome International. Organisation Membership requires a fee and in exchange basic support and advice is provided, member organisations participate as partners or stakeholders in our activities and we promote our member organisations' work. The maximum annual fee charged for Organisation Membership is £300.

Some DSi member organisations purchase merchandise from our shop related to World Down Syndrome Day for sale or distribution in their own countries. DSi also makes grants to certain member organisations, as set out in note 6 of these notes to the accounts.

The Down's Syndrome Association (DSA) is a member of DSi. DSi uses office space at DSA's headquarters. The Chief Executive of DSA, Carol Boys, is a trustee of Down Syndrome International. DSi's Executive Director, Andrew Boys, is Carol's son. DSA is the payroll agency for DSi.

General donations and restricted grants are given by DSA to DSi to support our work. Donations for certain events and activities organised together are shared equally.

DSA made the following payments to DSi during the year:	2023/24 £	2022/23 £
Donations and grants	40,000	42,500
Membership fee	300	300
Income to fund Inclusive Participation Training UK	26,000	20,000
Income to fund Programme Team	75,000	0
Merchandise	15,498	10,962
Total	156,798	73,762

DSi made the following payments to DSA during the year:	2023/24 £	2022/23 £
Merchandise	1,090	1,906
Total	1,090	1,906

DSi received £20,960 funds (2022/23: £2,350) from 3 (2022/23: 2) other member organisations in 2023/24 - £2,985 from Down Syndrome Australia, £16,000 from National Down Syndrome Society and £1,975 (2022/23: £1,350) from Instituto Alana.

DSi received grants of £54,844 (2022/23: £30,889) from International Disability Alliance (IDA) in 2023/24 for various projects. DSi is a member of IDA.

10. Taxation

The charity is exempt from corporation tax. All its income is charitable and is applied for charitable purposes.

11. Movement in funds (current year)					
For the year ended 31 March 2024					
	At the start of the year £	Incoming resources and gains £	Outgoing resources and funds £	Transfers £	At the end of the year £
Restricted funds:					
Listen Include Respect - IDA Bridge Consultation	-	42,844	42,844	-	-
Listen Include Respect - Translations	-	1,975	1,975	-	-
Inclusive Organisations Training	-	26,000	26,000	-	-
Inclusive Organisations - DSI Staff Member with Down Syndrome	-	7,100	1,577	-	5,523
Programme Team Funding	-	75,000	75,000	-	-
World Down Syndrome Day Conference	-	12,790	12,790	-	-
Total restricted funds	-	165,709	160,187	-	5,523
Unrestricted funds:					
Designated funds:					
Supporting DSI Network	-	20,000	10,000	-	10,000
World Down Syndrome Day Partnership	-	16,000	16,000	-	-
World Down Syndrome Congress Consultancy	-	2,985	2,985	-	-
Total designated funds	-	38,985	28,985	-	10,000
General funds	25,543	218,263	208,413	-	35,393
Total unrestricted funds	25,543	257,248	237,398	-	45,393
Total funds	25,543	422,957	397,585	-	50,915

Purpose of restricted funds

Listen Include Respect - IDA Bridge Consultation

Consultation on how to make the BRIDGE CRPD-SDGs training more accessible for people with intellectual disabilities. BRIDGE CRPD-SDGs is a training programme developed and run by IDA and International Disability and Development Consortium (IDDC). It helps advocates with disabilities speak up for their rights. Survey, workshop and report completed.

Listen Include Respect - Translations

Translating the Listen Include Respect guidelines into Portuguese. Self-advocates took part in consultations to make sure that the translations stayed in plain language and were accessible for people with intellectual disabilities.

Inclusive Organisations Training

Working with the Down's Syndrome Association to train self-advocates with Down syndrome in the UK to become consultants on inclusive organisations. Training completed and they will go on to work as consultants for the Down's Syndrome Association, consulting with UK government departments, as well as international disability and development NGOs, training staff to include people with intellectual disabilities in policy making and government consultations.

Inclusive Organisations - DSI Staff Member with Down Syndrome

Recruited a permanent staff member with Down syndrome, Emma Bishop, as Programme Officer. Emma is an advocate for the rights of people with disabilities, who has spoken at the UN Conference of State Parties (COSP) on disability.

Programme Team Funding

Funding for the salaries of our programme team, to enable much of our work on crucial projects and the development and delivery of our strategy.

World Down Syndrome Day Conference

13th World Down Syndrome Day Conference, which took place over two days in New York. Launch of campaign and project on health equity. Event attended by people with Down syndrome, families, organisation and government representatives and many health stakeholders. People with Down syndrome involved in planning and speaking at the event.

Purpose of designated funds

Supporting DSI Network

Developing and signposting to resources and information to help people with Down syndrome and their families get support. Putting people in contact with our member organisations to get the support they need at the local level.

World Down Syndrome Day Partnership

Working with National Down Syndrome Society and the Down's Syndrome Association to bring WDSD to public attention. Running WDSD website and social media pages. Promoting theme "End the Stereotypes". Delivering awareness and advocacy messages. Partnering with CoorDown on their 2024 video "Assume that I can". Running Lots of Socks campaign.

World Down Syndrome Congress Consultancy

Working with Down Syndrome Australia to help plan the next World Down Syndrome Congress, taking place in Brisbane in July 2024. The Congress is an event where people and organisations come together to share experiences and best practices.

12. Legal status of the charity

The charity is a company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £10.

Accounts

DOWN SYNDROME INTERNATIONAL (DSi)



REPORT OF TRUSTEES (AND DIRECTORS) AND FINANCIAL STATEMENTS

for the period from 1 April 2022 to 31 March 2023

Reference and administrative information

Company number	04327941
Country of incorporation	United Kingdom
Charity number	1091843
Country of registration	England and Wales

Registered Office

Down Syndrome International
Langdon Down Centre
2A Langdon Park
Teddington
Middlesex
TW11 9PS
United Kingdom

Operational Address

Down Syndrome International
7/9 Chapel Street
Exmouth
Devon
EX8 1HR
United Kingdom

Trustees

The trustees are the members of the DSi board.

They are also the company directors.

The trustees who served during this year were:

B Snedden	(President)
R Faragher	(Vice President)
JP Clarke	(Treasurer)
V dos Santos	
P Robertson	
C Boys	
J Tang	
A L Arellano	
D Warkcup	

Principal Staff

A Boys (Executive Director)
 (Company Secretary)

Principal Bankers

HSBC
16 King Street
Covent Garden
London
WC2E 8JF

Solicitors

Russell Cooke
2 Putney Hill
London
SW15 6AB

Introduction

In this document, the trustees of DSi are sharing a report and financial statements for the year ending 31 March 2023.

These statements cover the last 12 months, starting from 1 April 2022.

The information in the “Reference and administrative information” section above, is part of this report.

These financial statements follow:

- the rules required by the law (known as statutory requirements).
- the rules of DSi (our articles of association).
- a set of recommended accounting rules for charities (the Statement of Recommended Practice – Accounting and Reporting by Charities: SORP FRS 102).

For a list of our member organisations, please refer to Annex 1.

Because our organisation earned more than £25,000 in the year ending 31 March 2023, we had to get an independent examination of our financial statements.

Objectives and activities

Charity objects

DSi has charity “objects” which are written in our official document (our articles of association). The objects are:

- To promote and protect the physical and mental health of those with Down syndrome through the provision of support and resources to people with Down syndrome, their families and carers, and the professionals who work with them with specific focus on developing countries.
- To undertake any other charitable activities in connection with Down syndrome and other learning disabilities as the trustees shall determine.

These objects tell the Charity Commission of England and Wales what we are trying to achieve and what kinds of activities we do.

The Charity Commission are appointed by the UK government to check we are doing work charities should do and that we are doing it in the right way.

Our purpose, vision, activities and strategy

DSi’s purpose is to improve quality of life for people with Down syndrome worldwide and promote their human rights.

We have a long-term vision of people with Down syndrome living healthy and meaningful lives in the community.

DSi leads an international network of member organisations carrying out activities, providing support, advice, information, training, and representation for the global Down syndrome community.

These activities are part of a plan (known as our strategy) which helps us to deliver goals we set for ourselves, which then contribute to our vision.

We are currently working on a new plan (strategy) which will be published in October 2023.

We always make sure we follow guidelines from the Charity Commission (on public benefit) when making any plans and decisions.

How our activities help people (how we deliver public benefit)

Our work is all about helping people with Down syndrome to have opportunities to live better lives. We speak up for their human rights so that they will have these opportunities.

We work with our network of member organisations to represent people with Down syndrome and their families, making sure that it is people with Down syndrome themselves who can speak up.

This report describes what we have achieved this year to help people. All our activities deliver public benefit and happen for the purpose DSi was set up.

Who uses and benefits from our services?

DSi is a worldwide organisation with member organisations from 121 countries. We are an international organisation of persons with disabilities (OPD).

We work on national, regional, and global projects to improve the lives and the human rights of people with Down syndrome.

There are about 7 million people with Down syndrome worldwide. Since we opened our international office in 2009, we have seen a big increase in demand for our services.

We review our strategy and activities every year. This report looks at what we have achieved and how our work has helped the people we aim to support. It also helps us make sure we stay focused on our purpose and our goals.

Achievements and performance

The work we do is based on 3 approaches:

1. Policy and practice, information, support and advice

- We play a leading role globally working on new policies, documents and other published information about issues that affect people with Down syndrome.
- We work with our member organisations and partners to make sure accurate information is available.
- We give advice and help to member organisations and others when they need it.

2. Network development and training

- We make our member organisation network stronger by involving member organisations in all our work and improving communication.
- We develop and support networks, alliances and advocacy groups among our member organisations.
- We provided training to help our member organisations and those who represent them.

3. Advocacy and campaigning

- We run worldwide campaigns and events.
- We support local, regional and global activities that fight for the rights of people with Down syndrome.
- We take part in international meetings on disability and human rights to represent the global Down syndrome community.



Most of this work will involve one or more of these issues that affect a lot of people with Down syndrome:

- **the right to an education**
- **the right to work**
- **the right to health**
- **being included in important decision making**

The next part of this report will summarise all of our activities from April 2022 to March 2023.

The report is split into projects that fit within the 3 approaches on the previous page.

Many of these projects provide examples of work on the issues listed above.

1. Policy and practice, information, support and advice

Launch of the Listen Include Respect guidelines

In June 2022 we launched the Listen Include Respect guidelines.

These are guidelines for organisations on how to include people with intellectual disabilities. We developed them with Inclusion International (II).

We launched the guidelines at the Conference of State Parties (COSP) in New York. This is a conference about the UN Convention on the Rights of Persons with Disabilities (CRPD).

Self-advocates working on this project with DSI and II explained how the guidelines were created and how they can be used by giving practical examples.

This project was funded partly by International Disability Alliance (IDA), SightSavers and II.



World Down Syndrome Congress (WDSC)

We have been working with Down Syndrome Australia to help plan the next World Down Syndrome Congress, in Brisbane 2024.

The Congress is an event where people and organisations come together to share experiences and best practices.

The Congress happens every few years and we support them to make sure it goes well.



Review of heart conditions in people with Down syndrome

In January 2023, our review on understanding heart conditions in people with Down syndrome was published in the Circulation medical journal.

Heart conditions that require operations or treatment are very common in people with Down syndrome. But the quality of care people get is not always good.

We worked with a team of heart experts from around the world to write the review.

The team looked carefully at research that has taken place. They also asked DSi and our member organisations what we think.

The team then wrote the review that gives great advice to all heart doctors and other health professionals. The review talks about the conditions to look out for and what can be done to provide good care.

This review will improve medical care around the world for people with Down syndrome who have heart conditions.

This project was funded by Janssen.



Working as a member of the International Disability Alliance

We continued our work as a full member of the International Disability Alliance (IDA). IDA and its members work together as a global alliance representing persons with disabilities from around the world.

We advocate for disability rights at the United Nations and in international development work.

Within IDA we make sure the voices of people with Down syndrome and their families are heard and push for inclusive projects and programmes.

Providing resources and information on Down syndrome

One important job of DSi is to make sure people with Down syndrome and their families have the information they need to help with challenges.

People with Down syndrome can have problems with getting good healthcare, doing well in school, getting a job and in other areas of life. The COVID-19 pandemic made many challenges even harder.

We work every year to provide information and support and show people where help is available from our member organisations and others in countries around the world.

This project is partly funded by National Lottery Community Fund.

2. Network development and training

Lessons learned workshop in Rwanda

In November 2022 we organised a 4-day workshop in Kigali, Rwanda, with our member organisations from Kenya, Nigeria, Rwanda and Uganda.

This workshop happened at the end of our 2020 to 2023 employment advocacy project, in partnership with IDA. The project was funded by the Norwegian Agency for Development Cooperation (NORAD).



16 people, including 4 self-advocates with Down syndrome, came to the workshop.

The workshop helped our member organisations plan future employment advocacy. It also helped us see what went well in the project and areas we can improve on next time.

Inclusive employment reports

We supported our member organisations in Kenya, Nigeria, Rwanda and Uganda to write research reports on inclusive employment.

They spoke to people with intellectual disabilities, family members, employers and others about barriers and good practices in employment.

The reports were published in December 2022 and translated into local languages: Kinyarwanda, Luganda, Nigerian Pidgin and Swahili. Member organisations also ran webinars to share their findings.

This was part of our 2020 to 2023 employment advocacy project, in partnership with IDA and funded by NORAD.

Turkey visit



We visited Down Türkiye, our member in Turkey.

We visited the office and a school with the Down Türkiye team and self-advocates.

We also met with leaders of Down Türkiye. We asked them how they are doing as an organisation and how DSi can provide more help to continue the great work they are doing.

Rwanda fundraising support

We worked with the Rwanda Down Syndrome Organisation to help them get better at raising money. This is so they can carry on their important work supporting people with Down syndrome in Rwanda.

We helped them to review their fundraising and plan how to raise the money they need in the future.

This project was funded by The Southall Trust.



Preparation for UK Listen Include Respect project

In January 2023 we began preparing for our new UK Listen Include Respect project.

In this project we will work with the Down's Syndrome Association to train self-advocates with Down syndrome to become consultants on inclusive organisations.

We consulted with our Listen Include Respect working group and created a work plan for the project. We also started looking at training materials and plans for how to recruit the right people to work on the project.

This project is funded by the Down's Syndrome Association.

Ambassadors work

We have a committee of people with Down syndrome called the DSi ambassadors. They represent the DSi member organisations in their countries.



There are currently ambassadors from 19 countries.

We meet monthly with the ambassadors to discuss important topics and work on projects.

Some examples from this year included:

- Doing research about self-advocacy in their countries.
- Helping us create a plan for future self-advocacy work.
- Creating and running a new training on good support for people with intellectual disabilities.
- Running a self-advocacy workshop for a conference in South Africa.

Ambassadors in programme strategy working group

In August 2022, DSi ambassadors Stuart Campbell from Scotland and Janet Charchuk from Canada joined our programme strategy working group.

This is a working group of the DSi board that meets on Zoom every 3 months. The group discusses work we are doing and plans for the future. The group then gives advice and recommends things to the DSi board.

Stuart and Janet have been active and made valuable contributions in every meeting. They have helped us to understand how to make all of our governance more accessible.

We will be using what we have learned to improve all our governance processes, including our board meetings and working with our network.

Inclusive organisation review and action plan

This year the DSi staff team conducted a review of how inclusive DSi is.

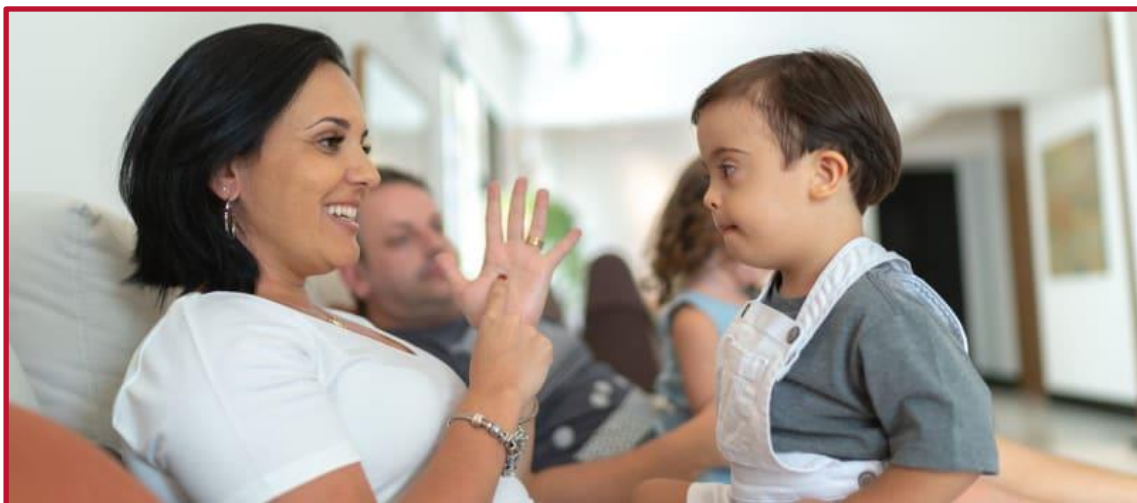
We looked at all areas of the organisation and discussed where we are now and where we want to be. We used these conversations to make an action plan.

This action plan lists everything we want to do to be more inclusive.

All departments within DSi are taking clear steps towards being more inclusive. We are reviewing this plan regularly.

This project is part of our work to support organisations to become more inclusive. We made a process for organisations to check how inclusive they are and make a plan to improve. We then tested this on ourselves.

We are using the Listen Include Respect guidelines (see page 8) to take action. Of course, we hope that other organisations will do the same, especially our member organisations.



Making a new strategy for the DSi network

This year we made a lot of progress with our new strategy for DSi. This is a plan for how our network will work together to make the world better.

Our staff, board of trustees, ambassadors and member organisations have all been working on this new Strategy.

We prepared to make a new strategy by:

- looking at other organisations' strategies and reviewing our activities.
- looking at why people with Down syndrome are excluded in society and what can make this better.

We wrote updated statements of who we are and our purpose. We also created principles that we must follow in all our work.

Then we created long-term goals for the DSi network and looked at how best to achieve them.

We will publish the strategy in an accessible format in October 2023.

3. Advocacy and campaigning

Africa employment advocacy

This year we supported member organisations in Kenya, Nigeria, Rwanda and Uganda with employment advocacy.



They worked with their self-advocacy groups to speak up for inclusive employment in their countries.

Self-advocates spoke to lots of organisations and government officials, and one even went on a TV talk show.

This was part of our 2020 to 2023 employment advocacy project, in partnership with IDA. The project was funded by the Norwegian Agency for Development Cooperation (NORAD).

Uganda visit

In May 2022 we visited Uganda and ran a workshop about employment advocacy with self-advocates.



We had previously supported our members in Uganda to start a self-advocacy group for people with Down syndrome and intellectual disabilities.

In this workshop self-advocates shared their experiences of work and the challenges they have faced. They also talked about their rights to employment.

This was part of our 2020 to 2023 employment advocacy project, in partnership with IDA and funded by NORAD.

UK inclusive education research and advocacy project

This year we completed our inclusive education project in the UK.

We did lots of research about how inclusive the UK education system is. We also advocated for it to be more inclusive. Project activities included:

- Talking to students, families, teachers and other people involved in the education system.
- Publishing a weekly education blog series, with over 25 blogs going out to an education mailing list of over 1000 people.
- Developing a collection of written and video education resources.
- Running 2 webinars with over 400 people attending.

We worked with our member organisations in the UK, Down's Syndrome Association and Down's Syndrome Scotland. This project was funded by Down's Syndrome Association.

Listen Include Respect advocacy

We did lots of advocacy work to push for organisations to use the Listen Include Respect guidelines. Some examples include:

- Presenting to organisations at the Conference of State Parties (COSP) in New York. This is a conference about the UN Convention on the Rights of Persons with Disabilities (CRPD).
- Online presentations to lots of different international organisations.

- Running a stakeholder group for international organisations using the guidelines.

We want organisations to follow the guidelines, so they are more inclusive of people with intellectual disabilities.

World Down Syndrome Day 2023

On the 21st of March every year, we bring the global Down syndrome community together for World Down Syndrome Day (WDSD).

The theme for 2023 was “With Us Not For Us”. This was decided by consultations with our member organisations and ambassadors.



This was the first year since the COVID-19 pandemic that we could have in-person events at the United Nations in New York and Geneva:

- New York – World Down Syndrome Conference – about legal capacity, supported decision making and easy-to-understand communication.

- Geneva – side event to the Committee on the Rights of Persons with Disabilities – about easy-to-understand communication.

People with Down syndrome were involved in planning and speaking at the events. We had a diverse range of speakers from around the world.

We stayed on in New York to meet with UN agencies about the Listen Include Respect guidelines.

We also run the WDSO website and the WDSO social media pages. This provides online places where anyone around the world can go to learn more about the day and see how they can take part.

We run the Lots of Socks campaign too. We ask people worldwide to wear interesting socks on 21st March, to get people talking about WDSO.

Overall WDSO goes from strength to strength, bringing in people from the Down syndrome and disability community, but also the general public.

Zero Conference

This year, we attended the Zero Conference at the UN Office in Vienna, Austria.



Robin from the programme team attended with Bethan Kendrick, a self-advocate from the Down's Syndrome Association (UK).

They talked about the Listen Include Respect guidelines and the importance of easy-to-understand communication.

Kami – virtual influencer

In 2022 we helped create Kami, the first virtual influencer with Down syndrome. Kami was made using the portraits of over 100 women with Down syndrome from around the world.

The aim of Kami is to push for digital spaces to be more inclusive.

Kami was created together with creative agency Forsman & Bodenfors (F&B) and global digital modelling agency The Diigitals.



Other international advocacy work

We did lots of other advocacy work throughout the year, including:

- On a Resolution by the UN General Assembly about easy-to-understand communication.

- Working with Virtus to campaign for a new impairment category in the Paralympics, so that athletes with Down syndrome can take part.
- On the World Health Organization's new health equity report.
- Working with the UK Foreign, Commonwealth & Development Office on its new guidance for engaging with organisations of persons with disabilities.
- On US AID's update to its LGBT policy.
- On the International Fund for Agricultural Development's new disability policy.
- As part of a Technical Advisory Group on Negative Stereotyping & Livelihoods, part of the Disability Inclusive Livelihoods programme.



Raising funds

To keep DSi running well and helping those who need us, we need money.

We have 2 types of income:

- **Restricted income** – this is money we receive that we have to spend on projects. We agree detailed budgets with the organisations who provide this money.
- **Unrestricted income** – this is money we receive that we can spend on anything, as long as it is for DSi. So, we can spend this on projects if we need to. But we can also spend it on other things that help keep DSi running. Or we can save it (as reserves) to keep DSi financially stable.

Restricted income - April 22 to March 23

This year restricted income went down.

We did already have some of the money in the bank that we needed to do projects this year. Also, some of our projects ended this year, so we did not receive any money to use for next year.

But the money we received this year for projects did not include enough to cover what it costs us to pay staff to manage the projects. So, we had to use some of our unrestricted income for this.

To meet the growing demand for our work, we need to find more money for projects. This will pay for us to do projects, including paying staff to manage them.

We are carefully planning how we can find more money in our financial and fundraising strategies.

Unrestricted income - April 22 to March 23

This year unrestricted income also went down.

The main reason for this was that a 2-year funding agreement with an organisation came to an end.

Other than this, we achieved similar levels of unrestricted income from things like donations from people and companies, donations from trusts and foundations and sales of merchandise.

We are confident that these things will continue to deliver income in future years.

As mentioned in the previous section, currently we need to raise lots of unrestricted funds to pay for our projects.

If we can find new restricted funding for projects, this will make unrestricted money available to spend on other important things we need to do.

Importantly this will also help us to save some money as reserves, to keep DSi financially stable.



Financial review

Income

In the 12 months starting from 1 April 2022 (2022-23), DSi's total income was £316,812. This was a lot less than in the 12 months from 1 April 2021 (2021-22), when it was £413,569.

Restricted income went down a lot in 2022-23 compared to 2021-22.

We already had some of the money in the bank that we needed to do projects this year. Also, some of our projects ended this year, so we did not receive any money to use for next year.

But overall, we did not receive as much income for projects as we hoped to.

We received money from Norwegian Agency for Development Cooperation to complete our employment advocacy project in Africa.

We also received money from International Disability Alliance (IDA) to contribute to paying our project staff.

We received money from SightSavers to work with Inclusion International on our Listen Include Respect Guidelines.

We also received money from our member organisation the Down's Syndrome Association (DSA) to deliver training on inclusive participation.

Unrestricted income in 2022-23 also went down compared to 2021-22.

This was due to a 2-year funding agreement with a charitable trust ending.

But we did achieve similar levels to last year of unrestricted income from things like donations from people and companies, small donations from trusts and foundations and sales of merchandise.

Expenditure (costs)

In the 12 months starting from 1 April 2022 (2022-23), DSi's total costs were £402,758. This was more than in the 12 months from 1 April 2021 (2021-22), when it was £359,482.

Part of this extra cost happened because we spent more money we had received for projects in this year, compared to last year.

Another key reason for this is that we made a decision to increase staff salaries to a more fair level compared to others in the charity sector.

Other costs remained at similar levels to previous years.

Overall

When we subtract our costs from our income, we achieve an overall financial position for the year. This might be a surplus (if we had more income than costs) or a deficit (if we had more costs than income).

In the 12 months starting from 1 April 2022 (2022-23), DSi had a deficit of £85,946. This compares to the 12 months from 1 April 2021 (2021-22), when we had a surplus of £54,087.

We also have some money saved (total funds) that we carry over from previous years. We carried over £111,489 from 2021-22.

When we subtract this year's deficit from total funds we carried over from last year, this leaves us with total funds on 31 March 2023 of £25,543.

Some of last year's total funds carried over were restricted and we spent all of this. So, the total funds of £25,543 we have is all unrestricted.

We have a policy (reserves policy) which requires DSi to keep a certain amount of unrestricted funds saved (called "free reserves"). At the end of this year, we have a lot less free reserves than we should have.

So, after this year, we really need to manage our finances carefully and we need very good financial and fundraising strategies to help us become more financially stable.

Reserves policy and going concern

We have a policy (reserves policy) which requires DSi to keep a certain amount of unrestricted funds saved (called “free reserves”).

The policy says that we should keep between 3 and 6 months of our annual costs in reserve.

Based on our 2022-23 costs (£402,758), 3 months reserves would be £100,690 and 6 months would be £201,379.

At this level the trustees agree that if our income dropped suddenly, we would still be able to continue doing our work.

The trustees also agree that if income did drop suddenly, we would think very carefully about how to replace that income or reduce our costs.

Our free reserves for 2022-23 are £25,543. This means we have less than 1-month costs in reserve, compared to the minimum of 3 months required by our policy.

We do have something in our accounts called gifts in kind. This is where people or organisations provide us with free things, but because those things have a value, we include them both as income and costs. We would still be able to do our work without these things.

This year the gifts in kind were £46,978. This makes DSi’s costs look a bit bigger than they really are. If you take this out of our costs, this shows we have about 1-month costs in reserve. But this is still a lot less than the 3 months minimum required.

DSi also has an overdraft agreement with creditor the Down’s Syndrome Association (DSA). DSA pays staff for DSi and DSi repays DSA every quarter. DSA allows an overdraft facility to DSi, up to a maximum of £35,000, to help DSi if we cannot repay DSA when it asks for the quarterly repayment.

Risk Management

We look carefully at risks to DSi. We have a policy for risk and also a risk management plan.

We decide which risks are most important and we take any action we can to reduce the risks that could have a negative impact on DSi. Some of the most important risk areas are:

Funding: We don't have money saved (reserves). A sudden loss of funding could mean we run out money and have to stop what we do. So, we focus on trying to get new funding and long-term funding from different people and organisations.

Leadership: It is important we have good leaders to take us forward and keep everyone at DSi happy. Our leaders will change as time passes. We need to make sure when that happens, our new leaders will be just as good. So, we plan for what will happen when leadership changes.

Staff: It is important that our staff feel happy to work for us and believe that they are important to DSi's success. So, we treat them well, we ask them how they are doing, we ask them what they think about DSi and we listen to what they tell us.

Project activities: We need to do our project work well. We need to do what we say we will do. Our projects need to be completed on time and at the same cost we agreed. We also need to make a big impact. So, we make sure we check how we are doing, we ask others how we are doing and we always try to do things better.

Operational systems: We have a small staff team and we have a lot of different things we need to do to keep DSi running well and following the law. So, we use software and we have systems to help us do all of these things in the right way, as quickly and as cheaply as we can.

Reputation: It is really important that everyone we work with believes DSi is a good organisation and trusts us. So, we make sure all of our work is relevant to people and makes an impact. We also make sure we are run really well. We listen to what people tell us and we always try to make good decisions.

Plans for the future

Activities we have planned for next year starting 1 April 2023 include:

Policy and practice, information, support and advice

- In August 2023 we will be launching our new World Down Syndrome Awards. These are awards aimed at sharing projects, achievements or practices that make the lives of people with Down syndrome better.
- Next year we will be just 1 year away from the World Down Syndrome Congress in Brisbane, Australia. We will be supporting Down Syndrome Australia to get things ready. We will be looking for speakers and we hope people will sign up to come.
- We will work with a number of large international organisations to help them become more inclusive, using the Listen Include Respect guidelines.

Network development and training

- Using funding from The Clare Milne Trust, we will employ a person with Down syndrome to join the DSi team, in our office in Exmouth.
- The DSi board of trustees will appoint a person with Down syndrome to join the board. This will be the first time a person with Down syndrome has been on the board.
- We will support the Down's Syndrome Association to launch a new campaign to promote inclusive education in the UK.
- We will create a clear description of the DSi ambassador and the support person roles. This will be used to recruit new ambassadors.

- We will publish our new 10-year strategy in October 2023.
- We will be do some research with member organisations to understand how they are working on human rights and advocacy.
- The ambassadors will continue to work with and influence the work of DSi.
- We will launch a UK Listen Include Respect project, to train self-advocates with Down syndrome to become consultants on inclusive organisations.

Advocacy and campaigning

- In June 2023 we will attend the Conference of State Parties (COSP). We will support people with Down syndrome to speak up about the right to easy-to-understand communication.
- We will attend the International Congress and Convention Association (ICCA) Middle East Summit, to talk about inclusive conferences.
- We will organise activities for World Down Syndrome Day 2024. This will include deciding on a theme and an advocacy campaign, organising our UN conferences in New York and Geneva, running the website and social media pages and running the Lots of Socks awareness campaign.
- We will continue our international advocacy work to speak up for the rights of people with Down syndrome.

Raising funds

- We will try to find more funds for our projects from different types of organisations who make project grants. So that we do not have to use money we want to keep in reserves.
- We will try to increase funds we get from donations, events and sales so that we can save more and improve our reserves position.
- We will look for new ways to raise money and grow our organisation. But make we are financially safe so we can keep doing what we do.



Structure, governance, and management

DSi is a company (a charitable company limited by guarantee) and is also a registered charity.

We became a company on 23 November 2001 and we became a charity on 1 May 2002.

DSi was started by a legal document called our Articles of Association.

This document has information about what our purpose is, what we need to do and what we cannot do.

We also have a Code of Governance. This guidance document helps our trustees know what their responsibilities are and how we all need to behave.

The Code of Governance also has a guide on how trustees come on to the board and how they leave the board.

All of the trustees are volunteers and receive no benefits from DSi.

Any expenses trustees reclaim from the charity are very small and can be seen in note 7 of the accounts.



Members and trustees

Charity members and other members

Our legal document (Articles of Association) says that we have members (who we can call the “charity members”) who have a vote at all important meetings, like the annual general meeting.

The charity members are all individual people and they are different from our member organisations.

The charity members are also the trustees. When you become a trustee of DSi you also become a charity member. When you are no longer a trustee, you are no longer a charity member.

We are also able to have other types of members, but our legal document is clear that these members are not charity members and so they do not have a vote at important meetings.

We have 2 other types of members at the moment:

- Representative members – for organisations only.
- Affiliate members – for organisations only.

Appointment of trustees

The board of trustees manages the business of the charity.

We currently have 9 trustees.

All trustees are elected by the charity members and we can have between 5 and 21 trustees.

Each time we have an annual general meeting (AGM), one third of the trustees must retire. To make it fair this happens on a rotation system. So, each trustee gets 3 years before they retire.

When trustees retire, they have the option to seek re-election. If they do this, then the other trustees decide by vote if they will re-elect each person.

The trustees can also vote to bring in new trustees at other times of year for a specific reason. If they do this, the new trustee will be in their post until the next AGM. Then they can seek re-election alongside the other trustees who are retiring.

Recruitment of trustees

A policy on how to recruit trustees can be found in our Code of Governance.

The trustees must be open and honest in any search for new people.

Trustees must be aware of the legal rules on who can and cannot be a trustee.

Trustees should consider whether any candidates might have “conflicts of interest”. This is something that might make a trustee act in a certain way that is not in the best interests of DSi.

The trustees should look for people with the right skills to join, especially if there are skills that the current board does not have. But this is not the only thing to consider.

As a priority, we should ask our representative member organisations first if they have candidates to consider. Then we should ask our affiliate member organisations. After this we can look wider.

The trustees need to make sure that:

- 55% of the board are people with Down syndrome or family members.
- There is a maximum of 2 people from any country.
- There is at least 1 person from Europe, North America, South America, Africa, Asia and Australia (continent).

- At least 25% of the board are from “developing economies” (defined by International Monetary Fund’s World Economic Outlook Report, April 2015).

Induction of new trustees

All trustees must understand the charity’s purpose and aims and their duties and responsibilities.

They are then able to explain this to new trustees.

The trustees must make sure that they, rather than staff, have overall responsibility for inducing new trustees.

The board should provide all new trustees with induction material, such as governing documents, annual reports, meeting minutes, strategy and management documents.

This allows new trustees to understand their charitable purposes, financial position and current issues.



Related parties and connected organisations

DSi works with many Down syndrome, disability and international development organisations worldwide.

We have a close working relationship with the Down's Syndrome Association (DSA) in United Kingdom. We share a registered office with DSA in Teddington. We also share some resources and we have a funding agreement.

We receive membership organisation fees and we work on projects with many member organisations throughout the world. See Annex 1 for a list of our member organisations.

At the regional level, we support the work of European Down Syndrome Association, African Down Syndrome Network, Federación Iberoamericana de Síndrome de Down (Latin America) and Asia Pacific Down Syndrome Federation.

DSi is in special consultative status with the Economic and Social Council of the United Nations (UN).

DSi is a member of International Disability Alliance (IDA)

We also work with Inclusion International on projects.

Remuneration (pay) policy

We pay our staff fairly to get the best people for the job while using our money wisely.

We decide on what to pay people by looking at what other people in similar charity roles get (on average) and we set our salaries at the same level.

All DSi staff get a pay rise every year based on changes to the cost of living where they live. In the UK (where most of our staff live) this is normally a 3% increase.

DSi will go ahead with these pay rises unless we cannot for financial reasons.

Any changes to this method of giving pay rises must be agreed by the trustees.

Some staff may get a higher pay rise if there are reasons for it. This must be agreed by the trustees.

Pay rises start from the start of the financial year, which is 1 April.

The trustees look at how well the executive director is doing and decide what to pay that person specifically each year.

They will look at how the executive director is doing based on performance targets they have set for the person. They will also think about what they need to pay to keep the best person for the job.

Fundraising

We make sure all the fundraising we do follows the rules and regulations charities must follow.

We always talk to our supporters in a fair and honest way.

We protect people who support us by keeping their information secure. We do not put pressure on people to give us money. We ask people if we can contact them.

We do all of our own fundraising. No one has ever complained about us.

The trustees reviewing fundraising activities regularly.



Statement of responsibilities of the trustees

The trustees (who are also the company directors of DSi) are responsible for writing this trustees' annual report and the financial statements.

The trustees make sure we have followed the law and accounting standards in the UK (United Kingdom Generally Accepted Accounting Practice) when writing this report.

Company law requires the trustees to write financial statements for each financial year which:

- give a true and fair view of DSi's financial position.
- provide details of the money coming in and how that money was spent, over the year (accounting period).

When writing this report, the trustees have to:

- choose good accounting methods and use them in all of the report.
- use the methods in the charity accounting standards (SORP).
- make sensible decisions.
- say whether we have used UK accounting standards and give details where we have not.
- write the financial statements based on the idea that DSi will continue to operate, unless we are not going to.

The trustees have to keep good accounting records that:

- can show accurately our financial position at any time.
- can show we comply with the Companies Act 2006.

The trustees must also keep the financial assets of DSi safe. So, they must try to prevent financial crimes like fraud and other bad behaviour. To the best of the trustees' knowledge:

- there is no audit information that our auditor does not know about.
- we have taken all steps we need to make sure we know about all audit information and the auditor does too.

The trustees are responsible for keeping all company and financial information on our website up to date and true.

Laws in the United Kingdom on financial statements might be different to laws in other countries.

Members of the charity (charity members) guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up.

The total number of such guarantees on 31 March 2023 was 9 (2022: 9).

The trustees are members of the charity, but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Independent examiner

DSi as a company has taken advantage of the small companies' exemption in preparing the report above.

The following person was appointed to carry out an independent examination of these accounts:

Mr Luke Burns
Fellow Member of the Association of Chartered Certified Accountants (ACCA)
65 Bulmershe Road, Reading, RG1 5RH, UK.

Trustee approval

The trustees' annual report has been approved by the trustees on 24 October 2023 and signed on their behalf by:



Bridget Snedden
President
Board of Trustees



Section A

Independent Examiner's Report

Report to the trustees	Down Syndrome International		
On accounts for the year ended	31 March 2023	Charity no (if any)	1091843
Set out on pages			

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2023**

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants (ACCA).

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

06/10/2023

Name:

Mr Luke Burns

Relevant professional
qualification(s) or body
(if any):

Fellow of the Association of Chartered Certified Accountants (ACCA)

Address:

1 Century Drive

Reading
RG7 1PE

Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

No material matters have come to my attention during the examination.

Annex 1: Member organisations

Member organisations in Africa

Botswana

Representative Organisation

Down's Syndrome Association of Botswana

Cameroon

Representative Organisation

Aidrikings Foundation

Congo

Affiliate Organisation

Lenire Asbl

Eritrea

Affiliate Organisation

National Association of Intellectual/Developmental Disability in Eritrea (NAIDDE)

Ethiopia

Affiliate Organisation

Ethiopian National Association on Intellectual Disabilities

Ghana

Representative Organisation

Robb Foundation

Affiliate Organisation

Inclusion Ghana

Kenya

Representative Organisation

Down Syndrome Society of Kenya

Liberia

Affiliate Organisation

My Heart's Appeal Inc

Libya

Representative Organisation

Libyan Down Syndrome Association

Madagascar

Representative Organisation

Down Syndrome Madagascar

Mauritius

Representative Organisation

Down Syndrome Association Mauritius

Morocco

Representative Organisation

Association Marocaine de Soutien et d'Aide aux Personnes Trisomiques (AMSAT)

Nigeria

Representative Organisation

Down Syndrome Foundation Nigeria

Affiliate Organisations

Larger Than I Developmental Foundation

Moyinoluwa Rainbow Foundation

Rwanda

Representative Organisation

Rwanda Down Syndrome Organisation (RDSO)

South Africa

Representative Organisation

Down Syndrome South Africa

Tanzania

Representative Organisation

Pearl of People with Down Syndrome Foundation

Affiliate Organisation

Elimisha

Morogoro Saving the Poor Organization

Togo

Representative Organisation

APAPE - Down Syndrome Togo

Tunisia

Affiliate Organisation

AMED (Association Mon Enfant Est Different)

Uganda

Representative Organisation

The Uganda Down Syndrome Association (TUDSA)

Affiliate Organisation

Inclusion Uganda

Angel's Center for Children with Special Needs

EmbraceKulture

Rowan's Down Syndrome Awareness Centre

Zimbabwe

Representative Organisation

Zimbabwe Down Syndrome Association

Member organisations in Asia Pacific

Australia

Representative Organisation

Down Syndrome Australia

Affiliate Organisation

e.motion 21

Bangladesh

Representative Organisation

Down Syndrome Society of Bangladesh

Affiliate Organisation

Bangladesh Down Syndrome
Association

Bhutan

Affiliate Organisation

Ability Bhutan Society

China

Representative Organisation

Macau Down Syndrome Association

Affiliate Organisation

Shanghai Hope Star Public Welfare
Development Center

Hong Kong, S.A.R, China

Representative Organisation

Hong Kong Down Syndrome
Association

India

Representative Organisation

Down Syndrome Federation of India

Affiliate Organisation

ALAN T21 Welfare Trust

Indonesia

Representative Organisation

Indonesia Down Syndrome Care
Foundation (YAPESDI)

Affiliate Organisation

Ikatan Sindroma Down Indonesia
(ISDI)

Japan

Representative Organisation

Japan Down Syndrome Society
(JDS)

Affiliate Organisation

DSIJ

Malaysia

Affiliate Organisation

Kiwanis Down Syndrome
Foundation

Maldives

Representative Organisation

Beautiful Eyes Down Syndrome
Association

Mongolia

Representative Organisation

Down Syndrome Association
Mongolia (DSAM)

Myanmar

Representative Organisation

Myanmar Down Syndrome
Association

Nepal

Representative Organisation

Down's Syndrome Association of
Nepal (DSAN)

Down Syndrome Society Nepal

New Zealand

Representative Organisation

New Zealand Down Syndrome Association

Pakistan

Representative Organisation

Karachi Down Syndrome Program

Pakistan Down Syndrome Association (PDSA)

Philippines

Affiliate Organisation

Down Syndrome Association of the Philippines, Inc.

Singapore

Representative Organisation

Down Syndrome Association Singapore

South Korea

Representative Organisation

Korea Down Syndrome Society

Sri Lanka

Representative Organisation

Jinendhi Resource Centre for Down Syndrome

Affiliate Organisation

Jinendhi Resource Centre for Down Syndrome

Kosala Dullewa Foundation for Children with Special Needs

Soulink Lanka

Taiwan

Affiliate Organisation

Down Syndrome Foundation ROC

Vietnam

Affiliate Organisation

My Future

Member organisations in Central Asia

Armenia

Representative Organisation

Sun Children

Georgia

Representative Organisation

Georgian Down Syndrome Association

Kazakhstan

Affiliate Organisation

Solnechnyi Mir

Kyrgyzstan

Representative Organisation

Public Fund of Parents of Children with Down syndrome "Sunterra"

Affiliate Organisation

Luch Dobra (The Ray of Kindness)

Russia

Representative Organisation

Downside Up

Affiliate Organisation

Regional public organization "Time of Changes"

Tajikistan

Representative Organisation

Nazari Digar

Affiliate Organisation

Public Organisation of Parents of Children with Down Syndrome "SiDa"

Public Organisation Open Hearts

Turkey

Representative Organisation

Down Turkiye Down Sendromu Dernegi

Ukraine

Representative Organisation

Ukrainian Charitable Organization "Down Syndrome"

Uzbekistan

Representative Organisation

Downside Sport Uzbekistan

Member organisations in Europe

Regional

Affiliate Organisation

European Down Syndrome Association (EDSA)

Albania

Representative Organisation

Down Syndrome Albania Foundation

Jonathan Center

Austria

Representative Organisation

Down-Syndrom Österreich

Belgium

Representative Organisation

Down Syndrome Foundation Belgium

Affiliate Organisation

APEM T21

Downsyndroom Vlaanderen

Inclusion ASBL

Bosnia & Herzegovina

Representative Organisation

Udruzenje Zivot Sa Down Syndromom

Bulgaria

Representative Organisations

Association of the Parents of
Children with Down Syndrome

Life with Down Syndrome

Croatia

Representative Organisation

Croatian Down Syndrome
Association

Cyprus

Representative Organisation

Pan Cyprian Down Syndrome
Association

Denmark

Representative Organisation

Landsforeningen Downs Syndrom

Estonia

Representative Organisation

Downi Sundroomi Uhing / Down
Syndrome Association Estonia

France

Representative Organisation

Trisomie 21 France

Germany

Representative Organisation

Deutsches Down-Syndrom
InfoCenter

Gibraltar

Representative Organisation

Down's Syndrome Support Group
Gibraltar (DSSGG)

Greece

Representative Organisation

Down Syndrome Association of
Greece

Hungary

Affiliate Organisation

Down Egyesület

Ireland

Representative Organisation

Down Syndrome Ireland

Affiliate Organisation

The Down Syndrome Centre
(Ireland)

Italy

Representative Organisation

Associazione Italiana Persone
Down

Affiliate Organisation

Coordinamento Nazionale
Associazioni delle Persone con
Sindrome de Down (CoorDown)

Kosova

Representative Organisation

Down Syndrome Kosova

Lithuania

Representative Organisation

Down Syndrome Lithuania

Macedonia

Affiliate Organisation

Trisomija 21 - Skopje

Malta

Representative Organisation

Down Syndrome Association Malta

Malta

Affiliate Organisation

Inspire

Netherlands

Affiliate Organisation

Stichting Down Syndroom (SDS)

Norway

Representative Organisation

Norsk Nettverk for Down Syndrom
(NNDS)

Poland

Affiliate Organisations

Ja Tez

Jeden Swiat

Legnickie Stowarzyszenie Rodzin i
Przyjaciol Dzieci z Zespolem Downa
Otworz Serce

Zakatek 21 Society of Parents and
Friends of Children with Down
Syndrome

Zespoldowna.info

Portugal

Affiliate Organisation

Pais21

Romania

Affiliate Organisation

Asociatia Down Bucuresti

Asociatia Ioana-Maria

European Centre for the Rights of
Children with Disabilities

Russia

Representative Organisation

Downside Up

Affiliate Organisation

Regional public organization "Time
of Changes"

Slovakia

Representative Organisation

Spolocnost' Downovho Syndromu
na Slovensku

Spain

Representative Organisation

Down Espana

Affiliate Organisation

ASNIMO

Sweden

Representative Organisation

Svenska Downforeningen

Switzerland

Representative Organisation

Insieme 21

Avventuno

Affiliate Organisation

Light for Sight Foundation

Turkey

Representative Organisation

Down Türkiye Down Sendromu
Derneği

Ukraine

Representative Organisation

Ukrainian Charitable Organization
"Down Syndrome"

United Kingdom

Representative Organisation

Down's Syndrome Association (UK)

Down's Syndrome Scotland

Affiliate Organisation

Cheshire Down's Syndrome Support
Group

Down Syndrome Extra 21

Down Syndrome Medical Interest
Group UK and Ireland (DSMIG-UK)

Down Syndrome Research
Foundation UK

Down's Heart Group

Sports Union for Athletes with Down
Syndrome (SU-DS)

Member organisations in Middle East

Bahrain

Affiliate Organisation

Maan Centre for Special Education

Iran

Representative Organisation

Aseman Nili Down Syndrome
Association

Affiliate Organisation

Down Syndrome Association of
Gilan

Iraq

Representative Organisation

Down Syndrome Association of Iraq
(Hiba Centre for Down Syndrome)

Israel

Representative Organisation

Yated Down Syndrome Parents
Association

Jordan

Representative Organisation

Jasmine Association for Children
with Down Syndrome

Lebanon

Representative Organisation

Lebanese Down Syndrome Association

Affiliate Organisation

National Rehabilitation and Development Center (NRDC)

Oman

Representative Organisation

Oman Down Syndrome Association

Palestinian Territory

Representative Organisation

Al-Raheem (Down Syndrome Friends) Association

Affiliate Organisation

Right to Live Society

Qatar

Representative Organisation

HOPE Qatar Center for children with special needs

Saudi Arabia

Affiliate Organisation

Werathah

Help Center

Gester

Sudan

Affiliate Organisation

Skill Up Training Center

Syria

Affiliate Organisation

White Hearts

United Arab Emirates

Representative Organisation

Emirates Down Syndrome Association

Yemen

Representative Organisation

Yemeni Down Syndrome Society (YDSS)

Member organisations in North America

Bahamas

Representative Organisation

The Bahamas Down Syndrome Association and Center

Bermuda

Representative Organisation

Bermuda Down Syndrome Support Group

Canada

Representative Organisation

Canadian Down Syndrome Society

Affiliate Organisation

Down Syndrome Resource Foundation

T21 Association Ouest Africaine

Dominican Republic

Representative Organisation

Asociacion Dominicana de
Sindrome de Down

Grenada

Representative Organisation

Grenada Down Syndrome
Association

Jamaica

Representative Organisation

Jamaica Down's Syndrome
Foundation

Trinidad and Tobago

Representative Organisation

Down Syndrome Family Network

United States

Representative Organisation

National Down Syndrome Society
(NDSS)

Affiliate Organisation

Alexander's Angels, Inc.

LuMind IDSC Foundation

National Down Syndrome Congress
(NDSC)

San Diego Down Syndrome
Organisation

Down Syndrome Affiliates in Action

Member organisations in South and Central America

Argentina

Representative Organisation

Asociacion Sindrome de Down de la
Republica Argentina (ASDRA)

Brazil

Representative Organisation

Federacao Brasileira das
Associacoes Sindrome de Down

Affiliate Organisation

Instituto Alana

MetaSocial Institute

Movimento Down

Chile

Representative Organisation

Fundacion down 21 Chile

Affiliate Organisation

Pro Inclusion Rayos de Sol

Colombia

Representative Organisation

Fundacion Sindrome de Down del
Caribe (Fundown Caribe)

Costa Rica

Representative Organisation

Fundacion El Futuro es de Todos

El Salvador

Representative Organisation

Fundacion Club de Amigos
Especiales a Distancia de El
Salvador (FUNCAEDES)

Guatemala

Representative Organisation

Asociacion Guatemalteca para el
Sindrome de Down

Affiliate Organisation

Fundacion Margarita Tejada Para
Sindrome Down

Honduras

Representative Organisation

Integrar, Fundacion Sindrome de
Down, Honduras

Affiliate Organisation

Centro de Educacion Activa

Mexico

Representative Organisation

Fundacion John Langdon Down

Affiliate Organisation

Comunidad Educativa Incluyente

Taller de Expresion y Desarrollo
Integral A.C. (TEDI)

Trisomia 21 A.C.

Nicaragua

Affiliate Organisation

Fundacion 21 Sindrome de Down
Nicaragua

Panama

Affiliate Organisation

Fundacion Down Panama

SD Padres en Accion

Paraguay

Affiliate Organisation

Asociacion de Padres de Personas
con Sindrome de Down de Itapua

Fundacion Saraki

Peru

Representative Organisation

Sociedad Peruana de Sindrome
Down (SPSD)

Affiliate Organisation

Asociacion Proyecto Yannick

Venezuela

Representative Organisation

Asociacion Venezolana para el
Sindrome de Down (AVESID)

Consolidated statement of financial activities (incorporating income and expenditure account)

For the year ended 31 March 2023

	Note	Unrestricted funds £	Restricted funds £	2022/23 total £	2021/22 total £
Income from:					
Donations and legacies	2	169,520	-	169,520	197,290
Charitable activities					
1. Policy and practice, information, advice and support	3		21,522	21,522	22,390
2. Network development and training	3		38,098	38,098	48,560
3. Advocacy and campaigning	3	2,130	14,268	16,398	75,899
Other trading activities	4	71,273	-	71,273	69,430
Total income		242,923	73,888	316,812	413,569
Expenditure on:					
Raising funds	5	140,347	-	140,347	118,639
Charitable activities					
1. Policy and practice, information, advice and support	5	32,484	46,326	78,811	67,145
2. Network development and training	5	32,811	52,317	85,128	92,473
3. Advocacy and campaigning	5	53,974	44,499	98,473	81,224
Total expenditure		259,616	143,142	402,758	359,482
Net income/(expenditure) for the year		-16,693	-69,253	-85,946	54,087
Net movement in funds		-16,693	-69,253	-85,946	54,087
Reconciliation of funds:					
Total funds brought forward		42,236	69,253	111,489	57,402
Total funds carried forward		25,543	-	25,543	111,489

All the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 11.

Balance Sheet			
As of 31 March 2023			
	Note	2022/23 £	2021/22 £
Fixed assets:			
Tangible assets		-	-
Investments		-	-
Total fixed assets:			-
Current assets:			
Stock			
Debtors		16,836	105,376
Accrued Gift Aid		2,402	-
Other current debtors		6279	764
Cash at bank and in hand		60,745	61,377
Total current assets:		86,261	167,517
Liabilities:			
Creditors: amounts falling due within one year		53,726	52,568
Accrued expenses		6,993	-
Member organisation fees paid in advance		-	3,460
Net current assets (liabilities):		25,543	111,489
Total net assets (liabilities):		25,543	111,489
Funds:	11		
Restricted income funds		-	69,253
Unrestricted income funds		25,543	42,236
Total funds:		25,543	111,489

- The company was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small companies.
- The member organisations have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.
- The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.
- These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies regime and in accordance with FRS102 SORP.

Approved by the trustees on 24 October 2023 and signed on their behalf by*:



Bridget Snedden – President, Board of Trustees

** This is also the signature of a director authenticating accounts being sent to Companies House.*

Consolidated statement of cash flows			
For the year ended 31 March 2023			
	Note	2022/23 £	2021/22 £
Cash flows from operating activities:			
Net cash used in operating activities		(633)	(4,423)
Cash flows from investing activities:			
Net cash used in investing activities		-	-
Change in cash and cash equivalents in the year		(633)	(4,423)
Cash and cash equivalents at the beginning of the year		61,377	65,801
Cash and cash equivalents at the end of the year		60,745	61,377

**Down Syndrome International
Notes to the financial statements
For the year ended 31 March 2023**

1. Accounting policies

a) Statutory information

Down Syndrome International is a charitable company limited by guarantee and is incorporated in England. The registered office address is Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS. The principal place of business is 7/9 Chapel Street, Exmouth, Devon, EX8 1HR.

b) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (August 2014) and the Companies Act 2006.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

c) Public benefit entity

The charitable company meets the definition of a public benefit entity under FRS 102.

d) Going concern

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

There are no key judgements that the charitable company has made which have a significant effect on the accounts.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

e) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Income generated from the supply of goods or services is included in the statement of financial activities in the period in which the supply is made.

Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when received.

Revenue grants are credited to the statement of financial activities when received or receivable whichever is earlier.

Where unconditional entitlement to grants receivable is dependent upon fulfilment of conditions within the charity's control, the incoming resources are recognised when there is sufficient evidence that conditions will be met. Where there is uncertainty as to whether the charity can meet such conditions, the incoming resource is deferred.

Member organisation income is included in full in the statement of financial activities when received.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

f) Donations of gifts, services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item or received the service, any conditions associated with the donation have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), volunteer time is not recognised so refer to the trustees' annual report for more information about their contribution.

On receipt, donated gifts, professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

g) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

h) Fund accounting

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

i) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Expenditure is classified under the following activity headings:

- Costs of raising funds relate to the costs incurred by the charitable company in inducing third parties to make voluntary contributions to it, as well as the cost of any activities with a fundraising purpose.
- Expenditure on charitable activities includes the costs of delivering services and campaigning undertaken to further the purposes of the charity and their associated support costs.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

j) Allocation of support costs

Resources expended are allocated to the particular activity where the cost relates directly to that activity. However, the cost of overall direction and administration of each activity, comprising the salary and overhead costs of the central function, is apportioned on the following basis which are an estimate, based on staff time, of the amount attributable to each activity.

Where information about the aims, objectives and projects of the charity is provided to potential beneficiaries, the costs associated with this publicity are allocated to charitable expenditure.

Support and governance costs are re-allocated to each of the activities on the following basis, which is an estimate, based on staff time, of the amount attributable to each activity:

• Cost of raising funds	25%
• Policy and practice, information, support and advice	25%
• Network development and training	25%
• Advocacy and campaigning	25%

Governance costs are the costs associated with the governance arrangements of the charity. These costs are associated with constitutional and statutory requirements and include any costs associated with the strategic management of the charity's activities.

k) Operating leases

Rental charges are charged on a straight-line basis over the term of the lease.

l) Tangible fixed assets

Items of equipment are capitalised where the purchase price exceeds £1,000. Depreciation costs are allocated to activities on the basis of the use of the related assets in those activities. Assets are reviewed for impairment if circumstances indicate their carrying value may exceed their net realisable value and value in use.

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

• Leasehold improvements	5 years
• Fixtures and fittings	5 years
• Computer equipment	3 years

m) Listed investments

Investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the balance sheet date using the closing quoted market price. Any change in fair value will be recognised in the statement of financial activities and any excess of fair value over the historic cost of the investments will be shown as a fair value reserve in the balance sheet. Investment gains and losses, whether realised or unrealised, are combined and shown in the heading "Net gains/(losses) on investments" in the statement of financial activities. The charity does not acquire put options, derivatives or other complex financial instruments. Investments in subsidiaries are at cost.

n) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks. Donated items of stock, held for distribution or resale, are recognised at fair value which is the amount the charity would have been willing to pay for the items on the open market.

o) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

p) Short term deposits

Short term deposits include cash balances that are invested in accounts with a maturity date of between 3 and 12 months.

q) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account. Cash balances exclude any funds held on behalf of service users.

r) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

s) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

t) Pensions

Payments to the stakeholder pension scheme are charged as an expense as they fall due.

2. Income from donations and legacies				
For the year ended 31 March 2023				
	Unrestricted funds £	Restricted funds £	2022/23 total funds £	2021/22 total funds £
Gifts	122,542	-	122,542	157,714
Legacies	-	-	-	-
Donated services	46,978	-	46,978	39,576
Total income from donations and legacies	169,520	-	169,520	197,290

3. Income from charitable activities				
For the year ended 31 March 2023				
	Unrestricted funds £	Restricted funds £	2022/23 total funds £	2021/22 total funds £
Inclusion International (Inclusive Participation Guidelines)	-		-	3,750
SightSavers via Inclusion International (Inclusive Participation Guidelines)	-	20,000	20,000	-
International Disability Alliance (Programme Team Funding)	-	3,521	3,521	12,740
International Disability Alliance (Inclusive Participation Guidelines)	-	(1,998)	(1,998)	5,900
Sub-total for Policy and Practice, Information, Support and Advice	-	21,522	21,522	22,390
Down Turkiye (Self-Advocacy Consultancy)	-	-	-	1,590
Down Syndrome Albania Foundation (Self-Advocacy Consultancy)	-	-	-	250
International Disability Alliance (Programme Team Funding)	-	3,521	3,521	12,740
Norwegian Agency for Development Cooperation via International Disability Alliance (NORAD Project)	-	11,577	11,577	33,980
W F Southall Trust (Rwanda Capacity Development)	-	3,000	3,000	-
Down's Syndrome Association UK (Inclusive Participation Training)	-	20,000	20,000	-
Sub-total for Network Development and Training	-	38,098	38,098	48,560
Down's Syndrome Association UK (Inclusive Education Study)	-	-	-	50,000
Centre for Acceleration of Social Technology CAST (Communication Solutions for People with Down Syndrome)	-	-	-	5,000
International Disability Alliance (Programme Team Funding)	-	3,521	3,521	12,740
International Disability Alliance via COVID-19 Pooled Fund - UK Aid (COVID-19 Project)	-	-	-	1,010
International Disability Alliance via Inclusion Works Consortium - UK Aid (Inclusion Works Project)	-	-	-	7,149
Norwegian Agency for Development Cooperation via International Disability Alliance (NORAD Project)	-	10,747	10,747	-
Instituto Alano (World Down Syndrome Day Conference)	1,350	-	1,350	-
Permanent Mission of Japan to UN (World Down Syndrome Day Conference)	780	-	780	-
Sub-total for Advocacy and Campaigning	2,130	14,268	16,398	75,899
Total income from charitable activities	2,130	73,888	76,018	146,848

4. Income from other trading activities				
For the year ended 31 March 2023				
	Unrestricted funds £	Restricted funds £	2022/23 total funds £	2021/22 total funds £
Fundraising events	-	-	-	-
Trading	71,273	-	71,273	69,430
Total income from other trading activities	71,273	-	71,273	69,430

5. Analysis of expenditure		Charitable activities						
	Cost of Raising Funds £	Policy and Practice, Information, Support, Advice £	Network Development Training £	Advocacy Campaigning £	Governance Costs £	Support Costs £	2022/23 Total £	2021/22 Total £
Staff costs (Note 7)	39,737	42,810	53,549	59,325	6,849	23,092	225,361	196,157
Cost of operating online shop	36,408	-	-	-	-	-	36,408	40,250
Fundraising event and other fundraising costs	848	-	-	-	-	-	848	1,433
Advertising, marketing and publicity	48,446	1,395	1,395	1,395	-	-	52,630	50,238
Grant making for projects and activities	-	-	10,614	9,714	-	-	20,328	32,015
Spending on projects and activities	-	19,653	4,618	13,087	-	-	37,359	9,902
Office running costs and equipment	-	-	-	-	-	9,212	9,212	9,735
Consultants and professional fees	-	-	-	-	48	525	573	1,048
Rent, insurance and maintenance	-	-	-	-	-	10,071	10,071	11,081
Travel, meetings and conferences	-	44	44	44	2,748	0	2,881	117
Management, communications, finance, data and storage operational Systems	-	-	-	-	-	7,088	7,088	7,504
Sub-total	125,439	63,902	70,219	83,565	9,645	49,988	402,758	359,482
Support costs	12,497	12,497	12,497	12,497	-	49,988		
Governance costs	2,411	2,411	2,411	2,411	9,645			
Total expenditure 2022/23	140,347	78,811	85,128	98,473			402,758	

6. Grant making		
For the year ended 31 March 2023		
	2022/23 total funds £	2021/22 total funds £
Rwanda Down Syndrome Organisation	2,455	10,731
Down Syndrome Society of Kenya	6,730	4,752
Down Syndrome Foundation Nigeria	6,310	4,800
Inclusion Uganda	4,833	7,904
Down Syndrome Society of Bangladesh	-	3,829
At the end of the year	20,328	32,015

7. Analysis of staff costs, trustee remuneration/expenses and cost of key management personnel		
For the year ended 31 March 2023		
	2022/23 total funds £	2021/22 total funds £
Salaries and wages	197,747	174,452
Social security costs	18,839	14,377
Employer's contribution to defined pension scheme	5,625	4,903
Total	222,210	193,732

1 employee earned more than £60,000 during the year (2021/22: £nil). The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £128,652.33 (2021/22: £124,427.18).

The charity trustees were neither paid nor received any other benefits from employment with the charity in the year (2021/22: £nil). No charity trustee received payment for professional or other services supplied to the charity (2021/22: £nil).

Trustees' expenses represent the payment or reimbursement of travel, accommodation and subsistence costs totalling £0 (2021/22: £0) incurred by 0 (2021/22: 0) member organisations relating to participation in project activities and governance meetings.

8. Staff numbers - average numbers of employees (head count based on number of staff employed) during the year		
For the year ended 31 March 2023		
	2022/23 No.	2021/22 No.
Raising funds	1	1
Charitable activities	6	7
Support	3	3
Governance	1	1
Total	11	12

9. Related party transactions

There are no donations from or to related parties which are outside the normal course of business.

Membership fee transactions have taken place during the year with many member organisations of Down Syndrome International. Organisation Membership requires a fee and in exchange basic support and advice is provided, member organisations participate as partners or stakeholders in our activities and we promote our member organisations' work. The maximum annual fee charged for Organisation Membership is £300.

Some DSi member organisations purchase merchandise from our shop related to World Down Syndrome Day for sale or distribution in their own countries. DSi also makes grants to certain member organisations, as set out in note 6 of these notes to the accounts.

The Down's Syndrome Association (DSA) is a member of DSi. DSi uses office space at DSA's headquarters. The Chief Executive of DSA, Carol Boys, is a trustee of Down Syndrome International. DSi's Executive Director, Andrew Boys, is Carol's son. DSA is the payroll agency for DSi.

General donations and restricted grants are given by DSA to DSi to support our work. Donations for certain events and activities organised together are shared equally.

DSA made the following payments to DSi during the year:	2022/23 £	2021/22 £
Donations and grants	42,500	56,000
Member organisation fee	300	180
Income to fund Inclusive Education UK Pilot Study	-	50,000
Income to fund Inclusive Participation Training UK	20,000	-
Merchandise	10,962	25,040
Total	73,762	131,220

DSi made the following payments to DSA during the year:	2022/23 £	2021/22 £
Merchandise	1,906	-
Total	1,906	-

DSi received £2,350 funds in 2022/23 (2021/22: £4,655) from 2 (2021/22: 3) other member organisations in 2022/23 - £1,000 from Down Syndrome Cheshire and £1,350 from Instituto Alana.

DSi received grants of £30,889 in 2022/23 (2021/22: £86,259) from International Disability Alliance (IDA) for various projects. DSi is a member of IDA. DSi also received £20,000 grants (2021/22: £3,750) from fellow IDA member and project partner Inclusion International.

10. Taxation

The charity is exempt from corporation tax. All its income is charitable and is applied for charitable purposes.

11. Movement in funds (current year)					
For the year ended 31 March 2023					
	At the start of the year £	Incoming resources and gains £	Outgoing resources and funds £	Transfers £	At the end of the year £
Restricted funds:					
NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa	3,630	22,325	25,955	-	-
Inclusive education UK pilot study	21,710	-	21,710	-	-
International guidelines for inclusive participation of people with intellectual disabilities	1,932	18,002	19,934	-	-
DSi programme team funding	28,665	10,562	39,227	-	-
Consensus statement on cardiac disorders in people with Down syndrome	13,317	-	13,317	-	-
Inclusive participation training UK	-	20,000	20,000	-	-
Rwanda fundraising capacity development	-	3,000	3,000	-	-
Total restricted funds	69,253	73,888	143,142	-	-
Unrestricted funds:					
Designated funds:					
The National Lottery Community Fund – resources, information and support	-	10,000	10,000		
World Down Syndrome Day	-	12,487	12,487	-	-
Total designated funds	-	22,487	22,487	-	-
General funds	42,236	220,436	237,129	-	25,543
Total unrestricted funds	42,236	242,923	259,616	-	25,543
Total funds	111,489	316,812	402,758	-	25,543

Purposes of restricted funds

NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa

Technical human rights training and COVID-19 advocacy training for our member organisations in Kenya, Nigeria, Rwanda and Uganda and self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda. Supporting all these organisations to deliver employment and COVID-19 related advocacy.

Inclusive education UK pilot study

A 12-month study researching the current state of inclusive education in the UK. Extensive consultation with a wide range of stakeholders to produce a report, running webinars and a campaign advocating for inclusive education, including a blog series and production of resources for use by parents and professionals.

International guidelines for inclusive participation of people with intellectual disabilities

Developing the International Guidelines for Inclusive Participation, jointly with Inclusion International. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can participate in decision making processes.

Programme team funding

Funding for the salaries of our programme team, specifically DSI's programme director, to enable the completion of crucial projects, the continuation of others and the development of a programme strategy.

Consensus statement on cardiac disorder in people with Down syndrome

Publishing a consensus statement on cardiac disorder in people with Down syndrome, following a systematic evidence review, detailed advice from world leading experts in this field and structured input from international stakeholders.

Inclusive participation training UK

Working with the Down's Syndrome Association to train self-advocates with Down syndrome in the UK to become consultants on inclusive organisations.

Rwanda fundraising capacity development

Working with Rwanda Down Syndrome Organisation to develop their capacity to raise their own funds.

Purposes of designated funds

The National Lottery Community Fund – resources, information and support

Developing and signposting to resources and information to help people with Down syndrome and their families get support. Putting people in contact with our member organisations to get the support they need at the local level.

World Down Syndrome Day

Organising the World Down Syndrome Day conferences in New York and Geneva. Running the World Down Syndrome Day website and social media.

12. Legal status of the charity

The charity is a company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £10.

Accounts

DOWN SYNDROME INTERNATIONAL (DSi)



REPORT OF TRUSTEES (AND DIRECTORS) AND FINANCIAL STATEMENTS

for the period from 1 April 2021 to 31 March 2022

Reference and administrative information

Company number	04327941
Country of incorporation	United Kingdom
Charity number	1091843
Country of registration	England and Wales

Registered Office

Down Syndrome International
Langdon Down Centre
2A Langdon Park
Teddington
Middlesex
TW11 9PS
United Kingdom

Operational Address

Down Syndrome International
7/9 Chapel Street
Exmouth
Devon
EX8 1HR
United Kingdom

Trustees

The trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows:

B Snedden	(President – appointed August 2021)
R Faragher	(Vice President – appointed August 2021)
JP Clarke	(Treasurer)
V dos Santos	
P Robertson	
C Boys	
J Tang	
P Almeida	(not re-elected as Trustee August 2021)
A L Arellano	
D Warkcup	(elected as Trustee August 2021)

Principal Staff

A Boys	(Executive Director)
	(Company Secretary)

Principal Bankers

HSBC
16 King Street
Covent Garden
London
WC2E 8JF

Solicitors

Russell Cooke
2 Putney Hill
London
SW15 6AB

Introduction

The trustees present their report and independently examined financial statements for the year ended 31 March 2022. The financial statements cover a 12-month period since the previous statements for the year ended 31 March 2021.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with the current statutory requirements, Down Syndrome International's memorandum and articles of association and the Statement of Recommended Practice – Accounting and Reporting by Charities: SORP applicable to charities preparing their accounts in accordance with FRS 102. For a list of members, please refer to Annex 1.

For the year ended 31 March 2022 the organisation's income is greater than £25,000, therefore an independent examination of the financial statements is required.

Objectives and activities

The charity objects of DSI, as stated in the memorandum and articles of association are:

- to promote and protect the physical and mental health of those with Down syndrome through the provision of support and resources to people with Down syndrome, their families and carers, and the professionals who work with them with specific focus on developing countries; and
- to undertake any other charitable activities in connection with Down syndrome and other learning disabilities as the trustees shall determine.

DSi's published mission, aims and objectives seek to take DSI forward as a membership led organisation, providing support and advice, building on and disseminating its pool of information, knowledge and experience, undertaking training and build the capacity of its members, advocating for, representing and campaigning on behalf of the global Down syndrome community. DSI's work improves the understanding of Down syndrome, the capacity to support people with Down syndrome, champions basic rights and ultimately improves quality of life for people with Down syndrome.

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing its mission, aims and objectives and in planning its future activities. In particular, the trustees consider how planned activities will contribute to the mission, aims and objectives they have set. DSI is currently working on a new strategic plan which will build on this.

How our activities deliver public benefit

The implementation of DSI's mission, aims and objectives and who it tries to help are described below. All its charitable activities focus on **enabling people with Down syndrome to live full and rewarding lives** and are undertaken to further its charitable purposes for the public benefit. DSI's mission, aims and objectives fully reflect the purposes the charity was set up to advance.

Who uses and benefits from our services?

DSi is an international organisation of persons with disabilities (OPD), comprising a membership of individuals and organisations from 170 countries, engaging in national, world regional and international activities, all designed to improve lives and ensure basic rights for people with Down syndrome on a full and equal basis with others.

DSi is the network that brings together the global Down syndrome community and its services are available worldwide. The number of people with Down syndrome living worldwide is estimated at 7 million. Demand for DSi's services has grown substantially since it opened its international office in November 2009, providing a dedicated first point of contact for those requiring its services.

The trustees review the aims, objectives and activities of the charity each year. This report looks at what the charity has achieved and the outcomes of its work in the reporting period. The trustees report the success of each key activity and the benefits the charity has brought to those groups of people that it is set up to help. The review also helps the trustees ensure the charity's aims, objectives and activities remained focused on its stated purposes.

Achievements and performance

The charity's main activities in 2021/22 and who we have tried to help are described immediately below in brief summary, based on 3 pillars. More information on each component then follows in this report:

1. Policy and practice, information, support and advice

Played a lead or advisory role in a number of initiatives considering policies and practices on key issues affecting people with Down syndrome, worked with our members and partners to ensure provision of accurate, up to date information and provided advice and support on demand to members and others who needed it around the world.

2. Network development and training

Strengthened our membership network through improving communications, developing alliances and networks of self-advocates, involving members more in our activities and through the delivery of training designed to build the capacity of national member organisations, people with Down syndrome, their families and other stakeholders.

3. Advocacy and campaigning

Ran global campaigns and events and supported regional and national activities advocating for the rights of people with Down syndrome and participated actively in international disability and human rights forums, representing the global Down syndrome community.

In the following report, our thematic areas of focus will be prominent, namely:

- **Advocacy (and self-advocacy)**
- **Early development and parent support**
- **Education**
- **Employment**
- **Health**
- **Inclusive participation**
- **Organisation support**
- **Situations of risk and humanitarian action**

1. POLICY AND PRACTICE, INFORMATION, SUPPORT AND ADVICE

POLICY AND PRACTICE

DSi and our network has a central role formulating and influencing national, regional and global policies and practices which specifically affect people with Down syndrome. 2021/22 saw a wide range of activities in this area.

Production of policy statements and guidelines

Education guidelines

Following the 2020 publication of our **International Guidelines for the Education of Learners with Down Syndrome**, the guidelines have been translated into Albanian, French, Tajik and Bosnian, with more languages likely to follow.

The guidelines provide best-practice guidance for learners, teachers and managers in pre-school, school and post-school education settings to promote life-long learning, in the context of education settings which are inclusive for all learners.

The guidelines are being disseminated via our global network, supported by toolkits, resources and training opportunities and have informed DSi's **Inclusive education pilot study in United Kingdom** (see page 18 below).

A quote from one of our international stakeholders - *"Situating all topics in scientific research conveys security and expands the possibility of deepening the subject. Anyone who reads it and puts it into practice can learn, make changes, and qualify its inclusive process."*



Cardiac consensus statement

As part of DSi's work in healthcare, we have collaborated with international clinical experts to create an up-to-date review and **expert consensus statement on cardiac disease in Down syndrome**.

This document will help health professionals around the world to better understand, diagnose, manage and care for people with Down syndrome with cardiac disease. The guidance will highlight best practice, but also acknowledge the differences that may exist between countries around the world.

A working group made up of 25 leading international specialists in cardiovascular disease and specialists in the treatment of people with Down syndrome, worked together to write and review this work, following selection of key topic areas (supported by our membership network as stakeholders) and a systematic review of evidence. A consensus statement for each topic area was prepared.

Our team published an article about the work we are doing in the Journal of Congenital Cardiology in early 2021. We are hoping to **publish the statement in a high impact factor cardiology journal in 2022.**

Once published, we anticipate this document will have a substantial and positive impact on the care provided by health professionals to people with Down syndrome with cardiac disease.



Inclusive participation guidelines

Throughout 2021/22, DSi and Inclusion International have continued working together on a project called **#ListenIncludeRespect**, developing guidelines for inclusive participation.

Right now, there are more self-advocate leaders than ever working for change. But people with an intellectual disability are often still not included meaningfully in the work that affects them. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) guarantees the right to accessibility and participation for people with an intellectual disability.

We have heard from many organisations, who want to include people with intellectual disabilities in their work. But they need guidance to be more inclusive. While there are also lots of organisations already working with people with intellectual disabilities who do this very well, we can all do better.

So we came together to develop the **International Guidelines for Inclusive Participation**. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can take part in a meaningful way.

In June 2022, following an extensive global consultation over 2 years, **we “soft released” the guidelines via a new website listenincluderespect.com** and we are currently seeking feedback ahead of a formal launch later in 2022. We are in discussions with a number of international agencies (including within the UN system) and global disability and civil society organisations, to adopt the guidelines into mainstream decision-making processes. We will also be working with a number of our member organisations to ensure this happens at regional and national levels.

Production of best practice reports, studies and resources

Inclusive employment case study and webinars

In late 2021, we published a **case study on best practices related to the employment of persons with Down syndrome and intellectual disabilities**, with a focus on Bangladesh. We also developed and ran a **webinar series on inclusive employment** of persons with intellectual disabilities. Both projects were funded by Inclusive Futures (Inclusion Works), a UK Aid-funded consortium of 16 disability and development organisations led by Sightsavers.

The case study investigated the barriers that persons with intellectual disabilities face in Bangladesh in finding and retaining inclusive employment and highlighted good practices in providing an inclusive and accessible work environment.

The case study finished with recommendations for the government of Bangladesh and employers, including measures to prevent discrimination, incentivise employment in the private sector, and train the workforce to create inclusive environments for persons with intellectual disabilities and others.



We recruited 5 self-advocates with intellectual disabilities from our member organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda, who helped us **deliver the webinar series on best practices related to inclusive employment of persons with intellectual disabilities**. The self-advocates led the webinars, speaking on behalf of people with intellectual disabilities in their country. Some key quotes from the webinars are included below:

"We have a right to live well. We need clothes, we need food, we need houses. For us to get money to buy all these things we need work. I have a right to work." – Muthoni from Kenya

"We have experiences and skills we can share with employers if given a chance. It is upon you, employers, to give us that chance, so people become aware that we exist and we are working, we can live an infinite life." – Samuel from Uganda

"If people with disabilities don't get opportunities then we will never know what they are capable of." – Eric from Uganda

"We are loyal to our employers." – Favour from Nigeria

"Employers do not want to give us jobs as they do not understand our needs." – Fahim from Bangladesh

World Down Syndrome Congress (WDSC)

The WDSC is an opportunity to disseminate research, information and good practice to a captive audience, while bringing experts, professionals and key stakeholders together to advance knowledge and ensure policy and practice is kept accurate and up to date.

DSi oversees and selects hosts for the WDSC from among our national member organisations. We then work closely with the hosts, providing consultancy services (based on our knowledge and experience from previous events) and maintaining oversight on the event programme.

The **first ever virtual WDSC event took place in November 2021**, hosted by Emirates Down Syndrome Association, in Dubai, United Arab Emirates. The event was a big success, with great online attendance and interactions with a range of speakers, including people with Down syndrome, family members, representatives of organisations, professionals and experts from around the world. DSi is very grateful to our hosts for organising such a fantastic event, a first of its kind.



The **next WDSC** (hosted by Down Syndrome Australia) **will be held in person in Brisbane, Australia in 2024**.

Advising on external projects related to Down syndrome and disability policy

Throughout 2021/22, we have regularly contributed to the preparation of international policy statements and comments by the International Disability Alliance (IDA), the UN CRPD Committee, the UN Special Rapporteur on Disability and similar policy influencers. DSi is in Special Consultative (ECOSOC) Status with the United Nations (UN) Department of Economic and Social Affairs.

We continued to play an important role within IDA this year, with DSi represented on the IDA board, programme committee and on task groups. IDA's programme committee advises the IDA board and secretariat on various major disability development programmes, funded by international development agencies, with IDA and its members working on stand-alone programmes and in large consortium programmes with disability development organisations, including members of International Disability and Development Consortium (IDDC). IDA **plays a key role in the positioning of a number of these programmes**, focusing on disability policy, monitoring and development work, ensuring UN CRPD compliance and contribution to UN Sustainable Development Goals (SDGs) via meaningful engagement of persons with disabilities and their representative organisations. IDA has a key role in human rights policy making and disability development programming, giving the perspective of persons with disabilities.



[List of members:](#)



INFORMATION

There is undoubtedly a great demand for up-to-date information resources and the latest research being undertaken and published, in key areas in the field of Down syndrome. There are information resources and research publications across the internet and the world. The extent to which they are provided free of charge, are accurate and evidence-based and are fully accessible (e.g. for people with disabilities, in different languages etc.), varies.

As of March 2022, we continue to work with our members and with key international partners to ensure that **free of charge, high quality and fully accessible information** and the **most important and highest quality research**, is promoted to the global Down syndrome community and beyond.

Our website currently provides information summaries in key areas and we regularly promote information resources and research initiatives to our members and on social media. Meanwhile, we are:

- exploring the production of DSi information resources;
- exploring the best way to promote external information resources and
- considering the most effective way to promote external research,

working with our members and partners including Trisomy 21 Research Society, NIH Down Syndrome Consortium, Alana Foundation, Lumind IDSC Foundation, International Association for the Scientific Study of Intellectual and Development Disabilities, DSMIG UK and DSMIG USA, among others.

We send regular updates and e-newsletters to over 12,000 people around the world including the latest news, updates, research and best practices related to people with Down syndrome.

COVID-19 response

At the time of this report, the COVID-19 pandemic continues. Initially, the pandemic required an urgent and specific response from DSI, in line with our commitment to support people with Down syndrome and their families in situations of humanitarian crises.

Throughout the last 2 years, we have responded to the evolving situation and supported our members and the global Down syndrome community. Our response has included:

➤ Compiling and sharing information

We have continued to share up-to-date and accurate information on COVID-19 and appropriate responses to it. In the last year this has included publishing and disseminating **information and resources on COVID-19 vaccination advocacy** (see “COVID-19 response advocacy” on page 16 below).

➤ Gathering experiences and evidence

We have worked with our member organisations to gather experiences of people with Down syndrome, families and advocates and other evidence related to COVID-19 and its impact. This has included:

- the availability of information in accessible formats;
- how people with Down syndrome and their families have been included in pandemic responses;
- impact of quarantines on people with Down syndrome and their families;
- support available for people with Down syndrome and their families during the pandemic;
- provision of healthcare for people with Down syndrome affected by COVID-19;
- impact of the pandemic in key areas of life such as education and work and
- availability and prioritisation of vaccinations for people with Down syndrome.

➤ Support for member organisations

We have been working with our member organisations to identify the challenges they are facing and the support they need in responding to the COVID-19 pandemic in their countries.

In the last year, we have been **assisting a number of our member organisations with funding, training and resources to deliver COVID-19 response advocacy activities** (see “COVID-19 response advocacy” on page 16 below).

➤ International collaboration

We have been working with the international disability community and IDA to ensure a disability inclusive response to the COVID-19 pandemic.



SUPPORT AND ADVICE

We receive many enquiries for support and advice from around the world, particularly in Global South countries. This year again, we:

- responded to enquiries from many individuals around the world and
- had regular conference calls with and provided strategic and operational advice to more than 40 member organisations, primarily in Africa, Asia and South America.

We were also able to respond to specific support requests from our member organisations where the need was great and funding could be sourced (see “Member organisation support” on page 12 below).

2. NETWORK DEVELOPMENT AND TRAINING

NETWORK DEVELOPMENT

DSi is a global network made up of member organisations in 170 countries. We maintain close contact with our members to keep them informed on relevant research, best practices and strategies to advocate for the rights of people with Down syndrome. We also seek regular feedback on our work and receive information from countries and regions, to help guide our strategy.

We are continuously:

- developing more effective ways to communicate with and be accountable to members;
- developing national and international advocacy networks of people with Down syndrome;
- supporting national and regional alliances of our members and making alliances with other partners in the Down syndrome and disability movement;
- developing opportunities to engage our members in our activities, ranging from stakeholder consultation in policy and practice activities to participation in our advocacy and campaigning activities and
- building the capacity of our national member organisations through the provision of support, advice, capacity assessment and training.



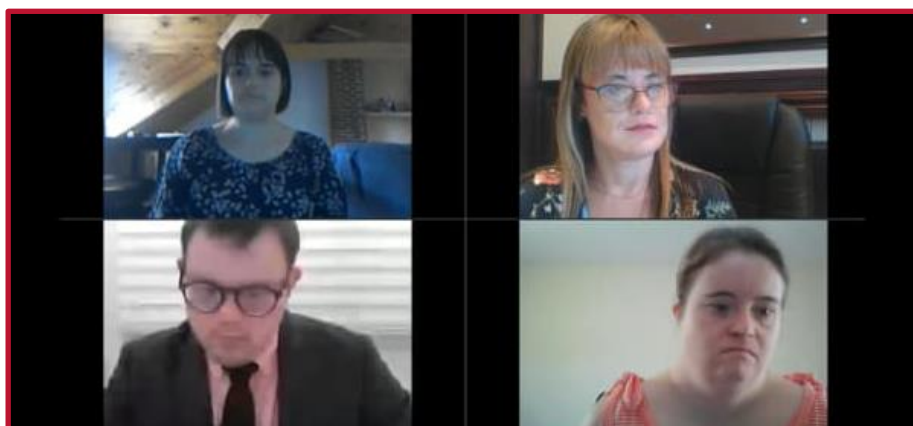
Working with self-advocates

Down Syndrome International Ambassadors

We have a committee of national representatives with Down syndrome, known as the **DSi Ambassadors**, which currently has members from 20 countries. They represent people with Down syndrome in their country and frequently give us input into our work.

This year, the DSi Ambassadors were actively involved in a lot of our work. This ranged from participating in and leading project activities (such as our “2022 WSDS advocacy campaign” on page 20 below), to advising us on our strategy for future programmes, to participating in governance discussions with our Board of Trustees.

Moving into next year, we will be seeking some crucial contributions from this group, helping us to understand how DSi can become more inclusive, leading our strategy on self-advocacy work and becoming more formally involved in our governance procedures.



Inclusive participation with CAST

Supported by a charity called CAST (Centre for Acceleration of Social Technology), in 2021/22 we completed a project to **find solutions for the key problem that people with Down syndrome are not involved enough in the work of organisations that represent them**, something which was exacerbated by the COVID-19 pandemic and the transition to online communications.

Working with self-advocates and DSi member organisations, the project initially went through some key consultation stages to test the problem and find potential solutions. Then in 2021/22, we tested specific applications and approaches designed to deliver meaningful participation of people with Down syndrome. Our tests successfully identified solutions which we are now able to use with different groups and share with DSi member organisations and other organisations where representation is so important. Crucially all of this work has been led by people with Down syndrome, who of course are best placed to identify solutions that enable participation.

Other work with self-advocates

Self-advocates with Down syndrome and intellectual disabilities have played a key role, leading and consulting on our inclusive participation guidelines project (see page 5 above) - on the staff team, leading high-level advocacy webinars and via global consultations.

In March 2022, self-advocates moderated and spoke in all of our World Down Syndrome Day 2022 advocacy campaign webinars (see “2022 WDSO advocacy campaign” on page 20 below).

We are also **working with self-advocates via most of our projects with member organisations** (see “Inclusive employment case study and webinars” on page 6 above, “Self-advocacy facilitation training” on page 14 below and “Other member organisation advocacy” on page 17 below).



Member organisation support

We strongly believe that national Down syndrome organisations know their country best; what they need from DSI is support, to build their capacity and skills.

We **support national Down syndrome organisations with ongoing support, ad hoc strategic and operational advice**. We deliver training within the remit of specific funded projects (see “Training” on page 14 below). Where funding allows, we also support the development of member organisations through grant making and bespoke support, including to deliver advocacy activities (see “Other member organisation advocacy” on page 17 below).

Through all of this work, we are looking to develop members’ capacity to do their own work, develop their strategic and operational systems and evaluate the quality of activities delivered and the impact they have.

World Down Syndrome Forum

In early 2021 we launched our new **World Down Syndrome Forum**, a new web-based communication platform for our member organisations. This forum enables our members to connect more effectively with DSI, but crucially also to communicate directly with other DSI members. Via direct messaging, discussion forums, news and events posting and publication of resources, the forum is a global hub providing continuous learning opportunities for leaders and staff of DSI member organisations. During 2021/22 our members started to use the platform and we consulted with them on its usefulness, how they are using it and what they would like to see to make it work better.

Rwanda

We have been working in Rwanda for the last 5 years, **supporting the development of Rwanda Down Syndrome Organisation** (RDSO - the first Down syndrome specific OPD in Rwanda).

In Rwanda people with Down syndrome and their families are often isolated and lack important information about key issues affecting their lives. They struggle to participate in society due to negative attitudes and have limited access to basic healthcare and education.

In 2016, we supported the establishment of RDSO. As of March 2022, they are supporting in excess of 500 families, who previously had no support and often very little understanding of what Down syndrome was or how it might affect their child. RDSO has had a major impact in the past year on the lives of people with Down syndrome, providing essential early support for parents and basic early development support for children with Down syndrome.

RDSO has also successfully established Rwanda's first self-advocacy group for persons with Down syndrome, where young people and adults with Down syndrome learn to speak up for themselves and advocate for their rights (see "Self-advocacy facilitation training" on page 14 below).

Notwithstanding the challenges presented by the COVID-19 pandemic, with our support RDSO has taken steps towards financial independence. They have received their first international development funding through a project funded by the Norwegian Agency for Development Cooperation (NORAD - see "Employment-based advocacy projects in Africa and Bangladesh" on page 14 below) and are receiving capacity building support from Humanity and Inclusion. They have also started receiving some small donations and support from within Rwanda.



United Kingdom

Following DSI's commission to:

- undertake a review of the website of the Down's Syndrome Association (DSA – England, Wales and Northern Ireland);
- outline a new website structure for them and
- source a development team to build a new website,

DSA **launched their fantastic new website in June 2021.**

TRAINING

Employment-based advocacy project in Africa and Bangladesh

In 2020, DSI began a new 3-year project to advocate for access to employment for people with Down syndrome and intellectual disabilities.

The project, taking place in partnership with International Disability Alliance, with funding from Norwegian Agency for Development Cooperation (NORAD) and partly from Inclusive Futures (Inclusion Works - UK Aid), comprises the following:

- **technical human rights training and COVID-19 advocacy training** for our member organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda;
- **self-advocacy facilitation training** for our member organisations in Kenya, Rwanda and Uganda (following completion of similar training with Bangladesh and Nigeria) and
- **employment-based advocacy activities** from all 5 member organisations, led by self-advocacy groups (see “Other member organisation advocacy” on page 17 below).

Technical human rights training and COVID-19 advocacy training

This took place in 2020, attended through a combination of live online workshops and resources and exercises to review and complete between sessions.

Topics covered included an introduction to human rights and development, the UN Convention on the Rights of Persons with Disabilities (CRPD) and Sustainable Development Goals (SDGs), public policy and network building and organisations of persons with disabilities and inclusive participation.



Self-advocacy facilitation training

In 2021/22 we completed self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda.

People with Down syndrome often have a limited voice in the decisions and changes that affect them. Decisions are often made without consideration of their opinions and preferences. As a result, their rights are frequently violated.

Prior to this year, we have trained 71 self-advocacy group facilitators from our member organisations in 5 countries: Turkey, Nigeria, Bangladesh, United Arab Emirates and Kosovo. These facilitators have started 8 self-advocacy groups so far with a total of 73 self-advocates with Down syndrome.

The groups support people with Down syndrome to learn about human rights and build their self-advocacy skills, enabling them to engage in a variety of advocacy activities.

Participation in the self-advocacy groups has also had a very positive impact on the individuals with Down syndrome. This has included increased confidence, more positive attitudes towards having Down syndrome, and better ability to express opinions and advocate for their rights.

These projects are based on the following methodology:

- initial visit to train self-advocacy group facilitators and work with our member organisation on general understanding of self-advocacy;
- trained facilitators empower self-advocates to start groups and meet regularly over a 10 month period, during which time group discussions lead to advocacy activities;
- DSi returns for a follow up training and monitoring visit 6 months after initial training;
- DSi provides structured support and advice to the facilitators over full 12 months of project;
- After 12 months, the projects are completed, with a report to review success and outcomes;
- member organisations continue and look to build on the project going forward, supported by DSi.

Due to the COVID-19 pandemic and travel restrictions, the delivery of the projects in Kenya, Rwanda and Uganda partly moved online, but still with good results and this training was well supported by a project fellow employed in Uganda.

Through these ground-breaking projects, it is an absolute pleasure to see the increase in confidence of self-advocates. We are incredibly proud of each of the self-advocates and all that they have achieved and we look forward to working with them and their organisations to bring about positive change for people with Down syndrome and intellectual disabilities.



Rights-based advocacy training for people with Down syndrome

DSi also works directly with self-advocates with Down syndrome in various international forums, developing their rights-based advocacy skills so they have the tools to speak out. See “Working with self-advocates” on page 11 above.

Self-advocacy facilitation support in Turkey and Albania

This year, we also provided some limited training and support for our members Down Turkiye and Down Syndrome Albania Foundation, both organisations that are committed to empowering people with Down syndrome to advocate for their rights.

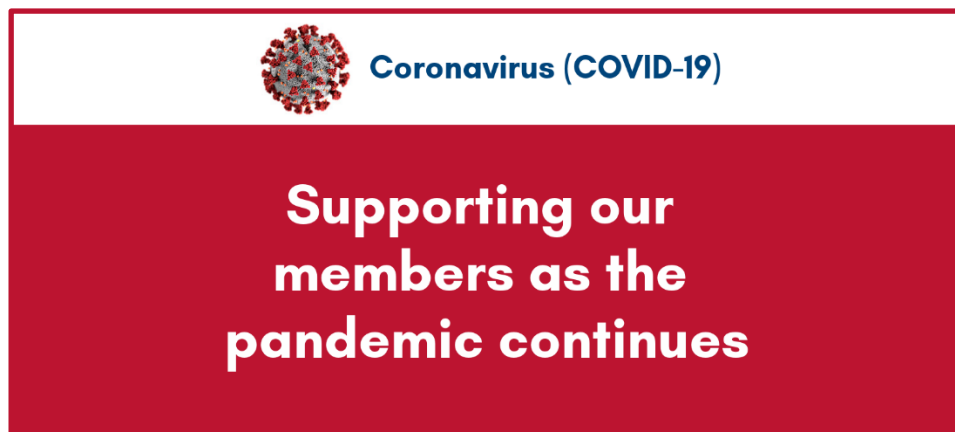
3. ADVOCACY AND CAMPAIGNING

A key part of DSI's role is to **advocate for the rights of people with Down syndrome in line with the UN CRPD**. We do this at national, regional and international levels, working with our members and partners, participating in disability and human rights forums and campaigning to raise awareness in wider society.

COVID-19 response advocacy

Advocating for the rights of people with Down syndrome where the pandemic has had an impact and required responses (see "COVID-19 response" on page 9 above) has again been a key focus in 2021/22.

We have worked with international partners to undertake global advocacy, we have worked with and supported our national member organisations to deliver crucial advocacy activities and we have supported the global Down syndrome community, providing tools and resources for individuals and families to ensure people with Down syndrome are included in pandemic responses.



Supporting member organisations advocacy

In March 2021, we provided **grants to 5 of our national member organisations for COVID-19 specific advocacy activities**. We then supported these members - Down Syndrome Albania Foundation, Asociacion Sindrome de Down de la Republica Argentina (ASDRA), Federacao Brasileira das Associacoes Sindrome de Down (FBASD), Indonesia Down Syndrome Care Foundation (YAPESDI) and Down Syndrome South Africa – as they delivered crucial interventions.

Case study - Federacao Brasileira das Associacoes Sindrome de Down (FBASD)

The problem: People with Down syndrome, and other disabilities, in Brazil, were at increased risk during the COVID-19 pandemic. Many were unable to use precautions such as wearing masks or using alcohol gel. They were more likely to be exposed to the virus because of daily health care dependence.

The solution: FBASD advocated for priority health care and vaccination for people with Down syndrome. They produced scientific research to show the increased risk for this vulnerable population. They took their fight to the Superior Federal Court, the highest member of judicial power in Brazil, but they did not succeed.

In Brazil, local governments had the autonomy to prepare their own vaccination programmes. So, FBASD took their advocacy straight to the source. FBASD used the COVID-19 vaccination advocacy

toolkit, produced by DSi (see “COVID-19 vaccination advocacy” below) to develop their campaign - “I demand a dose of respect”.

The campaign was a success! The first state agreed to vaccine prioritisation and created a chain reaction across the country so that in each neighbouring state the demand succeeded. The success of this campaign enabled other disability segments to follow suit and pursue the same health rights.



These activities were funded by UK Aid via the COVID-19 Pooled Fund.

COVID-19 vaccination advocacy

In 2021, we published a **COVID-19 vaccination advocacy toolkit** to help our supporters advocate for the necessary prioritisation of people with Down syndrome in the COVID-19 vaccination rollout in countries worldwide. This followed a number of previous COVID-19 related global campaigns and distribution of information and resources throughout 2020 (see “COVID-19 response” on page 9 above).

The toolkit included information on:

- what we can do together to create a united global voice;
- potential advocacy activities;
- evidence to support the prioritisation of people with Down syndrome;
- what health and research organisations are doing;
- what disability and advocacy organisations are doing;
- supporting materials including letter templates.

The toolkit was welcomed and used by many of our members, including FBASD (see “Case study – FBASD” above).

Other member organisation advocacy

Employment-based advocacy project in Africa and Bangladesh

Following our technical human rights training, COVID-19 advocacy training and self-advocacy facilitation training for our members organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda (see “Employment-based advocacy project in Africa and Bangladesh” on page 14 above), in 2021/22 we supported **employment-based advocacy activities from all 5 member organisations, led by their self-advocacy groups.**

The self-advocacy groups have been active in terms of advocacy, with examples as follows:

In Kenya...

...self-advocates have spoken up on their right to employment to key stakeholders including the National Council for Persons with Disabilities and the former Chief Justice and President of the Supreme Court of Kenya. The group has also been working with United Disabled Persons of Kenya on a project promoting public participation of persons with disabilities.

In Nigeria...

...self-advocates have advocated on the right to employment to stakeholders including the Lagos State Ministry of Education, the Lagos State Office of Disability Affairs, and multiple businesses. Self-advocates have been offered paid work or voluntary work placements in a variety of workplaces including fashion, farming, and hair and beauty.

In Rwanda...

...self-advocates have been carrying out advocacy work with key stakeholders including the Ministry of Education and the Ministry of Local Government. Rwanda Down Syndrome Organization also participated in a meeting organised by the National Union of Disabilities' Organizations in Rwanda on promoting socio-economic development for persons with disabilities in Rwanda.

In Uganda...

...self-advocates from Uganda have spoken up about their right to employment to stakeholders including Members of Parliament, local government disability departments, and various employers. One of the self-advocates also appeared on a TV talk show to tell the public about inclusive employment.



Inclusive education pilot study in United Kingdom

From September 2021, we developed and ran a UK-wide research and advocacy project on 'Inclusive education', its definition and implementation.

We did this in collaboration with the Down's Syndrome Association (DSA - England, Wales and Northern Ireland) and Down's Syndrome Scotland (DSS).

This project was a pilot study with the aim of using the processes, resources and materials developed to have a positive impact on other education systems around the world.

Inclusive education for all learners, including those with Down syndrome

DSi, DSA and DSS, believe the split education system (mainstream/special schools) in the UK doesn't offer the best education to learners - 'disabled' or 'non-disabled' - or staff. Though we do recognise that education professionals are working very hard within the existing system.

Through this project and beyond, we are advocating for long term system change towards 'full' inclusion.

We encourage teaching staff to welcome neuro-diverse learners into their settings with the knowledge that everyone will benefit if it is done effectively, as part of a whole school culture of inclusion and belonging.

We understand that including learners with learning disabilities fully is a challenge for teachers and policymakers and that they need adequate support, resources, funding and training. Ultimately, for society to be more inclusive, education needs to reform, although education cannot bear the full responsibility for this change.

Developing the campaign

We surveyed and spoke directly with stakeholders about their experience of the UK education system.

Stakeholders included people with Down syndrome, their families, education professionals and policymakers.

Our research identified many frequently asked questions, plus areas where knowledge can be shared.

From January 2022 we ran a campaign to raise awareness and advocate for long-term system change:

- we shared weekly key messages on the subject of inclusive education for all learners, including those with Down syndrome;
- we distributed concise answers to FAQs, by professionals and people with lived experiences, including self-advocates and
- we provided training and materials for supporters to undertake their own advocacy campaigns.



World Down Syndrome Day

DSi brings together the global Down syndrome community on and around **21 March each year** for World Down Syndrome Day (WDSD). We coordinate a range of activities, all designed to advocate for the rights of people with Down syndrome and campaign to raise awareness.



Activities for WDSD in March 2022, included:

2022 WDSD advocacy campaign

Our annual WDSD international advocacy campaign, was based on the theme **"#InclusionMeans"**:

Why ask this question?

In its general principles, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) calls for:

"Full and effective participation and inclusion in society"

There are references throughout the UN CRPD to inclusion, for example:

"Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others."

"States Parties recognize the right of persons with disabilities...to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities."

In 2019, the UN Secretary General adopted the United Nations Disability Inclusion Strategy (UN DIS). This provides a path towards disability inclusion through all areas of the work of the United Nations: peace and security, human rights, and development.

Around the world, it is widely accepted that everyone should have the same opportunities, be able to go to the same places, take part in the same activities, and enjoy the same experiences in life.

But the reality is that people with Down syndrome and disabilities today do not benefit from full and effective participation and inclusion in society.

There are many reasons for this. One reason is that there is a lack of agreed understanding of what inclusion is and what inclusive systems look like in practice.

So on 21 March 2022, we would like people with Down syndrome, families, advocates, professionals, organisations and indeed anyone around the world, to tell us: "#InclusionMeans ..."

Why does this matter for World Down Syndrome Day (WDSD)?

WDSD is a unique opportunity for the global Down syndrome community to connect every year, so we can:

- share ideas, experiences and knowledge;*
- empower each other to advocate for equal rights for people with Down syndrome and*
- reach out to key stakeholders to bring about positive change.*

From now, up to 21 March 2022, we have an opportunity to share our collective understanding of inclusion.

In doing this, we can get a global conversation going, which will empower people around the world to advocate for full inclusion in society for people with Down syndrome and disabilities, and indeed for everyone.

What can you do?

Every year we encourage people with Down syndrome, families, advocates, professionals and organisations to observe WDSD with their own activities.

We want to see this again, more than ever in 2022. We encourage you to:

- 1. go ahead and plan whatever is possible and safe to do. This could be anything from a social media post to a large organised event...every contribution counts;*
- 2. whatever you decide to do, please provide responses that start with #InclusionMeans ... and make sure you advocate for full inclusion in society for people with Down syndrome and disabilities;*
- 3. let DSi know and we will make sure your voices are amplified.*



Through this campaign we worked with people with Down syndrome and those who support and work with them to empower them to tell us what inclusion means.

A wide variety of campaigning resources were used by our members and many other advocates throughout the global community. The campaign was popular around the world and, notwithstanding the continued restrictions of the COVID-19 pandemic, many organised their own campaigns, activities and events, mostly online.

2022 UN conferences and other events

Following the UN declaration of WDS in December 2011, DSI has organised advocacy events in New York and Geneva. In March 2022, the following events took place:

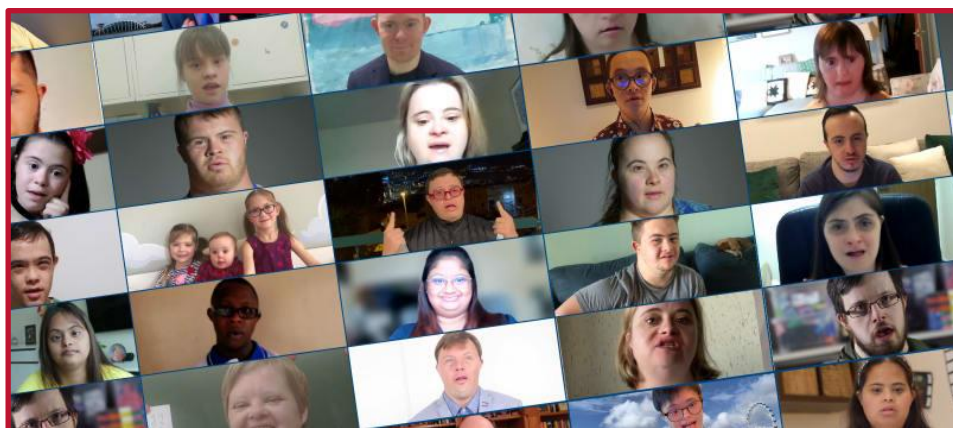
- our **12th annual WDS conference at United Nations (UN) HQ, New York**, held virtually on 21 March and
- our **6th annual, self-advocate led, side-event to the Committee on the Rights of Persons with Disabilities at UN Geneva**, held virtually on 21 March.

Our New York conference explored what inclusion means in terms of education, employment, healthcare and the work of organisations. Moderated by our DSI Ambassadors (see page 11 above), the event comprised a series of webinars, broadcast on UN Web TV and then merged into a YouTube playlist of fantastic contributions.

Our Geneva side-event was moderated by our DSI Ambassadors and led by self-advocates reaching out to key stakeholders to tell them what inclusion means. The event comprised a webinar, broadcast on UN Web TV and then merged into a YouTube playlist of contributions.

The DSI Ambassadors also led a webinar on 21 March called **“Learn about inclusion in my country”**.

These events were all very well attended and received and we are grateful to all of our event sponsors and fantastic speakers, many of whom were self-advocates.



Videos

Once again, **we worked with Down TV, a global portal for videos related to Down syndrome**. We encouraged people all over the world to upload videos to Down TV's WDS hub - videos highlighting activities, making a statement or in many cases saying what WDS means to them.

The annual video campaign organised by our member CoorDown (Italy) was again a big success. We were delighted to work with them again to **launch "Just the two of us", featuring a video promoting the right of people with Down syndrome to experience romantic and sexual relationships** and receive good and accessible information to enjoy a full and healthy sexual freedom:

"Love Needs Space."

"People with Down syndrome have the right to an independent love life."



#LotsOfSocks awareness campaign and merchandise

For the 10th year for WSD 2022, DSI launched the #LotsOfSocks campaign, with the stated aim of asking people across the world to wear socks that draw attention on 21 March 2022, wherever they were, to get people talking.

The campaign was again successful, **generating substantial support on social media**. The DSI office received lots of requests for information, many committed to raise funds, we sold and distributed socks and worked with many organisations, global companies, influencers and the global community to generate global reach on 21 March.

WSDS website

The WSDS website worlddownsyndromeday.org (and associated social media channels) is a global hub for promoting WSDS events and activities, coordinated by DSI. The website is full of great features and is designed to be useful for the global Down syndrome community and the wider public. In addition to key information about Down syndrome and WSDS, our website features a growing list of stories shared by people with Down syndrome from around the world and includes a wide range of ideas and resources to enable people to participate and take action on WSDS.

Other advocacy activities

International human rights forums

In June 2021, DSI participated in the annual Conference of States Parties to the CRPD at UN, New York (COSP), held virtually.

Raising funds

As the demand for the charity's services is increasing year on year, **it is imperative to maintain sufficient funding for DSI to operate.**

Income from restricted sources, including trusts, foundations and development agencies reduced overall in 2021/22 but with significant funded projects at different stages of completion. The challenge we have is our ability to generate sufficient restricted funding to carry out all of our charitable activities, but with corresponding programme management income and non-programme attributable (operational) income to cover the costs of carrying out those activities. As of March 2022, a significant proportion of our unrestricted income is used to fund our programme and operational management functions. DSI needs to generate more restricted funds to meet the rising demand for services, while making sure we receive the corresponding programme and operational management income needed to complete our activities successfully. This is something we analyse in detail in our financial forecasting and in our strategy to raise funds.

The income generated from unrestricted and designated sources increased significantly in 2021/22, following the appointment of our fundraising officer in 2020/21 and beginning the rolling out our comprehensive fundraising strategy. We have been able to make steady progress towards finding new funding opportunities, while also focusing on the sustainability of existing funding channels. Going forward though, DSI needs to generate even more unrestricted income and use it primarily to improve our unrestricted reserves position. We are grateful to Joffe Charitable Trust, who have supported our fundraising activities in the last 2 years.



Financial review

Down Syndrome International's **total income in 2021/22 was £413,569** (2021: £411,852). Restricted income from charitable activities reduced significantly, primarily due to various projects being at different stages in their cycles. We received instalments of grants from IDA (onward granted from UK AID and Norwegian Agency for Development Cooperation) for employment, self-advocacy, COVID-19 response and inclusive participation projects, as well as a direct grant from IDA to fund our programme team. We received a grant from Inclusion International for our inclusive participation project. We received a further grant from Centre for Acceleration of Social Technology (CAST) for our project finding digital solutions for people with Down syndrome to participate. We received a grant from the Down's Syndrome Association (DSA) for our inclusive education UK pilot study. We also received significant unrestricted donations from the Joffe Charitable Trust, The National Lottery Community Fund and the DSA. Unrestricted funding from donations and other trading activities both increased significantly.

Total expenditure in 2021/22 was £359,482 (2021: £382,291). This reduction again reflects substantially reduced expenditure on charitable activities, due to various projects being at different stages in their cycles. We had a significant increase in spending on raising funds due to increased spending on trading activities and the employment of a fundraising officer.

Overall there was a **surplus in the 12 month period of £54,087** (2021: surplus £29,560). This surplus, combined with funds brought forward from 2020/21 of £57,402, resulted in **total funds available on 31 March 2022 of £111,489**. Of this, £69,253 is restricted, leaving unrestricted funds available on 31 March 2022 of £42,236.

The above indicates a stronger financial position at the end of 2021/22 compared to the previous year, but **DSi still has insufficient free reserves as required by our reserves policy**. Furthermore, we will require more operational capacity going forward to fulfil activities. So careful financial management, combined with a robust strategy to move towards a position of financial sustainability, will be required.

Reserves policy and going concern

The reserves policy states that the unrestricted funds not committed or invested in tangible fixed assets and stocks ('the free reserves') held by the charity should be between 3 to 6 months of the resources expended. That equates to between £89,871 and £179,741 in general funds, based on this year's costs.

At this level the trustees feel that they would be able to continue the current activities of the charity in the event of a significant drop in funding. The trustees are aware that should this occur, consideration would need to be given to how such funding would be replaced or the activities changed.

Currently the free reserves available equate to £42,236, **equivalent to 1.5 months of the resources expended**. It should be noted that gifts in kind totalling approximately £39,576 (based on this year's costs) would not necessarily need to be replaced or change DSi's current activities if they were not received. But even with this allowed for, the current free reserves available are equivalent to just under 3 months of the resources expended.

It should be noted that DSi has an informal "overdraft" agreement with creditor the Down's Syndrome Association (DSA). DSA acts as a payroll agency for DSi and recovers the salary costs from DSi on a quarterly basis. Under the agreement, DSA allows an informal "overdraft" facility to DSi, up to a maximum of £35,000, to help cover cashflow troughs, should a quarterly invoice not be able to be paid immediately on request.



Risk management

As part of our risk management framework, **major risk reviews are carried out periodically** by the trustees. Top down and bottom up risks are considered, ranked in order of likelihood and impact, those risks needing attention are prioritised and responsibility is allocated for managing each risk. Those responsible provide updates to the trustees on their progress against action plans designed to manage the risks identified. Some of the major risk areas are described below:

Funding: DSi needs to ensure that the services we offer are relevant to beneficiaries, while providing sustainable income. A sudden loss of funding is a major risk for DSi right now, with limited reserves in place. In order to mitigate this, we have a fundraising strategy designed to strengthen and diversify our existing income streams and develop new means of generating both unrestricted and restricted income.

Leadership: The trustees and executive director recognise the importance of ensuring strong direction, motivation of purpose and continuity of leadership. The trustees have reviewed DSi's leadership, have considered the risks of leadership changes and are satisfied with progress, albeit this needs to remain under regular review.

Core activities: High quality and efficient delivery of DSi's core activities are key to its success. Delivery is monitored closely by the executive director and trustees, supplemented by engagement of staff and stakeholders. The trustees are aware that better systems will be required going forwards, as our activities increase, to improve accountability and monitor progress.

Staff: Staff need to feel engaged and have a stake in the organisation. Their engagement is currently monitored by the president and executive director via staff reviews. Going forwards, staff satisfaction surveys, an organisational health check and new HR policies will be required.

Operational systems: It is critical that operational systems support our core activities, ensuring that the DSi office is run efficiently and effectively. In the last 4 years, DSi has undertaken a lot of work to improve our management, communication, finance, data and storage operational systems, introducing standard operating procedures, automating tasks and ensuring compliance with statutory requirements such as GDPR. This work will continue, with systems undergoing regular testing and review.

Reputation: The retention of confidence of members, stakeholders and donors is key to DSi's effectiveness. Any external facing work needs to be relevant and robust and internal support needs to be well managed. DSi puts a lot of focus on engaging with stakeholders and this will be built upon.



Plans for the future

2022/23 will see some significant activities, including:

Policy and practice, information, support and advice

- Continued dissemination of our **international education guidelines** via our global network, including development of further complementary toolkits, resources and training opportunities, making the document accessible in more languages and formats and its playing a key role in all of DSI's future education projects.
- Publication of our **expert consensus statement on cardiac disease in Down syndrome**, followed by post-launch activities to engage with member organisations and the global community and a review of DSI's priorities for health going forward.
- Formal publication of the **International Guidelines for Inclusive Participation** and continued discussions with international agencies and global disability and civil society organisations, to adopt the guidelines into mainstream decision-making processes.
- **Working closely with the hosts of the next WDSC** to start detailed planning for the next WDSC in Brisbane in 2024.
- **Working as a member of IDA** supporting its work and its role in major international disability development programmes, including Inclusive Futures.
- **Continuing our COVID-19 response as required**, compiling and sharing information, gathering experiences and evidence, collaborating with international partners and supporting our member organisations with specific activities.



Network development and training

- Continuing to develop systems which deliver more **effective member communications**, making us more responsive and accountable.
- Working in more depth with the **DSi Ambassadors**, who will help us to deliver training and other project work, support our internal inclusive participation review and become more involved in DSI governance, among other activities.
- Continuing to **support national member organisations to develop their capacity**, via the World Down Syndrome Forum, ad hoc support and advice from DSI and other support resources planned.
- Continuing to **support our member in Rwanda** as they deliver more impact and move towards financial sustainability.
- Work with as many member organisations as possible to **facilitate self-advocacy**.

- Providing more **rights-based advocacy training for people with Down syndrome** via various international forums.

Advocacy and campaigning

- Follow up with members delivering **crucial COVID-19 response advocacy activities**.
- Follow up to ensure success of our **global advocacy campaign on COVID-19 vaccination prioritisation**.
- Support our members to complete **employment-based advocacy activities from 5 member organisations in Africa and Bangladesh** and then review the lessons learnt from the project and plan future activities.
- Complete our **inclusive education advocacy project in United Kingdom** and plan future related activities in the UK and in other countries.
- **Delivery of WDSO 2023 activities**, including the launch of the 2022 WDSO advocacy campaign, delivery of our WDSO UN conferences in New York and Geneva (whether they are in-person or virtual), other WDSO events, WDSO video projects, “Lots of Socks” awareness campaign and merchandise sales and coordinating the WDSO website and social media.
- **Participation in international human rights forums** such as COSP.



Raising funds

- Seeking to **increase income from restricted sources**, including trusts, foundations and development agencies, to cover the operational costs of carrying out activities.
- Seeking to **increase income from unrestricted sources**, via general donations, events and merchandise sales, to improve our unrestricted reserves position.
- Overall, looking for new opportunities while **maintaining focus on the sustainability** of existing funding.

2022/23 will also be a very important year as we finalise a new strategy for the next few years. With a new fundraising strategy now in place and a new communications strategy in progress, we have been reviewing our programme activities, purpose, resources, our environment and seeking feedback from our stakeholders ahead of publishing new strategic and operational plans. Given our increased activity levels, increased funding and our need to manage risks, this work will be crucial for DSI to set a clear path to a sustainable future.

Structure, governance and management

The organisation is a charitable company limited by guarantee, registered as a charity on 1 May 2002 and incorporated on 23 November 2001. The organisation was established under a Memorandum and Articles of Association, which set out the objects and powers of the organisation.

The trustees operate under a Code of Governance, which sets out the basis of board and staff responsibilities, conduct and procedure and a specific procedure for the constitution of the board of trustees to ensure an equitable cross-section of persons and countries.

All of the trustees give their time voluntarily and receive no benefits from the charity. Any expenses reclaimed from the charity are minimal and are set out in note 7 of the accounts.

Appointment of trustees

The Articles of Association state **the charity has members who all have one vote at general meetings**. The members are the trustees and a member stops being such if he/she ceases to be a trustee.

The trustees can establish other classes of membership as they see fit and the board may admit and remove such members in accordance with regulations made by them, notwithstanding that such members are not members of the charity for the purposes of the Articles of Association or the Companies Act. For the avoidance of doubt, **DSi currently has 2 such classes of membership** – representative membership and affiliate membership.

The **board of trustees manages the business of the charity** and as of 31 March 2022 consists of 9 members, elected by the charity members. The Articles of Association allow for not less than 5 and no more than 21 trustees.

At each annual general meeting one third of the trustees must retire but are all eligible for re-election. Those board members who must retire are decided upon on a rotation basis so that a different third retire each year and an individual will not therefore be required to retire any more frequently than once in every 3-year period.

The board of trustees may co-opt additional members provided that the rules as to the total number of board members and its make-up are not transgressed. Such appointed or co-opted board members should be appointed for a specific purpose and their appointment is subject to a board vote in the usual manner. Such co-opted board members will hold office until the next annual general meeting. They will then be eligible for re-election and to vote at the meetings of the board.



Recruitment, selection and induction of trustees

The Articles of Association require that the board use reasonable endeavours to ensure that there is a wide geographical representation on its board.

The Code of Governance includes a full policy on recruitment, selection and induction of trustees. The board must use open and transparent methods, with posts filled by the person most likely to fill the requirements of DSI as determined by a skills audit, but with reference to a number of recruitment and selection procedures. Existing trustees must examine the charity's purpose and aims and their duties and responsibilities as trustees, so that they can explain this to new trustees. The board must ensure that they, rather than staff, retain overall responsibility for the process. Trustees must also be aware of the legal rules on eligibility and should consider conflicts of interest.

The board is first required to consider suitable candidates from among DSI's representative members. In the unlikely event that a suitable candidate cannot be found from there, the board may then consider affiliate members and applications from the wider international community.



Notwithstanding the search for candidates with the required skills, the board must be aware of the following key requirements for its composition in their decision-making process:

- 55% of the board must be **persons with Down syndrome or family members** of persons with Down syndrome;
- a maximum of 2 people from any country can be board members at the same time;
- the board will use best endeavours to ensure there is a widespread geographical representation from around the World and there should be at least 1 person from Europe, North America, South America, Africa, Asia and Australia (continent) on the board at all times and
- the board will use best endeavours to ensure that **at least 25% of its members are from “developing economies”** according to the International Monetary Fund's World Economic Outlook Report, April 2015.”

On induction, the board provides all trustees with induction material (including governing documents, annual reports, meeting minutes, strategy and management documents) to allow them to understand their charitable purposes, financial position and current issues.

Related parties and connected organisations

DSi has good links with a large number of Down syndrome, disability and international development organisations worldwide.

We have a close working relationship with the Down's Syndrome Association (DSA), which has led to the location of our registered office in Teddington, information and resource sharing and funding.

Other notable members include Down Syndrome Ireland, Down Syndrome South Africa, Down Syndrome Foundation Nigeria, Down Syndrome Society of Bangladesh, Down Syndrome Federation of India, Down Syndrome Association Singapore, Down Syndrome Australia, Federacao Brasileira das Associacoes Sindrome de Down (Brazil), Down's Syndrome Scotland, Emirates Down Syndrome Association (United Arab Emirates), National Down Syndrome Society (United States), Down España (Spain) and Trisomie 21 France among many others.

At the regional level, we support the work of European Down Syndrome Association, African Down Syndrome Network, Federación Iberoamericana de Síndrome de Down (Latin America) and Asia Pacific Down Syndrome Federation.

DSi is in special consultative status with the Economic and Social Council of the United Nations (UN), is a member of International Disability Alliance (IDA) and we work closely with Inclusion International.



Remuneration policy

DSi is committed to ensuring a proper balance between paying our staff and others who work for us fairly so that we attract and retain the best people for the job and careful management of our charity funds. In so doing we will ensure the greatest effectiveness in delivering our charitable objectives and meeting the needs of our beneficiaries.

When determining the salary for a newly created post, we will collect information about comparable roles in other organisations, preferably within the voluntary sector. We will use this information to benchmark our own salaries, normally aiming to set it at a level that appears to represent the market average. We will also seek advice from colleagues within other organisations, if applicable, when we know they employ people in similar roles.

All DSi staff will be entitled to an annual pay increase in line with the cost of living in their country of residence. For DSi staff working in the UK, this would normally be 3% per annum unless there are significant monetary reasons why this should not happen. Any variance to the annual cost of living increase as stated above must be agreed by the Board of Trustees. Individual staff may be entitled to an annual pay increase over and above the cost of living increase in exceptional circumstances, which must

be agreed by the Board of Trustees. Annual pay increases are paid from the beginning of the financial year.

The board as a whole is responsible for appraising the executive director and deciding on a remuneration package annually, with principles to be observed including a package which is sufficient to attract, retain and motivate, while providing for full disclosure all elements of the package, with any performance-related elements linked to the achievement of specific and measurable targets which are reviewed annually.

Fundraising

We regularly review all our fundraising processes and procedures to ensure that we adhere to the relevant codes of practice and that we are dealing with supporters or potential supporters in a way which aligns with our values.

Vulnerable people are protected as we never share personal data, never put any of our supporters under undue pressure, always seek consent for contact and anyone can opt out of hearing from us at any time.

We do not work with any commercial participators or professional fundraisers. We have never received any complaints related to our fundraising. All fundraising activities are reported on regularly and reviewed by the executive director and trustees.



Statement of responsibilities of the trustees

The trustees (who are also directors of Down Syndrome International for the purposes of company law) **are responsible for preparing the trustees' annual report and the financial statements** in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to **prepare financial statements for each financial year** which give a true and fair view of the state of affairs of the charitable company and group and of the incoming resources and application of resources, including the income and expenditure, of the charitable company and group for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;

- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and group and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Members of the charity guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 March 2022 was 9 (2021: 9). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Independent examiner

The company has taken advantage of the small companies' exemption in preparing the report above.

The following person was appointed to carry out an independent examination of these accounts:

Mr Luke Burns

Fellow Member of the Association of Chartered Certified Accountants (ACCA)

65 Bulmershe Road, Reading, RG1 5RH, UK.

The trustees' annual report has been approved by the trustees on 25 August 2021 and signed on their behalf by:



Bridget Snedden
President
Board of Trustees



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

Down Syndrome International

On accounts for the year
ended

31 March 2022

Charity no 1091843

Responsibilities and
basis of report

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2022**.

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants (ACCA).

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

=

Signed:

Date: 13/11/2022

Name: Mr Luke Burns

Relevant professional
qualification(s) or body
(if any):

Fellow of the Association of Chartered Certified Accountants (ACCA)

Address:

1 Century Drive

Reading

RG7 1PE

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

No material matters have come to attention during the examination.

Annex 1: Membership

Organisation members in Africa

Botswana

Representative Organisation

Down's Syndrome Association of Botswana

Cameroon

Representative Organisation

Aidrikings Foundation

Congo

Affiliate Organisation

Lenire Asbl

Eritrea

Affiliate Organisation

National Association of Intellectual/Developmental
Disability in Eritrea (NAIDDE)

Ethiopia

Affiliate Organisation

Ethiopian National Association on Intellectual
Disabilities

Ghana

Representative Organisation

Robb Foundation

Affiliate Organisation

Inclusion Ghana

Kenya

Representative Organisation

Down Syndrome Society of Kenya

Liberia

Affiliate Organisation

My Heart's Appeal Inc

Libya

Representative Organisation

Libyan Down Syndrome Association

Madagascar

Representative Organisation

Down Syndrome Madagascar

Mauritius

Representative Organisation

Down Syndrome Association Mauritius

Morocco

Representative Organisation

Association Marocaine de Soutien et d'Aide aux
Personnes Trisomiques (AMSAT)

Nigeria

Representative Organisation

Down Syndrome Foundation Nigeria

Affiliate Organisations

Larger Than I Developmental Foundation

Moyinoluwa Rainbow Foundation

Rwanda

Representative Organisation

Rwanda Down Syndrome Organisation (RDSO)

South Africa

Representative Organisation

Down Syndrome South Africa

Tanzania

Representative Organisation

Pearl of People with Down Syndrome Foundation

Affiliate Organisation

Elimisha

Morogoro Saving the Poor Organization

Togo

Representative Organisation

APAPE - Down Syndrome Togo

Tunisia

Affiliate Organisation

AMED (Association Mon Enfant est Different)

Uganda

Representative Organisation

The Uganda Down Syndrome Association (TUDSA)

Affiliate Organisation

Inclusion Uganda

Angel's Center for Children with Special Needs

EmbraceKulture

Rowan's Down Syndrome Awareness Centre

Zimbabwe

Representative Organisation

Zimbabwe Down Syndrome Association

Organisation members in Asia Pacific

Australia

Representative Organisation

Down Syndrome Australia

Affiliate Organisation

e.motion 21

Bangladesh

Representative Organisation

Down Syndrome Society of Bangladesh

Affiliate Organisation

Bangladesh Down Syndrome Association

Bhutan

Affiliate Organisation

Ability Bhutan Society

China

Representative Organisation

Macau Down Syndrome Association

Affiliate Organisation

Shanghai Hope Star Public Welfare Development Center

Hong Kong, S.A.R, China

Representative Organisation

Hong Kong Down Syndrome Association

India

Representative Organisation

Down Syndrome Federation of India

Affiliate Organisation

ALAN T21 Welfare Trust

Indonesia

Representative Organisation

Indonesia Down Syndrome Care Foundation (YAPESDI)

Affiliate Organisation

Ikatan Sindroma Down Indonesia (ISDI)

Japan

Representative Organisation

Japan Down Syndrome Society (JDS)

Affiliate Organisation

DSIJ

Malaysia

Affiliate Organisation

Kiwanis Down Syndrome Foundation

Maldives

Representative Organisation

Beautiful Eyes Down Syndrome Association

Mongolia

Representative Organisation

Down Syndrome Association Mongolia (DSAM)

Myanmar

Representative Organisation

Myanmar Down Syndrome Association

Nepal

Representative Organisation

Down's Syndrome Association of Nepal (DSAN)

Down Syndrome Society Nepal

New Zealand

Representative Organisation

New Zealand Down Syndrome Association

Pakistan

Representative Organisation

Karachi Down Syndrome Program

Pakistan Down Syndrome Association (PDSA)

Philippines

Affiliate Organisation

Down Syndrome Association of the Philippines, Inc.

Singapore

Representative Organisation

Down Syndrome Association Singapore

South Korea

Representative Organisation

Korea Down Syndrome Society

Sri Lanka

Representative Organisation

Jinendhi Resource Centre for Down Syndrome

Affiliate Organisation

Jinendhi Resource Centre for Down Syndrome

Kosala Dullewa Foundation for Children with Special Needs

Soulink Lanka

Taiwan

Affiliate Organisation

Down Syndrome Foundation ROC

Vietnam

Affiliate Organisation

My Future

Organisation members in Central Asia

Armenia

Representative Organisation

Sun Children

Georgia

Representative Organisation

Georgian Down Syndrome Association

Kazakhstan

Affiliate Organisation

Solnechnyi Mir

Kyrgyzstan

Representative Organisation

Public Fund of Parents of Children with Down syndrome "Sunterra"

Affiliate Organisation

Luch Dobra (The Ray of Kindness)

Russia

Representative Organisation

Downside Up

Affiliate Organisation

Regional public organization "Time of Changes"

Tajikistan

Representative Organisation

Nazari Digar

Affiliate Organisation

Public Organisation of Parents of Children with Down Syndrome "SiDa"

Public Organisation Open Hearts

Turkey

Representative Organisation

Down Turkiye Down Sendromu Dernegi

Ukraine

Representative Organisation

Ukrainian Charitable Organization "Down Syndrome"

Uzbekistan

Representative Organisation

Downside Sport Uzbekistan

Organisation members in Europe

Regional

Affiliate Organisation

European Down Syndrome Association (EDSA)

Albania

Representative Organisation

Down Syndrome Albania Foundation

Jonathan Center

Austria

Representative Organisation

Down-Syndrom Österreich

Belgium

Representative Organisation

Down Syndrome Foundation Belgium

Affiliate Organisation

APEM T21

Downsyndroom Vlaanderen

Inclusion ASBL

Bosnia & Herzegovina

Representative Organisation

Udruzenje Zivot Sa Down Syndromom

Bulgaria

Representative Organisations

Association of the Parents of Children with Down Syndrome

Life with Down Syndrome

Croatia

Representative Organisation

Croatian Down Syndrome Association

Cyprus

Representative Organisation

Pan Cyprian Down Syndrome Association

Denmark

Representative Organisation

Landsforeningen Downs Syndrom

Estonia

Representative Organisation

Downi Sundroomi Uhing / Down Syndrome Association Estonia

France

Representative Organisation

Trisomie 21 France

Germany

Representative Organisation

Deutsches Down-Syndrom InfoCenter

Gibraltar

Representative Organisation

Down's Syndrome Support Group Gibraltar (DSSGG)

Greece

Representative Organisation

Down Syndrome Association of Greece

Hungary

Affiliate Organisation

Down Egyesület

Ireland

Representative Organisation

Down Syndrome Ireland

Affiliate Organisation

The Down Syndrome Centre (Ireland)

Italy*Representative Organisation*

Associazione Italiana Persone Down

Affiliate Organisation

Coordinamento Nazionale Associazioni delle Persone con Sindrome de Down (CoorDown)

Kosova*Representative Organisation*

Down Syndrome Kosova

Lithuania*Representative Organisation*

Down Syndrome Lithuania

Macedonia*Affiliate Organisation*

Trisomija 21 - Skopje

Malta*Representative Organisation*

Down Syndrome Association Malta

Malta*Affiliate Organisation*

Inspire

Netherlands*Affiliate Organisation*

Stichting Down Syndroom (SDS)

Norway*Representative Organisation*

Norsk Nettverk for Down Syndrom (NNDS)

Poland*Affiliate Organisations*

Ja Tez

Jeden Swiat

Legnickie Stowarzyszenie Rodzin i Przyjaciol Dzieci z Zespołem Downa Otworz Serce

Zakatek 21 Society of Parents and Friends of Children with Down Syndrome

Zespoldowna.info

Portugal*Affiliate Organisation*

Pais21

Romania*Affiliate Organisation*

Asociatia Down Bucuresti

Asociatia Ioana-Maria

European Centre for the Rights of Children with Disabilities

Russia*Representative Organisation*

Downside Up

Affiliate Organisation

Regional public organization "Time of Changes"

Slovakia*Representative Organisation*

Spolocnost' Downovho Syndromu na Slovensku

Spain*Representative Organisation*

Down Espana

Affiliate Organisation

ASNIMO

Sweden*Representative Organisation*

Svenska Downforeningen

Switzerland*Representative Organisation*

Insieme 21

Avventuno

Affiliate Organisation

Light for Sight Foundation

Turkey

Representative Organisation

Down Turkiye Down Sendromu Dernegi

Ukraine

Representative Organisation

Ukrainian Charitable Organization "Down Syndrome"

United Kingdom

Representative Organisation

Down's Syndrome Association (UK)

Down's Syndrome Scotland

Affiliate Organisation

Cheshire Down's Syndrome Support Group

Down Syndrome Extra 21

Down Syndrome Medical Interest Group UK and Ireland (DSMIG-UK)

Down Syndrome Research Foundation UK

Down's Heart Group

Sports Union for Athletes with Down Syndrome (SU-DS)

Organisation members in Middle East

Iran

Representative Organisation

Aseman Nili Down Syndrome Association

Affiliate Organisation

Down Syndrome Association of Gilan

Iraq

Representative Organisation

Down Syndrome Association of Iraq (Hiba Centre for Down Syndrome)

Israel

Representative Organisation

Yated Down Syndrome Parents Association

Jordan

Representative Organisation

Jasmine Association for Children with Down Syndrome

Lebanon

Representative Organisation

Lebanese Down Syndrome Association

Affiliate Organisation

National Rehabilitation and Development Center (NRDC)

Oman

Representative Organisation

Oman Down Syndrome Association

Palestinian Territory

Representative Organisation

Al-Raheem (Down Syndrome Friends) Association

Affiliate Organisation

Right to Live Society

Qatar

Representative Organisation

HOPE Qatar Center for children with special needs

Saudi Arabia

Affiliate Organisation

Werathah

Help Center

United Arab Emirates

Representative Organisation

Emirates Down Syndrome Association

Yemen

Representative Organisation

Yemeni Down Syndrome Society (YDSS)

Organisation members in North America

Bahamas

Representative Organisation

The Bahamas Down Syndrome Association and Center

Bermuda

Representative Organisation

Bermuda Down Syndrome Support Group

Canada

Representative Organisation

Canadian Down Syndrome Society

Affiliate Organisation

Down Syndrome Resource Foundation

T21 Association Ouest Africaine

Dominican Republic

Representative Organisation

Asociacion Dominicana de Sindrome de Down

Grenada

Representative Organisation

Grenada Down Syndrome Association

Jamaica

Representative Organisation

Jamaica Down's Syndrome Foundation

Trinidad and Tobago

Representative Organisation

Down Syndrome Family Network

United States

Representative Organisation

National Down Syndrome Society (NDSS)

Affiliate Organisation

Alexander's Angels, Inc.

LuMind IDSC Foundation

National Down Syndrome Congress (NDSC)

San Diego Down Syndrome Organisation

Down Syndrome Affiliates in Action

Organisation members in South and Central America

Argentina

Representative Organisation

Asociacion Sindrome de Down de la Republica Argentina (ASDRA)

Brazil

Representative Organisation

Federacao Brasileira das Associacoes Sindrome de Down

Affiliate Organisation

Instituto Alana

MetaSocial Institute

Movimento Down

Chile

Representative Organisation

Fundacion down 21 Chile

Affiliate Organisation

Pro Inclusion Rayos de Sol

Colombia

Representative Organisation

Fundacion Sindrome de Down del Caribe (Fundown Caribe)

Costa Rica

Representative Organisation

Fundacion El Futuro es de Todos

El Salvador

Representative Organisation

Fundacion Club de Amigos Especiales a Distancia de El Salvador (FUNCAEDES)

Guatemala

Representative Organisation

Asociacion Guatemalteca para el Sindrome de Down

Affiliate Organisation

Fundacion Margarita Tejada Para Sindrome Down

Honduras

Representative Organisation

Integrar, Fundacion Sindrome de Down, Honduras

Affiliate Organisation

Centro de Educacion Activa

Mexico

Representative Organisation

Fundacion John Langdon Down

Affiliate Organisation

Comunidad Educativa Incluyente

Taller de Expresion y Desarrollo Integral A.C. (TEDI)

Trisomia 21 A.C.

Nicaragua

Affiliate Organisation

Fundacion 21 Sindrome de Down Nicaragua

Panama

Affiliate Organisation

Fundacion Down Panama

SD Padres en Accion

Paraguay

Affiliate Organisation

Asociacion de Padres de Personas con Sindrome de Down de Itapua

Fundacion Saraki

Peru

Representative Organisation

Sociedad Peruana de Sindrome Down (SPSD)

Affiliate Organisation

Asociacion Proyecto Yannick

Venezuela

Representative Organisation

Asociacion Venezolana para el Sindrome de Down (AVESID)

Down Syndrome International					
Consolidated statement of financial activities (incorporating and income and expenditure account)					
For the year ended 31 March 2022					
	Note	Unrestricted funds £	Restricted funds £	2021/22 total funds £	2020/21 total funds £
Income from:					
Donations and legacies	2	197,290	-	197,290	190,589
Charitable activities					
1. Policy and practice, information, advice and support	3	-	22,390	22,390	60,396
2. Network development and training	3	1,840	46,720	48,560	95,168
3. Advocacy and campaigning	3	-	75,899	75,899	40,735
Other trading activities	4	69,430	-	69,430	24,964
Total income		268,561	145,008	413,569	411,852
Expenditure on:					
Raising funds	5	118,639	-	118,639	52,240
Charitable activities					
1. Policy and practice, information, advice and support	5	54,310	12,835	67,145	113,443
2. Network development and training	5	52,792	39,681	92,473	127,288
3. Advocacy and campaigning	5	39,663	41,562	81,224	89,320
Total expenditure		265,404	94,078	359,482	382,291
Net income/(expenditure) for the year		3,157	50,930	54,087	29,560
Net movement in funds		3,157	50,930	54,087	29,560
Reconciliation of funds:					
Total funds brought forward		39,079	18,323	57,402	27,842
Total funds carried forward		42,236	69,253	111,489	57,402
All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 21 to the financial statements.					

Down Syndrome International			
Balance Sheet			
As at 31 March 2022			
	Note	2021/22 £	2020/21 £
Fixed assets:			
Tangible assets		-	-
Investments		-	-
Total fixed assets:		-	-
Current assets:			
Stock			
Debtors		105,376	36,739
Laptop reimbursement		764	-
Cash at bank and in hand		61,377	65,801
Total current assets:		167,517	102,539
Liabilities:			
Creditors: amounts falling due within one year		52,568	45,138
Membership fees paid in advance		3,460	
Net current assets (liabilities):		111,489	57,402
Total net assets (liabilities):		111,489	57,402
Funds:	11		
Restricted income funds		69,253	18,323
Unrestricted income funds		42,236	39,079
Total funds:		111,489	57,402

- The company was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small companies.
- The members have not required the company to obtain an audit in accordance with section 476 of Companies Act 2006.
- The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.
- These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies regime and in accordance with FRS102 SORP.

Approved by the trustees on 7 December 2022 and signed on their behalf by*:



Bridget Snedden – President, Board of Trustees

* this is also the signature of a director authenticating accounts being sent to Companies House.

Down Syndrome International			
Consolidated statement of cash flows			
For the year ended 31 March 2022			
	Note	2021/22 £	2020/21 £
Cash flows from operating activities:			
Net cash used in operating activities		4,423	1,315
Cash flows from investing activities:		-	-
Net cash used in investing activities		-	-
Change in cash and cash equivalents in the year		4,423	1,315
Cash and cash equivalents at the beginning of the year		65,801	64,486
Cash and cash equivalents at the end of the year		61,377	65,801

Down Syndrome International
Notes to the financial statements
For the year ended 31 March 2022

1. Accounting policies

a) Statutory information

Down Syndrome International is a charitable company limited by guarantee and is incorporated in England. The registered office address is Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS. The principal place of business is 7/9 Chapel Street, Exmouth, Devon, EX8 1HR.

b) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (August 2014) and the Companies Act 2006.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

c) Public benefit entity

The charitable company meets the definition of a public benefit entity under FRS 102.

d) Going concern

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

There are no key judgements that the charitable company has made which have a significant effect on the accounts.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

e) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Income generated from the supply of goods or services is included in the statement of financial activities in the period in which the supply is made.

Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when received.

Revenue grants are credited to the statement of financial activities when received or receivable whichever is earlier.

Where unconditional entitlement to grants receivable is dependent upon fulfilment of conditions within the charity's control, the incoming resources are recognised when there is sufficient evidence that conditions will be met. Where there is uncertainty as to whether the charity can meet such conditions, the incoming resource is deferred.

Membership income is included in full in the statement of financial activities when received.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

f) Donations of gifts, services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item or received the service, any conditions associated with the donation have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), volunteer time is not recognised so refer to the trustees' annual report for more information about their contribution.

On receipt, donated gifts, professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

g) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

h) Fund accounting

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

i) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Expenditure is classified under the following activity headings:

- Costs of raising funds relate to the costs incurred by the charitable company in inducing third parties to make voluntary contributions to it, as well as the cost of any activities with a fundraising purpose;
- Expenditure on charitable activities includes the costs of delivering services and campaigning undertaken to further the purposes of the charity and their associated support costs;

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

j) Allocation of support costs

Resources expended are allocated to the particular activity where the cost relates directly to that activity. However, the cost of overall direction and administration of each activity, comprising the salary and overhead costs of the central function, is apportioned on the following basis which are an estimate, based on staff time, of the amount attributable to each activity.

Where information about the aims, objectives and projects of the charity is provided to potential beneficiaries, the costs associated with this publicity are allocated to charitable expenditure.

Support and governance costs are re-allocated to each of the activities on the following basis which is an estimate, based on staff time, of the amount attributable to each activity:

• Cost of raising funds	25%
• Policy and practice, information, support and advice	25%
• Network development and training	25%
• Advocacy and campaigning	25%

Governance costs are the costs associated with the governance arrangements of the charity. These costs are associated with constitutional and statutory requirements and include any costs associated with the strategic management of the charity's activities.

k) Operating leases

Rental charges are charged on a straight-line basis over the term of the lease.

l) Tangible fixed assets

Items of equipment are capitalised where the purchase price exceeds £1,000. Depreciation costs are allocated to activities on the basis of the use of the related assets in those activities. Assets are reviewed for impairment if circumstances indicate their carrying value may exceed their net realisable value and value in use.

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

• Leasehold improvements	5 years
• Fixtures and fittings	5 years
• Computer equipment	3 years

m) Listed investments

Investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the balance sheet date using the closing quoted market price. Any change in fair value will be recognised in the statement of financial activities and any excess of fair value over the historic cost of the investments will be shown as a fair value reserve in the balance sheet. Investment gains and losses, whether realised or unrealised, are combined and shown in the heading "Net gains/(losses) on investments" in the statement of financial activities. The charity does not acquire put options, derivatives or other complex financial instruments. Investments in subsidiaries are at cost.

n) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks. Donated items of stock, held for distribution or

resale, are recognised at fair value which is the amount the charity would have been willing to pay for the items on the open market.

o) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

p) Short term deposits

Short term deposits include cash balances that are invested in accounts with a maturity date of between 3 and 12 months.

q) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account. Cash balances exclude any funds held on behalf of service users.

r) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

s) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

t) Pensions

Payments to the stakeholder pension scheme are charged as an expense as they fall due.

2. Income from donations and legacies

	Unrestricted funds £	Restricted funds £	2021/22 total funds £	2020/21 total funds £
Gifts	157,714	-	157,714	143,098
Legacies	-	-	-	-
Donated services	39,576	-	39,576	47,491
Total income from donations and legacies	197,290	-	197,290	190,589

3. Income from charitable activities

Down Syndrome International – Income from Charitable activities				
For the year ended 31 March 2022				
	Unrestricted funds £	Restricted funds £	2021/22 total funds £	2020/21 total funds £
Actelion Pharmaceuticals (Cardiac Consensus Statement)	-	-	-	15,965
Inclusion International (Inclusive Participation Guidelines)	-	3,750	3,750	-
International Disability Alliance (Programme Team Funding)	-	12,740	12,740	-
International Disability Alliance (via Inclusion Works Consortium - UK Aid)	-	-	-	14,831
International Disability Alliance (Inclusive Participation Guidelines)	-	5,900	5,900	29,600
Sub-total Policy and Practice, Information, Support and Advice	-	22,390	22,390	60,396
Nazari Digar (Human Rights and Education Consultancy)	-	-	-	1,976
Down Turkiye (Self-Advocacy Consultancy)	1,590	-	1,590	-
Down Syndrome Albania Foundation (Self-Advocacy Consultancy)	250	-	250	-
Centre for Acceleration of Social Technology CAST (Communication Solutions for People with Down Syndrome)	-	-	-	10,000
International Disability Alliance (Programme Team Funding)	-	12,740	12,740	-
International Disability Alliance (via UK Aid)	-	-	-	-
International Disability Alliance (via Norwegian Agency for Development Cooperation)	-	33,980	33,980	83,192
Sub-total for Network Development and Training	1,840	46,720	48,560	95,168
Down's Syndrome Association UK (Inclusive Education UK Pilot Study)	-	50,000	50,000	-
Cente for Acceleration of Social Technology CAST (Communication Solutions for People with Down Syndrome)	-	5,000	5,000	-
International Disability Alliance (Programme Team Funding)	-	12,740	12,740	-
International Disability Alliance (via COVID-19 Pooled Fund - UK Aid)	-	1,010	1,010	29,465
International Disability Alliance (via Inclusion Works Consortium - UK Aid)	-	7,149	7,149	11,270
Sub-total for Advocacy and Campaigning	-	75,899	75,899	40,735
Total income from charitable activities	1,840	145,008	146,848	196,299

4. Income from other trading activities

	Unrestricted funds £	Restricted funds £	2021/22 total funds £	2020/21 total funds £
Fundraising events	-	-	-	-
Trading	69,430	-	69,430	24,964
Total income from other trading activities	69,430	-	69,430	24,964

5. Analysis of expenditure		Charitable activities						
	Cost of Raising Funds £	Policy and Practice, Information, Support and Advice £	Network Development and Training £	Advocacy and Campaigning £	Governance Costs £	Support Costs £	2021/22 Total £	2020/21 Total £
Staff costs (Note 7)	50,147	36,651	31,118	44,727	11,838	21,677	196,157	159,109
Cost of operating online shop	40,250	-	-	-	-	-	40,250	6,399
Fundraising event and other fundraising costs	1,433	-	-	-	-	-	1,433	5,713
Advertising, marketing and publicity	11,088	13,050	13,050	13,050	-	-	50,238	51,983
Grant making for projects and activities	-	-	28,505	3,510	-	-	32,015	94,754
Spending on projects and activities	-	1,684	4,041	4,177	-	-	9,902	37,524
Office running costs and equipment	-	-	-	-	-	9,735	9,735	9,203
Consultants and professional fees	-	-	-	-	48	1,000	1,048	1,048
Rent, insurance and maintenance	-	-	-	-	-	11,081	11,081	9,476
Travel, meetings and conferences	-	39	39	39	-	-	117	422
Management, communications, finance, data and storage operational Systems	-	-	-	-	-	7,504	7,504	6,662
Sub-total	102,919	51,424	76,753	65,504	11,886	50,996	359,482	382,291
Support costs	12,749	12,749	12,749	12,749	-	(50,996)		
Governance costs	2,971	2,971	2,971	2,971	(11,886)			
Total expenditure 2021/22	118,639	67,145	92,473	81,224			359,482	

6. Grant making

	2021/22 total funds £	2020/21 total funds £
Cost		
Rwanda Down Syndrome Organisation	10,731	17,840
Down Syndrome Society of Kenya	4,752	18,536
Down Syndrome Foundation Nigeria	4,800	4,250
Inclusion Uganda	7,904	20,295
Down Syndrome Society of Bangladesh	3,829	9,843
Down Syndrome Albania Foundation	-	4,550
Asociacion Sindrome de Down de la Republica Argentina (ASDRA)	-	3,735
Federacao Brasileira das Associacoes Sindrome de Down	-	5,715
Indonesia Down Syndrome Care Foundation (YAPESDI)	-	5,050
Down Syndrome South Africa	-	4,940
At the end of the year	32,015	94,754

7. Analysis of staff costs, trustee remuneration/expenses and cost of key management personnel

Staff costs were as follows:

	2021/22 total funds £	2020/21 total funds £
Salaries and wages	174,452	140,254
Social security costs	14,377	12,258
Employer's contribution to defined pension schemes	4,903	4,520
Total	193,732	157,032

No employee earned more than £60,000 during the year (2020/21: £nil). The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £59,189 (2020/21: £59,197).

The charity trustees were neither paid nor received any other benefits from employment with the charity in the year (2020/21: £nil). No charity trustee received payment for professional or other services supplied to the charity (2020/21: £nil).

Trustees' expenses represent the payment or reimbursement of travel, accommodation and subsistence costs totalling £0 (2020/21: £0) incurred by 0 (2020/21: 0) members relating to participation in project activities and governance meetings.

8. Staff numbers

The average numbers of employees (head count based on number of staff employed) during the year was as follows:

	2021/22 No.	2020/21 No.
Raising funds	1	1
Charitable activities	7	7
Support	3	3
Governance	1	1
Total	12	12

9. Related party transactions

There are no donations from or to related parties which are outside the normal course of business.

Membership fee transactions have taken place during the year with many members of Down Syndrome International. Membership requires a fee and in exchange basic support and advice is provided, members participate as partners or stakeholders in our activities and we promote our members' work. The maximum annual fee charged for membership is £240. Some DSI members purchase merchandise from our shop related to World Down Syndrome Day for sale or distribution in their own countries. DSI also makes grants to certain members, as set out in note 6 of these notes to the accounts.

The Down's Syndrome Association (DSA) is a member of DSI. DSI uses office space at DSA's headquarters. The Chief Executive of DSA, Carol Boys, is a trustee of Down Syndrome International. DSI's Executive Director, Andrew Boys, is Carol's son. DSA is the payroll agency for DSI.

General donations and restricted grants are given by DSA to DSI to support our work. Donations for certain events and activities organised together are shared equally.

DSA made the following payments to DSi during the year:	2021/22 £	2020/21 £
Donations and grants	56,000	55,000
Membership fee	180	240
Income to fund inclusive education UK pilot study	50,000	-
Merchandise	25,040	-
Total	131,220	55,240

DSi made the following payments to DSA during the year:	2021/22 £	2020/21 £
Staff costs for shared community fundraiser	-	813
Total	-	813

DSi received funds from 3 other members in 2021/22 - £1,590 from Down Turkiye and £250 from Down Syndrome Albania Foundation (both for self-advocacy consultancy) and a general grant of £2,815 from Alexander's Angels, Inc.

DSi received separate grants of £38,220, £5,900, £33,980, £1,010 and £7,149 in 2021/22 from International Disability Alliance (IDA) for various projects. DSi is a member of IDA. DSi also received £3,750 from fellow IDA member and project partner Inclusion International.

10. Taxation

The charity is exempt from corporation tax. All its income is charitable and is applied for charitable purposes.

11. Movement in funds

Down Syndrome International - Movement in funds (current year) - For the year ended 31 March 2022					
	At the start of the year £	Incoming resources and gains £	Outgoing resources and funds £	Transfers £	At the end of the year £
Restricted funds:					
Inclusion Works - employment and COVID-19 advocacy in Africa and Bangladesh	(3,073)	7,149	4,076	-	-
CAST - finding digital communication solutions for people with Down syndrome	-	5,000	5,000	-	-
NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa	6,147	33,980	36,496	-	3,630
Inclusive education UK pilot study	-	50,000	28,290	-	21,710
COVID-19 Pooled Fund - COVID-19 advocacy in Albania, Argentina, Brazil, Indonesia and South Africa	-	1,010	1,010	-	-
International guidelines for inclusive participation of people with intellectual disabilities	1,932	9,650	9,650	-	1,932
DSi programme team funding	-	38,220	9,555	-	28,665
International guidelines on cardiac disorders in people with Down syndrome	13,317	-	-	-	13,317
Total restricted funds	18,323	145,008	94,078	-	69,254
Unrestricted funds:					
Designated funds:					
The National Lottery Community Fund - COVID-19 response	-	10,000	10,000	-	-
The Joffe Charitable Trust - fundraising staff resources	-	26,000	26,000	-	-
Down Turkiye - self-advocacy consultancy	-	1,590	1,590	-	-
Down Syndrome Albania Foundation - self-advocacy consultancy	-	250	250	-	-
Total designated funds	-	37,840	37,840	-	-
General funds	39,079	230,721	227,564		42,236
Total unrestricted funds	39,079	268,561	265,404	-	42,236
Total funds	57,402	413,569	359,482	-	111,489

Purposes of restricted funds

Inclusion Works - employment and COVID-19 advocacy Bangladesh and webinar series

Supporting our member in Bangladesh to deliver employment and COVID-19 related advocacy. Preparation for and delivery of self-advocate led webinar series on inclusive employment of persons with intellectual disabilities.

CAST - finding digital communication solutions for people with Down syndrome

Running a project to look at and find solutions for the key problem that people with Down syndrome are not involved enough in the work of organisations that represent them, something which has been exacerbated by the COVID-19 pandemic and the transition to online communications.

NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa

Technical human rights training and COVID-19 advocacy training for our members organisations in Kenya, Nigeria, Rwanda and Uganda and self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda. Supporting all these organisations to deliver employment and COVID-19 related advocacy.

Inclusive education UK pilot study

A 12 month study researching the current state of inclusive education in the UK. Extensive consultation with a wide range of stakeholders to produce a report, running webinars and a campaign advocating for inclusive education, including a blog series and production of resources for use by parents and professionals.

COVID-19 Pooled Fund

Supporting 5 of our national member organisations developing COVID-19 specific advocacy activities.

International guidelines for inclusive participation of people with intellectual disabilities

Developing the International Guidelines for Inclusive Participation, jointly with Inclusion International. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can participate in decision making processes.

Programme team funding

Funding for the salaries of our programme team, specifically DSI's programme director, to enable the completion of crucial projects, the continuation of others and the development of a programme strategy.

Consensus statement on cardiac disorder in people with Down syndrome

Publishing a consensus statement on cardiac disorder in people with Down syndrome, following a systematic evidence review, detailed advice from world leading experts in this field and structured input from international stakeholders.

Purposes of designated funds

The National Lottery Community Fund - COVID-19 response

Undertaking vital work addressing the ongoing negative impact of the COVID-19 pandemic on people with Down syndrome and their families in the UK and around the world – including provision of information and resources and advocating for fully inclusive responses.

The Joffe Charitable Trust - Fundraising strategy research and fundraising staff resources

Publishing and rolling out a new fundraising strategy for DSI, delivered by our fundraising officer, to improve DSI's financial sustainability.

Down Turkiye - self-advocacy consultancy

Down Syndrome Albania Foundation - self-advocacy consultancy

Advising our members to facilitate self-advocacy, empowering people with Down syndrome to advocate for their rights.

12. Legal status of the charity

The charity is a company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £10.

Accounts

DOWN SYNDROME INTERNATIONAL (DSi)



REPORT OF TRUSTEES (AND DIRECTORS) AND FINANCIAL STATEMENTS

for the period from 1 April 2020 to 31 March 2021

Reference and administrative information

Company number	04327941
Country of incorporation	United Kingdom
Charity number	1091843
Country of registration	England and Wales

Registered Office

Down Syndrome International
Langdon Down Centre
2A Langdon Park
Teddington
Middlesex
TW11 9PS
United Kingdom

Operational Address

Down Syndrome International
7/9 Chapel Street
Exmouth
Devon
EX8 1HR
United Kingdom

Trustees

The trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows:

V dos Santos	(President)
B Snedden	(Vice President)
JP Clarke	(Treasurer)
P Robertson	
C Boys	
R Faragher	
J Tang	
P Almeida	
A L Arellano	

Principal Staff

A Boys	(Executive Director)
	(Company Secretary)

Principal Bankers

HSBC
16 King Street
Covent Garden
London
WC2E 8JF

Solicitors

Russell Cooke
2 Putney Hill
London
SW15 6AB



Introduction

The trustees present their report and independently examined financial statements for the year ended 31 March 2021. The financial statements cover a 12-month period since the previous statements for the year ended 31 March 2020.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with the current statutory requirements, Down Syndrome International's memorandum and articles of association and the Statement of Recommended Practice – Accounting and Reporting by Charities: SORP applicable to charities preparing their accounts in accordance with FRS 102. For a list of members, please refer to Annex 1.

For the year ended 31 March 2021 the organisation's income is greater than £25,000, therefore an independent examination of the financial statements is required.

Objectives and activities

The charity objects of DSI, as stated in the memorandum and articles of association are:

- to promote and protect the physical and mental health of those with Down syndrome through the provision of support and resources to people with Down syndrome, their families and carers, and the professionals who work with them with specific focus on developing countries; and
- to undertake any other charitable activities in connection with Down syndrome and other learning disabilities as the trustees shall determine.

DSi's published mission, aims and objectives seek to take DSI forward as a membership led organisation, providing support and advice, building on and disseminating its pool of information, knowledge and experience, undertaking training and build the capacity of its members, advocating for, representing and campaigning on behalf of the global Down syndrome community. DSI's work improves the understanding of Down syndrome, the capacity to support people with Down syndrome, champions basic rights and ultimately improves quality of life for people with Down syndrome.

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing its mission, aims and objectives and in planning its future activities. In particular, the trustees consider how planned activities will contribute to the mission, aims and objectives they have set. DSI is currently working on a new strategic plan which will build on this.

How our activities deliver public benefit

The implementation of DSI's mission, aims and objectives and who it tries to help are described below. All its charitable activities focus on **enabling people with Down syndrome to live full and rewarding lives** and are undertaken to further its charitable purposes for the public benefit. DSI's mission, aims and objectives fully reflect the purposes the charity was set up to advance.

Who uses and benefits from our services?

DSi is an international organisation of persons with disabilities (OPD), comprising a membership of individuals and organisations from 136 countries, engaging in national, world regional and international activities, all designed to improve lives and ensure basic rights for people with Down syndrome on a full and equal basis with others.

DSi is the network that brings together the global Down syndrome community and its services are available worldwide. The number of people with Down syndrome living worldwide is estimated at 7 million. Demand for DSi's services has grown substantially since it opened its international office in November 2009, providing a dedicated first point of contact for those requiring its services.

The trustees review the aims, objectives and activities of the charity each year. This report looks at what the charity has achieved and the outcomes of its work in the reporting period. The trustees report the success of each key activity and the benefits the charity has brought to those groups of people that it is set up to help. The review also helps the trustees ensure the charity's aims, objectives and activities remained focused on its stated purposes.

Achievements and performance

The charity's main activities in 2020/21 and who we have tried to help are described immediately below in brief summary, based on 3 pillars. More information on each component then follows in this report:

1. Policy and practice, information, support and advice

Played a lead or advisory role in a number of initiatives considering policies and practices on key issues affecting people with Down syndrome, worked with our members and partners to ensure provision of accurate, up to date information and provided advice and support on demand to members and others who needed it around the world.

2. Network development and training

Strengthened our membership network through improving communications, developing alliances and networks of self-advocates, involving members more in our activities and through the delivery of training designed to build the capacity of national member organisations, people with Down syndrome, their families and other stakeholders.

3. Advocacy and campaigning

Ran global campaigns and events and supported regional and national activities advocating for the rights of people with Down syndrome and participated actively in international disability and human rights forums, representing the global Down syndrome community.

In the following report, our thematic areas of focus will be prominent, namely:

- **Advocacy (and self-advocacy)**
- **Early development and parent support**
- **Education**
- **Employment**
- **Health**
- **Inclusive participation**
- **Organisation support**
- **Situations of risk and humanitarian action**

1. POLICY AND PRACTICE, INFORMATION, SUPPORT AND ADVICE

POLICY AND PRACTICE

DSi and our network has a central role formulating and influencing national, regional and global policies and practices which specifically affect people with Down syndrome. 2020/21 saw a wide range of activities in this area.

Production of policy statements and guidelines

Education guidelines

In July 2020, DSi published the **International Guidelines for the Education of Learners with Down Syndrome**. Informed by research, practice and international stakeholder feedback, the document was written by experts in the field, with coordination and oversight from DSi.

The guidelines provide best-practice guidance for learners, teachers and managers in pre-school, school and post-school education settings to promote life-long learning. They are an important starting point in enabling people with Down syndrome to receive the educational support needed to achieve their full potential. They will provide a global reference point and a lobbying tool for education professionals, learners, families and supporters, commissioners of services, national Down syndrome organisations, managers and charities to encourage adoption of best practice in their countries.

Following publication, the guidelines are being disseminated via our global network, supported by toolkits, resources and training opportunities. The document has been translated into French and further official translations will follow. The guidelines will also comprise the **basis for DSi's upcoming Inclusive education advocacy project in United Kingdom** (see page 20 below) and all future projects in the area of education.

A quote from one of our international stakeholders - *"Situating all topics in scientific research conveys security and expands the possibility of deepening the subject. Anyone who reads it and puts it into practice can learn, make changes, and qualify its inclusive process."*



Cardiac consensus statement

As part of DSi's work in healthcare, we are collaborating with international clinical experts to create an up-to-date review and **expert consensus statement on cardiac disease in Down syndrome**.

This document will help health professionals around the world to better understand, diagnose, manage and care for people with Down syndrome with cardiac disease. The guidance will highlight best practice, but also acknowledge the differences that may exist between countries around the world.

A working group made up of 25 leading international specialists in cardiovascular disease and specialists in the treatment of people with Down syndrome, has been working together to write and review this work, following selection of key topic areas (supported by our membership network as stakeholders) and a systematic review of evidence. A consensus statement for each topic area will be prepared.

The original aim was to submit the statement for journal publication before the end of 2020. This has been delayed for a number of reasons, with submission now likely in late 2021. As a preparatory step, our team **published an article about the work we are doing in the Journal of Congenital Cardiology in January 2021.**

Once published, we anticipate this document will have a substantial and positive impact on the care provided by health professionals to people with Down syndrome with cardiac disease.



Thyroid guidelines (UK)

In April 2020, a new UK health guideline **Thyroid Disorder in Children and Young People with Down Syndrome - Surveillance and When to Initiate Treatment**, developed by Down Syndrome Medical Interest Group UK and Ireland (DSMIG UK) was published. DSi was part of the Guideline Development Group.

A comprehensive process including expert and stakeholder input, a systematic review of evidence and robust recommendations was used to develop these guidelines, which are much needed to bring clarity for healthcare professionals in the UK working with children and young people with Down syndrome.

The guidelines have been endorsed by the Royal College of Paediatrics and Child Health (UK), the Royal College General Practitioners (UK), the Royal College of Nursing (UK), the Down's Syndrome Association (DSA - England, Wales and Northern Ireland) and Down's Syndrome Scotland. We hope that they will be a useful resource for medical professionals and improve the care and treatment of children and young people with Down syndrome with thyroid disorder.

Inclusive participation guidelines

Throughout 2020/21, **DSi and Inclusion International have been working together on a project called #ListenIncludeRespect**, developing guidelines for inclusive participation.

Right now, there are more self-advocate leaders than ever working for change. But people with an intellectual disability are often still not included meaningfully in the work that affects them. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) guarantees the right to accessibility and participation for people with an intellectual disability.



We have heard from many organisations, who want to include people with intellectual disabilities in their work. But they need guidance to be more inclusive. While there are also lots of organisations already working with people with intellectual disabilities who do this very well, we can all do better.

So, we have come together to develop the **International Guidelines for Inclusive Participation**. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can take part in a meaningful way.

The guidelines will be used and endorsed by our members, development organisations, UN agencies and governments to become the international standard and will be a reference point to help organisations to know what they need to do to include self-advocates in their work.

Our activities in the last 12 months have included:

- creating and sharing a survey in 10 languages and in an easy-read format;
- members running around 50 consultation events with self-advocates, family members and professionals;
- receiving feedback through the events and survey from over 900 people in 80 countries;
- running a UN Conference of State Parties to the CRPD side-event, led by self-advocates (see "International human rights forums" on page 24 below);
- employing self-advocate consultants in Uganda and Argentina to support the Inclusion International and Down Syndrome International staff team's work and
- starting the first draft of the guidelines using the information and feedback we have collected.

Production of best practice reports, studies and resources

Inclusive employment case study and webinars

In the second half of this year and moving into next year, we have been working on a **case study on best practices related to the employment of persons with Down syndrome and intellectual disabilities**, with a focus on Bangladesh. At the same time, we are also developing a **webinar series on inclusive employment of persons with intellectual disabilities**. Both projects are funded by Inclusive

Futures (Inclusion Works), a UK Aid-funded consortium of 16 disability and development organisations led by Sightsavers, working to create a future that is inclusive of people with disabilities.

We recruited a fellow in Bangladesh to lead the work on developing a case study on best practices related to the inclusive employment of persons with intellectual disabilities. He has undertaken a desk-based review and will go on to interview key stakeholders in Bangladesh, including jobseekers and employees with intellectual disabilities, family members, managers, co-workers, OPDs and NGOs working on employment programmes. Publication of the case study is scheduled for mid-2021.

As of the end of March 2021, we are about to recruit 5 self-advocates with intellectual disabilities from our member organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda to help us develop a webinar series on best practices related to inclusive employment of persons with intellectual disabilities. The self-advocates will lead the delivery of the webinars, scheduled for mid-2021.

World Down Syndrome Congress (WDSC)

The WDSC is an opportunity to disseminate research, information and good practice to a captive audience, while bringing experts, professionals and key stakeholders together to advance knowledge and ensure policy and practice is kept accurate and up to date.

DSi oversees and selects hosts for the WDSC from among our national member organisations. We then work closely with the hosts, providing consultancy services (based on our knowledge and experience from previous events) and maintaining oversight on the event programme.

The next WDSC event was originally scheduled for Dubai, United Arab Emirates (hosted by Emirates Down Syndrome Association) in November 2020. However this had to be delayed due to the COVID-19 pandemic. As of March 2021, with the pandemic continuing to limit international travel and meetings, **the proposal is to hold the first ever virtual WDSC from Dubai in November 2021.**



Following this event, it has also been announced that the next WDSC in Brisbane, Australia (working with hosts Down Syndrome Australia), will be delayed from 2022 until 2024.

Advising on external projects related to Down syndrome and disability policy

Throughout 2020/21, we have regularly contributed to the preparation of international policy statements and comments by the International Disability Alliance (IDA), the UN CRPD Committee, the UN Special Rapporteur on Disability and similar policy influencers. DSi is in Special Consultative (ECOSOC) Status with the United Nations (UN) Department of Economic and Social Affairs.

We continued to play an important role within IDA this year, with DSi represented on the IDA board, programme committee and on task groups. IDA's programme committee advises the IDA board and secretariat on various major disability development programmes, funded by international development agencies, with IDA and its members working on stand-alone programmes and in large consortium programmes with disability development organisations, including members of International Disability and Development Consortium (IDDC). IDA **plays a key role in the positioning of a number of these programmes**, focusing on disability policy, monitoring and development work, ensuring UN CRPD compliance and contribution to UN Sustainable Development Goals (SDGs) via meaningful engagement of persons with disabilities and their representative organisations. IDA has a key role in human rights policy making and disability development programming, giving the perspective of persons with disabilities.



[List of members:](#)



INFORMATION

There is undoubtedly a great demand for up-to-date information resources and the latest research being undertaken and published, in key areas in the field of Down syndrome. There are information resources and research publications across the internet and the world. The extent to which they are provided free of charge, are accurate and evidence-based and are fully accessible (e.g. for people with disabilities, in different languages etc.), varies.

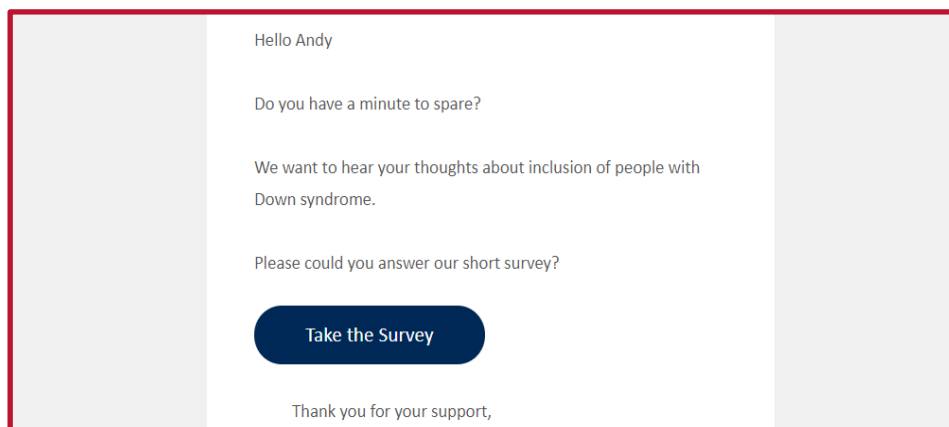
As of March 2021, we continue to work with our members and with key international partners to ensure that **free of charge, high quality and fully accessible information** and the **most important and highest quality research**, is promoted to the global Down syndrome community and beyond.

Our website currently provides information summaries in key areas and we regularly promote information resources and research initiatives to our members and on social media. Meanwhile, we are:

- exploring the production of DSi information resources;
- exploring the best way to promote external information resources and
- considering the most effective way to promote external research,

working with our members and partners including Trisomy 21 Research Society, NIH Down Syndrome Consortium, Alana Foundation, Lumind IDSC Foundation, International Association for the Scientific Study of Intellectual and Development Disabilities, DSMIG UK and DSMIG USA, among others.

We send regular updates and e-newsletters to over 12,000 people around the world including the latest news, updates, research and best practices related to people with Down syndrome.



COVID-19 response

At the time of this report, the COVID-19 pandemic continues. **The pandemic has required an urgent and specific response from DSI**, in line with our commitment to support people with Down syndrome and their families in situations of humanitarian crises.

We have been working hard to respond to the evolving situation and support our members and the global Down syndrome community during these difficult times.

Our response over the last year has included:

➤ Compiling and sharing information

We have been compiling and sharing up-to-date and accurate information on COVID-19 and appropriate responses to it. We created a dedicated area on our website for information and resources related to people with Down syndrome and COVID-19, and via our Global Support blog, email campaigns and social media, we have ensured our community is kept up to date with all new developments and key issues, as they relate to people with Down syndrome and their families.

As of the end of March 2021, we are preparing **information and resources on COVID-19 vaccination advocacy** (see "COVID-19 response advocacy" on page 18 below).

➤ Gathering experiences and evidence

We have worked with our member organisations to gather experiences of people with Down syndrome, families and advocates and other evidence related to COVID-19 and its impact. This includes:

- the availability of information in accessible formats;
- how people with Down syndrome and their families are being included in pandemic responses;
- impact of quarantines on people with Down syndrome and their families;
- support available for people with Down syndrome and their families during the pandemic;
- provision of healthcare for people with Down syndrome affected by COVID-19;

- impact of the pandemic in key areas of life such as education and work and
- availability and prioritisation of vaccinations for people with Down syndrome.

➤ **Support for member organisations**

We have been working with our member organisations to identify the challenges they are facing and the support they need in responding to the COVID-19 pandemic in their countries.

Early in the pandemic, we ran a **series of webinars with our member organisations** both to discuss the challenges and to deliver training on topics that could help them at that time. Subsequently, we are **assisting a number of our member organisations with funding, training and resources to deliver COVID-19 response advocacy activities** (see “COVID-19 response advocacy” on page 18 below).

➤ **International collaboration**

We have been working with the international disability community and IDA to ensure a disability inclusive response to the COVID-19 pandemic. This has included advocating at various stages for action from global bodies, such as World Health Organization (WHO).



SUPPORT AND ADVICE

We receive many enquiries for support and advice from around the world, particularly in Global South countries. This year again, we:

- responded to enquiries from many individuals around the world and
- had regular conference calls with and provided strategic and operational advice to more than 40 member organisations, primarily in Africa, Asia and South America.

We were also able to respond to specific support requests from our member organisations where the need was great and funding could be sourced (see “Member organisation support” on page 12 below).

2. NETWORK DEVELOPMENT AND TRAINING

NETWORK DEVELOPMENT

DSi is a global network made up of member organisations in 136 countries and over 1,000 individual members worldwide. We maintain close contact with our members to keep them informed on relevant research, best practices and strategies to advocate for the rights of people with Down syndrome. We

also seek regular feedback on our work and receive information from countries and regions, to help guide our strategy.



We are continuously:

- developing more effective ways to communicate with and be accountable to members;
- developing national and international advocacy networks of people with Down syndrome;
- supporting national and regional alliances of our members and making alliances with other partners in the Down syndrome and disability movement;
- developing opportunities to engage our members in our activities, ranging from stakeholder consultation in policy and practice activities to participation in our advocacy and campaigning activities and
- building the capacity of our national member organisations through the provision of support, advice, capacity assessment and training.

Working with self-advocates

Down Syndrome International Ambassadors

We have a committee of national representatives with Down syndrome, which currently has members from 23 countries. They represent people with Down syndrome in their country and frequently give us input into our work. This year they were renamed the **DSi Ambassadors**.

This year, the DSi Ambassadors were actively involved in a lot of our work. They advised us at key times throughout the year, in particular in respect of the impact of COVID-19. The Ambassadors contributed to a number of our webinars. They **led a webinar on how they like to be supported** (aligned with our work on inclusive participation, see “Inclusive participation guidelines” on page 5 above) and **a webinar “What changed for us in 2020”**, as part of our World Down Syndrome Day 2021 advocacy campaign (see “2021 WDSD advocacy campaign” on page 20 below). The Ambassadors met with our Board of Trustees and discussed their contribution to the work of DSi. These are only some of the highlights and moving into next year, we will be seeking some crucial contributions from this group in our project work and strategic and operational planning.

Inclusive participation with CAST

Supported by a charity called CAST (Centre for Acceleration of Social Technology), throughout 2020/21 we have been running a project to look at and **find solutions for the key problem that people with Down syndrome are not involved enough in the work of organisations that represent them,**

something which has been exacerbated by the COVID-19 pandemic and the transition to online communications.

Working with self-advocates and DSi member organisations, the project has gone through some key consultation stages (“Explore” and “Definition”) to test the problem and find potential solutions. As of March 2021, the project continues, with 2 self-advocacy networks testing an application and an approach designed to deliver meaningful participation of people with Down syndrome. If successful, we hope this can be utilised by DSi member organisations and other organisations where representation is so important.

Other work with self-advocates

Self-advocates with Down syndrome and intellectual disabilities have played a key role, leading and consulting on our inclusive participation guidelines project (see page 5 above) - on the staff team, leading high-level advocacy webinars and via global consultations.

In March 2021, self-advocates moderated and spoke in all of our World Down Syndrome Day 2021 advocacy campaign webinars (see “2021 WDSD advocacy campaign” on page 20 below).

We are also **working with self-advocates via most of our projects with member organisations** (see “Inclusive employment case study and webinars” on page 6 above, “Self-advocacy facilitation training” on page 16 below and “Other member organisation advocacy” on page 19 below).



Member organisation support

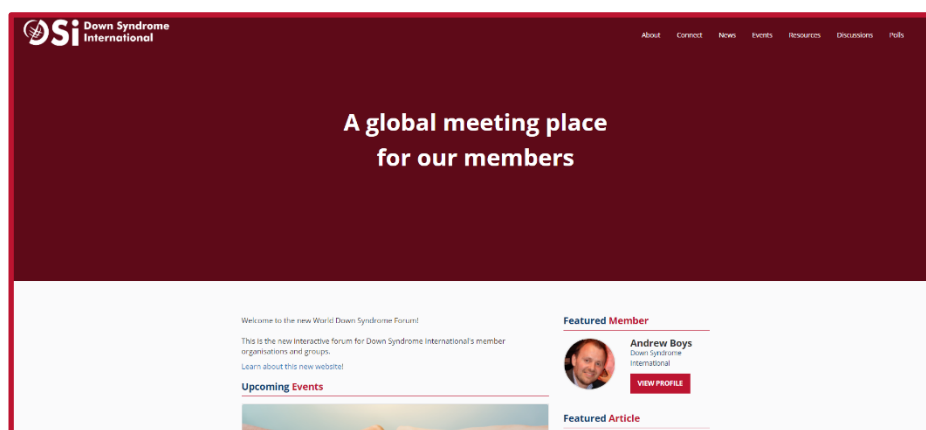
We strongly believe that national Down syndrome organisations know their country best; what they need from DSi is support, to build their capacity and skills.

We **support national Down syndrome organisations with ongoing support, ad hoc strategic and operational advice**. We deliver training within the remit of specific funded projects (see “Training” on page 15 below). Where funding allows, we also support the development of member organisations through grant making and bespoke support, including to deliver advocacy activities (see “Other member organisation advocacy” on page 19 below).

Through all of this work, we are looking to develop members’ capacity to do their own work, develop their strategic and operational systems and evaluate the quality of activities delivered and the impact they have.

World Down Syndrome Forum

In March 2021, we launched the **World Down Syndrome Forum**, a new web-based communication platform for our member organisations. This forum enables our members to connect more effectively with DSI, but crucially also to communicate directly with other DSI members. Via direct messaging, discussion forums, news and events posting and publication of resources, the forum is a global hub providing continuous learning opportunities for leaders and staff of DSI member organisations.



Rwanda

We have been working in Rwanda for the last 4 years, **supporting the development of Rwanda Down Syndrome Organisation** (RDSO - the first Down syndrome specific OPD in Rwanda).

In Rwanda people with Down syndrome and their families are often isolated and lack important information about key issues affecting their lives. They struggle to participate in society due to negative attitudes and have limited access to basic healthcare and education.

In 2016, we supported the establishment of RDSO. As of March 2021, they are supporting in excess of 500 families, who previously had no support and often very little understanding of what Down syndrome was or how it might affect their child.

RDSO has had a major impact in the past year on the lives of people with Down syndrome, including:

- providing 27 free speech and language therapy and occupational therapy sessions for children with Down syndrome, who often need extra support to learn to speak, play and develop essential skills to become more independent;
- providing essential support and advice to parents of children and babies with Down syndrome, who often come to RDSO knowing nothing about Down syndrome and
- establishing Rwanda's first self-advocacy group for persons with Down syndrome, where young people and adults with Down syndrome learn to speak up for themselves and advocate for their rights (see "Self-advocacy facilitation training" on page 16 below).

A success story

Joshua is a 5-year-old boy with Down syndrome from Kigali, Rwanda. When his mother first brought him to the RDSO office he could not walk and the physiotherapy sessions needed to help him learn were unaffordable. The RDSO team advocated for the local government authority to assist the family and in 2020 he received a month of physiotherapy sessions. Now he can walk independently and RDSO

staff are working with the family to find an adequate school and financial assistance to allow him to start attending.



Response to the pandemic

Despite the exceptionally difficult circumstances due to the COVID-19 pandemic and the restrictions imposed by it, RDSO has continued to provide its essential role supporting people with Down syndrome of all ages and their families in Rwanda.

The pandemic disrupted planned activities and many of the families that RDSO work with faced hunger and poverty due to lockdowns cutting off their sources of income. We supported them to respond dynamically, adapting how they delivered services and delivering support where possible to families.

While adapting their ways of working to respond to the pandemic they were also able to take major steps towards operating independently as an organisation.

Financial independence

With our support RDSO has taken the first steps towards financial independence. They are receiving their first international development funding through a project funded by the Norwegian Agency for Development Cooperation (NORAD - see “Employment-based advocacy projects in Africa and Bangladesh” on page 15 below) and are receiving capacity building support from Humanity and Inclusion. They have also started receiving some small donations and support from within Rwanda.

DSi will keep fundraising to support RDSO’s core running costs, while working with them to further reduce their reliance on this support. We are confident that RDSO will soon reach the stage where they can run without our support.

United Kingdom

Following DSi’s commission to:

- undertake a review of the website of the Down’s Syndrome Association (DSA – England, Wales and Northern Ireland);
- outline a new website structure for them and
- source a development team to build a new website,

DSA has spent this year developing their new website and working on content. They are **scheduled to launch their fantastic new website in June 2021**.

TRAINING

Employment-based advocacy project in Africa and Bangladesh

In 2020, DSi began a new 3-year project to advocate for access to employment for people with Down syndrome and intellectual disabilities.

The project, taking place in partnership with International Disability Alliance, with funding from Norwegian Agency for Development Cooperation (NORAD) and partly from Inclusive Futures (Inclusion Works - UK Aid), comprises the following:

- **technical human rights training and COVID-19 advocacy training** for our members organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda;
- **self-advocacy facilitation training** for our member organisations in Kenya, Rwanda and Uganda (following completion of similar training with Bangladesh and Nigeria last year) and
- **employment-based advocacy activities** from all 5 member organisations, led by self-advocacy groups (see “Other member organisation advocacy” on page 19 below).

Technical human rights training and COVID-19 advocacy training

Over 6 weeks in 2020, this training was characterised by interaction, discussions and sharing of experiences between participants. The sessions were attended through a combination of live online workshops and resources and exercises to review and complete between sessions.

The well attended training drew participation from leadership and staff from Down Syndrome Society of Bangladesh, Down Syndrome Society of Kenya, Down Syndrome Foundation Nigeria, Rwanda Down Syndrome Organisation, Inclusion Uganda and Uganda Down Syndrome Association.

Topics covered included:

- an introduction to human rights and development;
- The UN Convention on the Rights of Persons with Disabilities (CRPD) and Sustainable Development Goals (SDGs);
- public policy and network building and
- organisations of persons with disabilities and inclusive participation.



Self-advocacy facilitation training

As of end of March 2021, we are delivering self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda.

People with Down syndrome often have a limited voice in the decisions and changes that affect them. Decisions are often made without consideration of their opinions and preferences. As a result, their rights are frequently violated.

Prior to this year, we have trained 71 self-advocacy group facilitators from our member organisations in 5 countries: Turkey, Nigeria, Bangladesh, United Arab Emirates and Kosovo. These facilitators have started 8 self-advocacy groups so far with a total of 73 self-advocates with Down syndrome.

The groups support people with Down syndrome to learn about human rights and build their self-advocacy skills, enabling them to engage in a variety of advocacy activities.

Participation in the self-advocacy groups has also had a very positive impact on the individuals with Down syndrome. This has included increased confidence, more positive attitudes towards having Down syndrome, and better ability to express opinions and advocate for their rights.

These projects are based on the following methodology:

- initial visit to train self-advocacy group facilitators and work with our member organisation on general understanding of self-advocacy;
- trained facilitators empower self-advocates to start groups and meet regularly over a 10 month period, during which time group discussions lead to advocacy activities;
- DSi returns for a follow up training and monitoring visit 6 months after initial training;
- DSi provides structured support and advice to the facilitators over full 12 months of project;
- After 12 months, the projects are completed, with a report prepared to review success and outcomes;
- member organisations continue and look to build on the project going forward, supported by DSi.

Due to the COVID-19 pandemic and travel restrictions, the delivery of the projects in Kenya, Rwanda and Uganda has partly moved online, but still with good results and this training has been well supported by a project fellow employed in Uganda. See “Other member organisation advocacy” on page 19 below for some example advocacy activities undertaken by the groups.



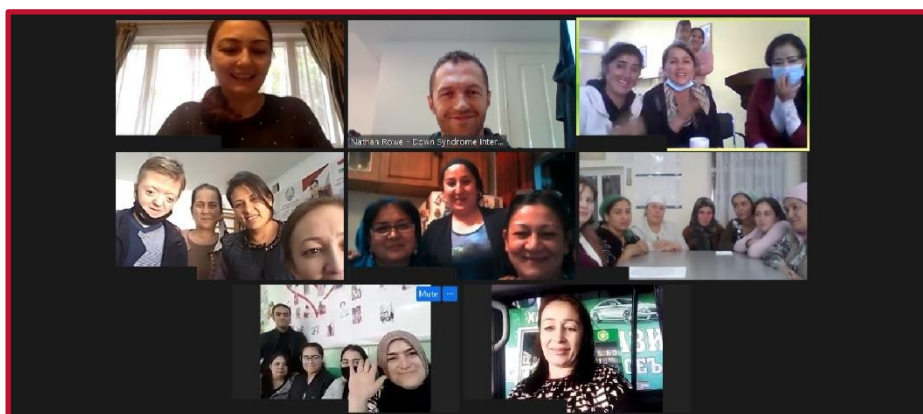
Through these ground-breaking projects, it is an absolute pleasure to see the increase in confidence of self-advocates. We are incredibly proud of each of the self-advocates and all that they have achieved and we look forward to working with them and their organisations to bring about positive change for people with Down syndrome and intellectual disabilities.

Rights-based advocacy training for people with Down syndrome

DSi also works directly with self-advocates with Down syndrome in various international forums, developing their rights-based advocacy skills so they have the tools to speak out. See “Working with self-advocates” on page 11 above.

Human rights training in Tajikistan

This year, as part of a larger advocacy project led by Nazari Digar, our member organisation in Tajikistan, we ran 2 days of online human rights training with parents and family members in Tajikistan and 2 days training with organisations representing people with Down syndrome and their families.



Training for parents and family members

The training included parents and family members from across Tajikistan and one from Russia, with children of varying ages. The participants shared their experiences raising children with Down syndrome and some of the difficulties they faced. Many of their children had faced discrimination and bullying and they had difficulties accessing services they needed. There were also common issues related to education, including rejection from mainstream schools, and requirements to travel long distances or board at special schools.

We provided **training on the rights that persons with Down syndrome have**, including the right to non-discrimination, healthcare, and inclusive education.

Training for organisations representing persons with Down syndrome

The training included organisations representing persons with Down syndrome from across Tajikistan. The issues raised by these representatives were similar to those raised by parents. We provided a **more in-depth advocacy training** for them, focusing on:

- The UN human rights system;
- The UN Convention on the Rights of Persons with Disabilities;
- The Sustainable Development Goals and
- international accountability mechanisms.

As of the end of March 2021, we are now supporting Nazari Digar and the other organisations in the training to plan an advocacy project, focusing on the key issues they identified. They have already conducted interviews with over 100 family members in the country to better understand the issues their children with Down syndrome face and provide good data to support their advocacy work.

As a part of this project we also delivered some basic training to the same representative group on DSI's recently published **International Guidelines for the Education of Learners with Down Syndrome** (see "Education guidelines" on page 4 above).

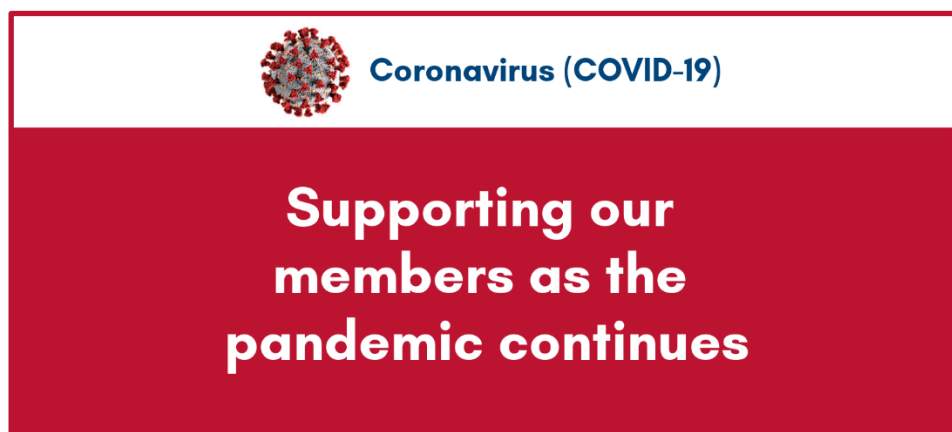
3. ADVOCACY AND CAMPAIGNING

A key part of DSI's role is to **advocate for the rights of people with Down syndrome in line with the UN CRPD**. We do this at national, regional and international levels, working with our members and partners, participating in disability and human rights forums and campaigning to raise awareness in wider society.

COVID-19 response advocacy

Advocating for the rights of people with Down syndrome where the pandemic has had an impact and required responses (see "COVID-19 response" on page 9 above) has been a key focus this year.

We have worked with international partners to undertake global advocacy (see "International collaboration" on page 10 above), we have worked with and supported our national member organisations to deliver crucial advocacy activities and we have supported the global Down syndrome community, providing tools and resources for individuals and families to ensure people with Down syndrome are included in pandemic responses.



In March 2021, we provided grants to 5 of our national member organisations for COVID-19 specific advocacy activities. We will be supporting these members - Down Syndrome Albania Foundation, Asociacion Sindrome de Down de la Republica Argentina (ASDRA), Federacao Brasileira das Associacoes Sindrome de Down, Indonesia Down Syndrome Care Foundation (YAPESDI) and Down Syndrome South Africa – as they prepare and deliver these crucial interventions.

These activities are funded by UK Aid via the COVID-19 Pooled Fund and DSI will be providing more support, resources and training related to COVID-19 response advocacy for other member organisations later in 2021.

As of the end of March 2021, we are preparing **information and advocacy resources on COVID-19 vaccination prioritisation** for people with Down syndrome, with a global campaign planned for mid-2021. This follows a number of previous COVID-19 related global campaigns and distribution of information and resources throughout 2020 (see “COVID-19 response” on page 9 above).

Other member organisation advocacy

Employment-based advocacy project in Africa and Bangladesh

Following our technical human rights training, COVID-19 advocacy training and self-advocacy facilitation training for our members organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda (see “Employment-based advocacy project in Africa and Bangladesh” on page 15 above), later in 2021 we will be supporting **employment-based advocacy activities from all 5 member organisations, led by their self-advocacy groups.**

In fact, the self-advocacy groups have been active this year in terms of advocacy as follows:

In Nigeria

The self-advocacy group visited the Nigerian Institute of Medical Research (NIMR) to advocate for free COVID-19 testing for people with intellectual disabilities. The NIMR agreed to offer free testing for people with intellectual disabilities and their supporters. In addition, NIMR delivered training for people with Down syndrome and their families about COVID-19 and the vaccine, including the effects and benefits for people with Down syndrome.

Nigeria’s self-advocates visited the local Government Chairman of Ifako-Ijaiye to advocate for free face masks, hand sanitiser and a mechanical hand wash machine, as well as free vaccines for people with Down syndrome. The Chairman agreed and is distributing these items via our member organisation.

Nigeria’s self-advocates visited the Kings Seed School in Iju Fagba to speak about inclusion. The self-advocates invited the school to participate in their 'Ring The Bell' campaign to raise awareness of the need to include people with disabilities.



In Uganda

Self-advocates spent time talking about their general wellbeing both at home and in the community. This helped build their confidence to speak up, express their views and learn that their contribution matters and has the power to impact their lives and those around them.

In Rwanda

Self-advocates met with staff from Rwanda Biomedical Center (RBC) to participate in COVID-19 testing. RBC offered to deliver training to the group about COVID-19 and the vaccine so they can make informed decisions.

In Kenya

Down Syndrome Society of Kenya worked with self-advocates to produce easy read materials explaining social distancing, hand washing and mask wearing. These were distributed to people with Down syndrome and their families using WhatsApp.

Inclusive education advocacy project in United Kingdom

Also planned for 2021, DSI will begin a project, working in partnership with our member Down's Syndrome Association (DSA - England, Wales and Northern Ireland), **advocating for inclusive education in United Kingdom**. Through this project, we will:

- use our International Guidelines for the Education of Learners with Down Syndrome (see "Education guidelines" on page 4 above) as a basis to prepare a comprehensive series of information and training resources;
- train and work with the Down syndrome community to advocate for full inclusion in education and
- analyse where key interventions can be made at the policy level and in the UK education system to deliver inclusive education and plan for future activities.

This project has the potential to make a big impact and provide a template for DSI to work with other member organisations on education in countries where our support is needed.

World Down Syndrome Day

DSi brings together the global Down syndrome community on and around **21 March each year** for World Down Syndrome Day (WDSD). We coordinate a range of activities, all designed to advocate for the rights of people with Down syndrome and campaign to raise awareness.



Activities for WDSD in March 2021, included:

2021 WDSD advocacy campaign

Our annual WDSD international advocacy campaign, was based on the theme **"#CONNECT"**:

“Why #CONNECT?”

In 2020 around the world, we all had to adapt the ways we connect with each other. It was a big challenge and many people have been left behind. But it was an opportunity to find new ways to connect. This can be a positive outcome from the COVID-19 pandemic.

*For WSDS 2021 we want to focus on improving connections to **ensure that all people with Down syndrome can CONNECT and participate on an equal basis with others.***

WSDS is a unique annual opportunity for the global Down syndrome community to connect.

We CONNECT so that we can:

- *share ideas, experiences and knowledge;*
- *empower each other to advocate for equal rights for people with Down syndrome, and*
- *reach out to key stakeholders to bring about positive change.*

From now, up to 21 March 2021, Down Syndrome International (DSi) will encourage the global community to CONNECT.

What can you do?

Every year we encourage people with Down syndrome, families, advocates, professionals and organisations to observe WSDS with your own activities.

We want to see this again, more than ever in 2021. So:

- *go ahead and plan whatever is possible and safe to do;*
- *advocate for equal rights for people with Down syndrome in your activities and*
- *if you can, include ideas about #CONNECT into your activities.”*

Through this campaign we worked with people with Down syndrome and those who support and work with them to empower them to advocate for opportunities to #CONNECT.

A wide variety of campaigning resources were used by our members and many other advocates throughout the global community. The campaign was popular around the world and, notwithstanding the continued restrictions of the COVID-19 pandemic, many organised their own campaigns, activities and events, mostly online.



2021 UN conferences and other events

Following the UN declaration of WDS in December 2011, DSi has organised advocacy events in New York and Geneva. In March 2021, the following events took place:

- our **10th annual WDS conference at United Nations (UN) HQ, New York**, held virtually from 17-19 March and
- our **5th annual, self-advocate led, side-event to the Committee on the Rights of Persons with Disabilities at UN Geneva**, held virtually on 19 March.

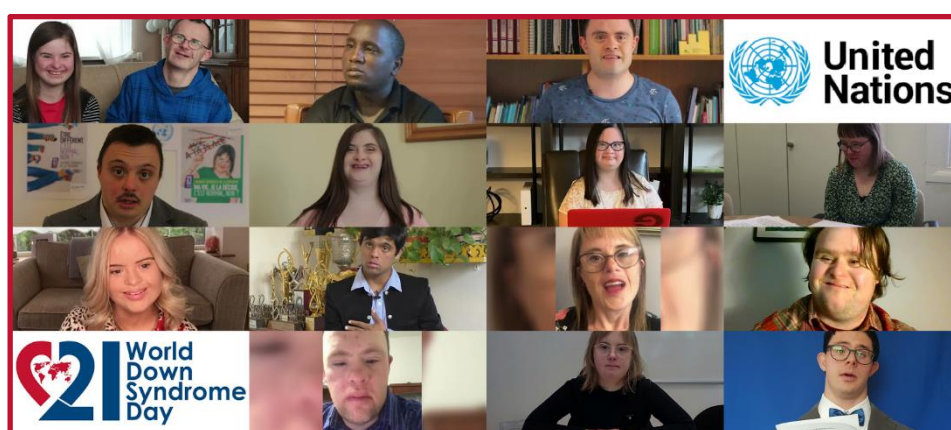
Our New York conference explored the importance of connecting for people with Down syndrome, inclusion and connection in education and barriers and solutions for connecting, all in the context of the COVID-19 pandemic. Moderated by our DSi Ambassadors (see page 11 above), the event comprised 3 webinars and was also broadcast on UN Web TV and Facebook.

Our Geneva side-event was led by self-advocates reaching out to key stakeholders to ensure all people with Down syndrome can #CONNECT and participate on an equal basis with others, particularly during the COVID-19 pandemic. The event comprised a webinar and was broadcast on UN Web TV and Facebook.

This year, DSi also organised the following WDS events:

- **“What changed for us in 2020”** – a webinar in which the DSi Ambassadors (see page 11 above) shared stories from over 100 people with Down syndrome from 14 countries;
- our **1st side-event to the Organization of American States (OAS)**, via webinar and live on Facebook on 16 March, held in Spanish on the subject of “Connect to Include” and
- **#CONNECT for World Down Syndrome Day in Africa** - Africa Down Syndrome Network and partner organisations, including African Union, African Disability Alliance and DSi connected virtually to explore the impact of COVID-19 on people with Down syndrome.

These events were all very well attended and received and we are grateful to all of our event sponsors and fantastic speakers, many of whom were self-advocates.



Videos

Once again, **we worked with Down TV, a global portal for videos related to Down syndrome**. We encouraged people all over the world to upload videos to Down TV’s WDS hub - videos highlighting activities, making a statement or in many cases saying what WDS means to them.

Following the cancellation in 2020 of the annual video campaign organised by our member CoorDown (Italy), we were delighted to work with them again to **launch "The Hiring Chain", featuring a video with an original song performed by 17-time Grammy award winning artist Sting**. The campaign message:

"The message to employers all over the world is that hiring a person with Down syndrome not only changes the life of the person concerned but can trigger a virtuous cycle of new opportunities for everyone. The punchy, joyful lyrics come to life on screen and bear witness to the "virtuous" chain of inclusion in the workplace.

On World Down Syndrome Day 2021, CoorDown takes up the challenge of the pandemic and the social crisis to affirm that job inclusion is not only a right to be guaranteed now more than ever for every person, but it brings benefits in the workplace and in society at large.

Employers inspired by this video should visit hiringchain.org to find contact details for organisations around the world that can provide information, support and encouragement to get people with Down syndrome into their workplace."



The Hiring Chain campaign, designed to find employers and other stakeholders willing to employ people with Down syndrome and advocate for their employment, was a success, with substantial positive feedback. Plans are now being put in place for later in 2021 for **DSi, its members and other partners to develop employment resources, forums and training opportunities** for those interested in this area.

#LotsOfSocks awareness campaign and merchandise

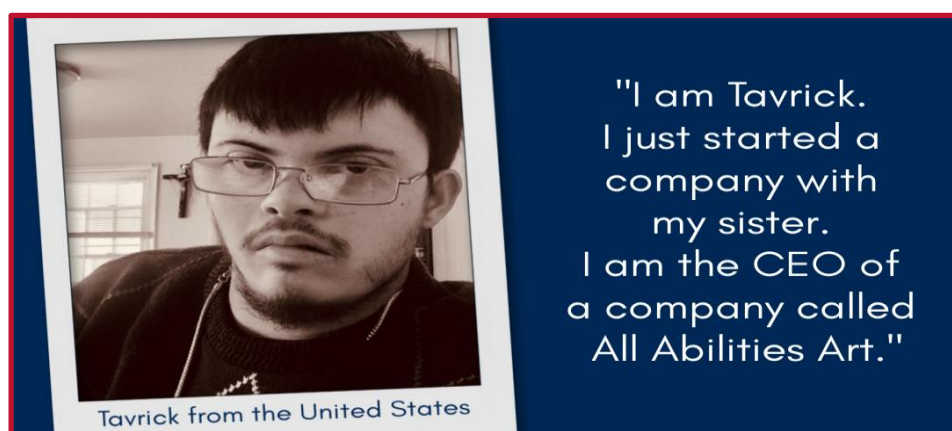
For the 9th year for WSDS 2021, DSi launched the #LotsOfSocks campaign, with the stated aim of asking people across the world to wear socks that draw attention on 21 March 2021, wherever they were, to get people talking.

The campaign was again successful, **generating substantial support on social media**. The DSi office received lots of requests for information, many committed to raise funds, we sold and distributed socks and worked with many organisations, global companies, influencers and the global community to generate global reach on 21 March.

WSDS website

The WSDS website worlddownsyndromeday.org (and associated social media channels) is a global hub for promoting WSDS events and activities, coordinated by DSi. For WSDS 2021, we relaunched the website with some new features, designed to be useful for the global Down syndrome community and

the wider public. In addition to key information about Down syndrome and WDS, our website now features a growing list of stories shared by people with Down syndrome from around the world and includes a wide range of ideas and resources to enable people to participate and take action on WDS.



Other advocacy activities

International human rights forums

In July 2020, DSI was represented at the High-Level Political Forum on Sustainable Development in New York (HLPF) in July, as a part of IDA's Stakeholder Group of Persons with Disabilities for Sustainable Development. In December 2020, DSI participated in the annual Conference of States Parties to the CRPD at UN, New York (COSP), including joint coordination of a side-event with Inclusion International, led by self-advocates, focusing on our **Inclusive participation guidelines** (see "Inclusive participation guidelines" on page 5 above).

Raising funds

As the demand for the charity's services is increasing year on year, **it is imperative to maintain sufficient funding for DSI to operate.**

Income from restricted sources, including trusts, foundations and development agencies increased in 2020/21 with significant projects in the pipeline and this trend looks set to continue in 2021/22. The challenge we have is our ability to generate sufficient restricted funding to carry out all of our charitable activities, but with corresponding programme management income and non-programme attributable (operational) income to cover the costs of carrying out those activities. As of March 2021, a significant proportion of our unrestricted income is used to fund our programme and operational management functions. DSI needs to generate more restricted funds to meet the rising demand for services, while making sure we receive the corresponding programme and operational management income needed to complete our activities successfully. This is something we analyse in detail in our financial forecasting and in our strategy to raise funds.

The income generated from unrestricted sources decreased slightly in 2020/21, but we have been able to fund our activities as described above. Going forward though, DSI needs to generate more unrestricted income and use it primarily to improve our unrestricted reserves position.

DSI's overall strategy for raising funds continues to develop as our activities increase year on year. In 2020/21 we looked for new funding opportunities while also focusing on the sustainability of existing funding channels. A thorough **fundraising strategy review also took place in 2020/21**, supported by

Joffe Charitable Trust, following which **we published a comprehensive fundraising strategy for the next 3 years and were able to appoint a new fundraising officer** to help us deliver this strategy - again thanks to the support of Joffe Charitable Trust.



Financial review

Down Syndrome International's **total income in 2020/21 was £411,852** (2020: £283,036). This increase was due mainly to receiving substantially more restricted funding for charitable activities. We received various instalments of grants from IDA (onward granted from UK AID and Norwegian Agency for Development Cooperation) for employment, self-advocacy, COVID-19 response and inclusive participation projects. We received the 2nd instalment of a grant from Actelion Pharmaceuticals to fund the production of our upcoming cardiac consensus statement. We received 2 grants from Centre for Acceleration of Social Technology (CAST) for our project finding digital solutions for people with Down syndrome to participate. We also received significant unrestricted donations from the Joffe Charitable Trust, The National Lottery Community Fund and the Down's Syndrome Association (DSA).

Total expenditure in 2020/21 was £382,291 (2020: £305,597). This increase reflects substantially higher restricted project expenditure in line with the increase in restricted project income.

Overall there was a **surplus in the 12 month period of £29,560** (2020: deficit £22,561). This surplus, combined with funds brought forward from 2019/20 of £27,841, resulted in **total funds available on 31 March 2021 of £57,402**. Of this, £18,323 is restricted, leaving unrestricted funds available on 31 March 2021 of £39,079.

The above indicates a stronger financial position at the end of 2020/21 compared to the previous year, but **DSi still has insufficient free reserves as required by our reserves policy**. Furthermore, we will require more operational capacity going forward in order to fulfil activities. So careful financial management, combined with a robust strategy to move towards a position of financial sustainability, will be required.

Reserves policy and going concern

The reserves policy states that the unrestricted funds not committed or invested in tangible fixed assets and stocks ('the free reserves') held by the charity should be between 3 to 6 months of the resources expended. That equates to between £95,573 and £191,146 in general funds, based on this year's costs.

At this level the trustees feel that they would be able to continue the current activities of the charity in the event of a significant drop in funding. The trustees are aware that should this occur, consideration would need to be given to how such funding would be replaced or the activities changed.

Currently the free reserves available equate to £39,079, **equivalent to just over 1 month of the resources expended**. It should be noted that gifts in kind totalling approximately £43,370 (based on this year's costs) would not necessarily need to be replaced or change DSI's current activities if they were not received. But even with this allowed for, the current free reserves available are equivalent to less than 3 months of the resources expended.

It should be noted that DSI has an informal "overdraft" agreement with one of its creditors, the Down's Syndrome Association (DSA). DSA acts as a payroll agency for DSI and recovers the salary costs from DSI on a quarterly basis. Under the agreement, DSA allows an informal "overdraft" facility to DSI, up to a maximum of £35,000, to help cover cashflow troughs, should a quarterly invoice not be able to be paid immediately on request.



Risk management

As part of our risk management framework, **major risk reviews are carried out periodically** by the trustees. Top down and bottom up risks are considered, ranked in order of likelihood and impact, those risks needing attention are prioritised and responsibility is allocated for managing each risk. Those responsible provide updates to the trustees on their progress against action plans designed to manage the risks identified. Some of the major risk areas are described below:

Funding: DSI needs to ensure that the services we offer are relevant to beneficiaries, while providing sustainable income. A sudden loss of funding is a major risk for DSI right now, with limited reserves in place. In order to mitigate this, we have a fundraising strategy designed to strengthen and diversify our existing income streams and develop new means of generating both unrestricted and restricted income.

Leadership: The trustees and executive director recognise the importance of ensuring strong direction, motivation of purpose and continuity of leadership. The trustees have reviewed DSI's leadership, have considered the risks of leadership changes and are satisfied with progress, albeit this needs to remain under regular review.

Core activities: High quality and efficient delivery of DSI's core activities are key to its success. Delivery is monitored closely by the executive director and trustees, supplemented by engagement of staff and

stakeholders. The trustees are aware that better systems will be required going forwards, as our activities increase, to improve accountability and monitor progress.

Staff: Staff need to feel engaged and have a stake in the organisation. Their engagement is currently monitored by the president and executive director via staff reviews. Going forwards, staff satisfaction surveys, an organisational health check and new HR policies will be required.

Operational systems: It is critical that operational systems support our core activities, ensuring that the DSI office is run efficiently and effectively. In the last 3 years, DSI has undertaken a lot of work to improve our management, communication, finance, data and storage operational systems, introducing standard operating procedures, automating tasks and ensuring compliance with statutory requirements such as GDPR. This work will continue, with systems undergoing regular testing and review.

Reputation: The retention of confidence of members, stakeholders and donors is key to DSI's effectiveness. Any external facing work needs to be relevant and robust and internal support needs to be well managed. DSI is putting a lot of focus on engaging with stakeholders and this will be built upon going forwards.



Plans for the future

2021/22 will see some significant activities, including:

Policy and practice, information, support and advice

- Continued dissemination of our **international education guidelines** via our global network, including development of further complementary toolkits, resources and training opportunities, making the document accessible in more languages and formats and its playing a key role in all of DSI's future education projects.
- Publication of our **expert consensus statement on cardiac disease in Down syndrome**, followed by post-launch activities to engage with member organisations and the global community and a review of DSI's priorities for health going forward.
- Further development of the **International Guidelines for Inclusive Participation**, working jointly with Inclusion International to draft, consult again and publish the final document.
- Via the Inclusive Futures project, **publish a case study on best practices related to the employment of persons with Down syndrome and intellectual disabilities**.
- Also via the Inclusive Futures project, **support self-advocates to deliver a webinar series on inclusive employment of persons with intellectual disabilities**.

- **Working closely with the hosts of the next WDSC** to organise the first ever virtual WDSC from Dubai in November 2021.
- **Working as a member of IDA** supporting its work and its role in major international disability development programmes, including Inclusive Futures.
- **Continuing to developing our COVID-19 response**, compiling and sharing information, gathering experiences and evidence, collaborating with international partners and supporting our member organisations with specific COVID-19 response advocacy activities.



Network development and training

- Continuing to develop systems which deliver more **effective member communications**, making us more responsive and accountable.
- Working in more depth with the **DSi Ambassadors**, who will assist us delivering training and other project work and will support an internal inclusive participation review, among other activities.
- Continuing to **progress the CAST project**, testing and hopefully promoting an approach designed to include people with Down syndrome in the work of organisations that represent them.
- Continuing to **support national member organisations to develop their capacity**, via the new World Down Syndrome Forum, ad hoc support and advice from DSi and other support resources planned.
- Continuing to **support our member in Rwanda** as they deliver more impact and move towards financial sustainability.
- Completing **self-advocacy facilitation training projects** with our members in Kenya, Rwanda and Uganda.
- Providing more **rights-based advocacy training for people with Down syndrome** via various international forums.
- Following up with our member organisation in Tajikistan as **they develop and execute advocacy activities**.

Advocacy and campaigning

- Supporting our members in Albania, Argentina, Brazil, Indonesia and South Africa **to prepare and deliver crucial COVID-19 response advocacy activities**.
- Launching a **global advocacy campaign on COVID-19 vaccination prioritisation**.

- Supporting **employment-based advocacy activities from 5 member organisations in Africa and Bangladesh**, led by their self-advocacy groups.
- Delivering a **new inclusive education advocacy project in United Kingdom**.
- **Delivery of WDS 2022 activities**, including the launch of the 2022 WDS advocacy campaign, delivery of our WDS UN conferences in New York and Geneva (whether they are in-person or virtual), other WDS events, WDS video projects, “Lots of Socks” awareness campaign and merchandise sales and coordinating the WDS website and social media.
- **Participation in international human rights forums** such as COSP and HLPF.



Raising funds

- Seeking to **increase income from restricted sources**, including trusts, foundations and development agencies, to cover the operational costs of carrying out activities.
- Seeking to **increase income from unrestricted sources**, via general donations, events and merchandise sales, to improve our unrestricted reserves position.
- Overall, looking for new opportunities while **maintaining focus on the sustainability** of existing funding.

2021/22 will also be a very important year as we finalise a new strategy for the next few years. With a new fundraising strategy now in place and a new communications strategy in progress, we have been reviewing our programme activities, purpose, resources, our environment and seeking feedback from our stakeholders ahead of publishing new strategic and operational plans. Given our increased activity levels, increased funding and our need to manage risks, this work will be crucial for DSi to set a clear path to a sustainable future.

Structure, governance and management

The organisation is a charitable company limited by guarantee, registered as a charity on 1 May 2002 and incorporated on 23 November 2001.

The organisation was established under a Memorandum and Articles of Association, which set out the objects and powers of the organisation.

The trustees operate under a Code of Governance, which sets out the basis of board and staff responsibilities, conduct and procedure and a specific procedure for the constitution of the board of trustees to ensure an equitable cross-section of persons and countries.

All of the trustees give their time voluntarily and receive no benefits from the charity. Any expenses reclaimed from the charity are minimal and are set out in note 7 of the accounts.

Appointment of trustees

The Articles of Association state that **the charity has members who all have one vote at general meetings**. The members are the trustees and a member stops being such if he/she ceases to be a trustee.

The trustees can establish other classes of membership as they see fit and the board may admit and remove such members in accordance with regulations made by them, notwithstanding that such members are not members of the charity for the purposes of the Articles of Association or the Companies Act. For the avoidance of doubt, **DSi currently has 2 such classes of membership** – representative membership and affiliate membership.

The **board of trustees manages the business of the charity** and as of 31 March 2021 consists of 9 members, elected by the charity members. The Articles of Association allow for not less than 5 and no more than 21 trustees.

At each annual general meeting one third of the trustees must retire but are all eligible for re-election. Those board members who must retire are decided upon on a rotation basis so that a different third retire each year and an individual will not therefore be required to retire any more frequently than once in every 3-year period.

The board of trustees may co-opt additional members provided that the rules as to the total number of board members and its make-up are not transgressed. Such appointed or co-opted board members should be appointed for a specific purpose and their appointment is subject to a board vote in the usual manner. Such co-opted board members will hold office until the next annual general meeting. They will then be eligible for re-election and to vote at the meetings of the board.



Recruitment, selection and induction of trustees

The Articles of Association require that the board use reasonable endeavours to ensure that there is a wide geographical representation on its board.

The Code of Governance includes a full policy on recruitment, selection and induction of trustees. The board must use open and transparent methods, with posts filled by the person most likely to fill the requirements of DSi as determined by a skills audit, but with reference to a number of recruitment and

selection procedures. Existing trustees must examine the charity's purpose and aims and their duties and responsibilities as trustees, so that they can explain this to new trustees. The board must ensure that they, rather than staff, retain overall responsibility for the process. Trustees must also be aware of the legal rules on eligibility and should consider conflicts of interest.

The board is first required to consider suitable candidates from among DSI's representative members. In the unlikely event that a suitable candidate cannot be found from there, the board may then consider affiliate members and applications from the wider international community.



Notwithstanding the search for candidates with the required skills, the board must be aware of the following key requirements for its composition in their decision-making process:

- 55% of the board must be **persons with Down syndrome or family members** of persons with Down syndrome;
- a maximum of 2 people from any country can be board members at the same time;
- the board will use best endeavours to ensure there is a widespread geographical representation from around the World and there should be at least 1 person from Europe, North America, South America, Africa, Asia and Australia (continent) on the board at all times and
- the board will use best endeavours to ensure that **at least 25% of its members are from “developing economies”** according to the International Monetary Fund's World Economic Outlook Report, April 2015.”

On induction, the board provides all trustees with induction material (including governing documents, annual reports, meeting minutes, strategy and management documents) to allow them to understand their charitable purposes, financial position and current issues.

Related parties and connected organisations

DSi has good links with a large number of Down syndrome, disability and international development organisations worldwide.

We have a close working relationship with the Down's Syndrome Association (DSA), which has led to the location of our registered office in Teddington, information and resource sharing and funding.

Other notable members include Down Syndrome Ireland, Down Syndrome South Africa, Down Syndrome Foundation Nigeria, Down Syndrome Society of Bangladesh, Down Syndrome Federation of India, Down Syndrome Association Singapore, Down Syndrome Australia, Federacao Brasileira das

Associacoes Sindrome de Down (Brazil), Down's Syndrome Scotland, Emirates Down Syndrome Association (United Arab Emirates), National Down Syndrome Society (United States), Down España (Spain) and Trisomie 21 France among many others.

At the regional level, we support the work of European Down Syndrome Association, African Down Syndrome Network, Federación Iberoamericana de Síndrome de Down (Latin America) and Asia Pacific Down Syndrome Federation.

DSi is in special consultative status with the Economic and Social Council of the United Nations (UN), is a member of International Disability Alliance (IDA) and we work closely with Inclusion International.



Remuneration policy

DSi is committed to ensuring a proper balance between paying our staff and others who work for us fairly so that we attract and retain the best people for the job and careful management of our charity funds. In so doing we will ensure the greatest effectiveness in delivering our charitable objectives and meeting the needs of our beneficiaries.

When determining the salary for a newly created post, we will collect information about comparable roles in other organisations, preferably within the voluntary sector. We will use this information to benchmark our own salaries, normally aiming to set it at a level that appears to represent the market average. We will also seek advice from colleagues within other organisations, if applicable, when we know they employ people in similar roles.

All DSi staff will be entitled to an annual pay increase in line with the cost of living in their country of residence. For DSi staff working in the UK, this would normally be 3% per annum unless there are significant monetary reasons why this should not happen. Any variance to the annual cost of living increase as stated above must be agreed by the Board of Trustees. Individual staff may be entitled to an annual pay increase over and above the cost of living increase in exceptional circumstances, which must be agreed by the Board of Trustees. Annual pay increases are paid from the beginning of the financial year.

The board as a whole is responsible for appraising the executive director and deciding on a remuneration package annually, with principles to be observed including a package which is sufficient to attract, retain and motivate, while providing for full disclosure all elements of the package, with any performance-related elements linked to the achievement of specific and measurable targets which are reviewed annually.

Fundraising

We regularly review all our fundraising processes and procedures to ensure that we adhere to the relevant codes of practice and that we are dealing with supporters or potential supporters in a way which aligns with our values.

Vulnerable people are protected as we never share personal data, never put any of our supporters under undue pressure, always seek consent for contact and anyone can opt out of hearing from us at any time.

We do not work with any commercial participators or professional fundraisers. We have never received any complaints related to our fundraising. All fundraising activities are reported on regularly and reviewed by the executive director and trustees.



Statement of responsibilities of the trustees

The trustees (who are also directors of Down Syndrome International for the purposes of company law) **are responsible for preparing the trustees' annual report and the financial statements** in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to **prepare financial statements for each financial year** which give a true and fair view of the state of affairs of the charitable company and group and of the incoming resources and application of resources, including the income and expenditure, of the charitable company and group for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and group and enable them to

ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Members of the charity guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 March 2021 was 9 (2020: 9). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Independent examiner

The company has taken advantage of the small companies' exemption in preparing the report above.

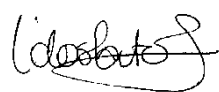
The following person was appointed to carry out an independent examination of these accounts:

Mr Luke Burns

Fellow Member of the Association of Chartered Certified Accountants (ACCA)

1 Century Drive, Reading, RG7 1PE, UK.

The trustees' annual report has been approved by the trustees on 25 August 2021 and signed on their behalf by:



Vanessa dos Santos
President
Board of Trustees



Section A

Independent Examiner's Report

Report to the
trustees/directors/
members of

Down Syndrome International

On accounts for the year
ended

31 March 2021

Charity no.:

1091843

Company no.:

04327941

Responsibilities and
basis of report

I report to the charity trustees on my examination of the accounts of the Company for the year ended **31/03/2021**.

As the charity's trustees of the Company (who are also the directors of the company for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ("the 2011 Act"). In carrying out my examination, I have followed the Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act).

Independent
examiner's statement

The company's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants (ACCA).

I have completed my examination. I confirm that no material matters have come to my attention which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the Companies Act 2006; or
- the accounts do not accord with such records; or
- the accounts do not comply with relevant accounting requirements under section 396 of the Companies Act 2006 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

08/08/2021

Name: Luke Burns

Relevant professional qualification(s) or body (if any):

Fellow of the Association of Chartered Certified Accountants (ACCA)

Address:

1 Century Drive

Reading

RG7 1PE

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

No material matters to note.

Annex 1: Membership

Organisation members in Africa

Botswana

Representative Organisation

Down's Syndrome Association of Botswana

Cameroon

Representative Organisation

Aidrikings Foundation

Congo

Affiliate Organisation

Lenire Asbl

Eritrea

Affiliate Organisation

National Association of Intellectual/Developmental
Disability in Eritrea (NAIDDE)

Ethiopia

Affiliate Organisation

Ethiopian National Association on Intellectual
Disabilities

Ghana

Representative Organisation

Robb Foundation

Affiliate Organisation

Inclusion Ghana

Kenya

Representative Organisation

Down Syndrome Society of Kenya

Liberia

Affiliate Organisation

My Heart's Appeal Inc

Libya

Representative Organisation

Libyan Down Syndrome Association

Madagascar

Representative Organisation

Down Syndrome Madagascar

Mauritius

Representative Organisation

Down Syndrome Association Mauritius

Morocco

Representative Organisation

Association Marocaine de Soutien et d'Aide aux
Personnes Trisomiques (AMSAT)

Nigeria

Representative Organisation

Down Syndrome Foundation Nigeria

Affiliate Organisations

Larger Than I Developmental Foundation

Moyinoluwa Rainbow Foundation

Rwanda

Representative Organisation

Rwanda Down Syndrome Organisation (RDSO)

South Africa

Representative Organisation

Down Syndrome South Africa

Tanzania

Representative Organisation

Pearl of People with Down Syndrome Foundation

Affiliate Organisation

Elimisha

Morogoro Saving the Poor Organization

Togo

Representative Organisation

APAPE - Down Syndrome Togo

Tunisia*Affiliate Organisation*

AMED (Association Mon Enfant est Different)

Uganda*Representative Organisation*

The Uganda Down Syndrome Association (TUDSA)

Affiliate Organisation

Angel's Center for Children with Special Needs

EmbraceKulture

Zimbabwe*Representative Organisation*

Zimbabwe Down Syndrome Association

Organisation members in Asia Pacific**Australia***Representative Organisation*

Down Syndrome Australia

Affiliate Organisation

e.motion 21

Bangladesh*Representative Organisation*

Down Syndrome Society of Bangladesh

Affiliate Organisation

Bangladesh Down Syndrome Association

Bhutan*Affiliate Organisation*

Ability Bhutan Society

China*Representative Organisation*

Macau Down Syndrome Association

Affiliate Organisation

Shanghai Hope Star Public Welfare Development Center

Hong Kong, S.A.R, China*Representative Organisation*

Hong Kong Down Syndrome Association

India*Representative Organisation*

Down Syndrome Federation of India

Affiliate Organisation

ALAN T21 Welfare Trust

Indonesia*Representative Organisation*

Indonesia Down Syndrome Care Foundation (YAPESDI)

Affiliate Organisation

Ikatan Sindroma Down Indonesia (ISDI)

Japan*Representative Organisation*

Japan Down Syndrome Society (JDS)

Affiliate Organisation

DSIJ

Malaysia*Affiliate Organisation*

Kiwanis Down Syndrome Foundation

Maldives*Representative Organisation*

Beautiful Eyes Down Syndrome Association

Mongolia*Representative Organisation*

Down Syndrome Association Mongolia (DSAM)

Myanmar*Representative Organisation*

Myanmar Down Syndrome Association

Nepal*Representative Organisation*

Down's Syndrome Association of Nepal (DSAN)

Down Syndrome Society Nepal

New Zealand

Representative Organisation

New Zealand Down Syndrome Association

Pakistan

Representative Organisation

Karachi Down Syndrome Program

Pakistan Down Syndrome Association (PDSA)

Philippines

Affiliate Organisation

Down Syndrome Association of the Philippines, Inc.

Singapore

Representative Organisation

Down Syndrome Association Singapore

South Korea

Representative Organisation

Korea Down Syndrome Society

Sri Lanka

Representative Organisation

Jinendhi Resource Centre for Down Syndrome

Affiliate Organisation

Jinendhi Resource Centre for Down Syndrome

Kosala Dullewa Foundation for Children with Special Needs

Soulink Lanka

Vietnam

Affiliate Organisation

My Future

Organisation members in Central Asia

Armenia

Representative Organisation

Sun Children

Georgia

Representative Organisation

Georgian Down Syndrome Association

Kazakhstan

Affiliate Organisation

Solnechnyi Mir

Kyrgyzstan

Representative Organisation

Public Fund of Parents of Children with Down syndrome "Sunterra"

Affiliate Organisation

Luch Dobra (The Ray of Kindness)

Russia

Representative Organisation

Downside Up

Affiliate Organisation

Regional public organization "Time of Changes"

Tajikistan

Representative Organisation

Nazari Digar

Affiliate Organisation

Public Organisation of Parents of Children with Down Syndrome "SiDa"

Public Organisation Open Hearts

Turkey

Representative Organisation

Down Turkiye Down Sendromu Dernegi

Ukraine

Representative Organisation

Ukrainian Charitable Organization "Down Syndrome"

Uzbekistan

Representative Organisation

Downside Sport Uzbekistan

Organisation members in Europe

Regional

Affiliate Organisation

European Down Syndrome Association (EDSA)

Albania

Representative Organisation

Down Syndrome Albania Foundation

Jonathan Center

Austria

Representative Organisation

Down-Syndrom Österreich

Belgium

Representative Organisation

Down Syndrome Foundation Belgium

Affiliate Organisation

APEM T21

Downsyndroom Vlaanderen

Inclusion ASBL

Bosnia & Herzegovina

Representative Organisation

Udruzenje Zivot Sa Down Syndromom

Bulgaria

Representative Organisations

Association of the Parents of Children with Down Syndrome

Life with Down Syndrome

Croatia

Representative Organisation

Croatian Down Syndrome Association

Cyprus

Representative Organisation

Pan Cyprian Down Syndrome Association

Denmark

Representative Organisation

Landsforeningen Downs Syndrom

Estonia

Representative Organisation

Downi Sundroomi Uhing / Down Syndrome Association Estonia

France

Representative Organisation

Trisomie 21 France

Germany

Representative Organisation

Deutsches Down-Syndrom InfoCenter

Gibraltar

Representative Organisation

Down's Syndrome Support Group Gibraltar (DSSGG)

Greece

Representative Organisation

Down Syndrome Association of Greece

Hungary

Affiliate Organisation

Down Egyesület

Ireland

Representative Organisation

Down Syndrome Ireland

Affiliate Organisation

The Down Syndrome Centre (Ireland)

Italy

Representative Organisation

Associazione Italiana Persone Down

Affiliate Organisation

Coordinamento Nazionale Associazioni delle Persone con Sindrome de Down (CoorDown)

Kosova*Representative Organisation*

Down Syndrome Kosova

Lithuania*Representative Organisation*

Down Syndrome Lithuania

Macedonia*Affiliate Organisation*

Trisomija 21 - Skopje

Malta*Representative Organisation*

Down Syndrome Association Malta

Malta*Affiliate Organisation*

Inspire

Netherlands*Affiliate Organisation*

Stichting Down Syndroom (SDS)

Norway*Representative Organisation*

Norsk Nettverk for Down Syndrom (NNDS)

Poland*Affiliate Organisations*

Ja Tez

Jeden Swiat

Legnickie Stowarzyszenie Rodzin i Przyjaciół Dzieci z
Zespołem Downa Otworzyć Serce

Zakątek 21 Society of Parents and Friends of Children
with Down Syndrome

Zespoldowna.info

Portugal*Affiliate Organisation*

Pais21

Romania*Affiliate Organisation*

Asociatia Down Bucuresti

Asociatia Ioana-Maria

European Centre for the Rights of Children with
Disabilities

Russia*Representative Organisation*

Downside Up

Affiliate Organisation

Regional public organization "Time of Changes"

Slovakia*Representative Organisation*

Spoločnosť Downovho Syndromu na Slovensku

Spain*Representative Organisation*

Down Espana

Affiliate Organisation

ASNIMO

Sweden*Representative Organisation*

Svenska Downforeningen

Switzerland*Representative Organisation*

Insieme 21

Affiliate Organisation

Light for Sight Foundation

Turkey*Representative Organisation*

Down Türkiye Down Sendromu Derneği

Ukraine*Representative Organisation*

Ukrainian Charitable Organization "Down Syndrome"

United Kingdom

Representative Organisation

Down's Syndrome Association (UK)

Down's Syndrome Scotland

Affiliate Organisation

Cheshire Down's Syndrome Support Group

Down Syndrome Extra 21

Down Syndrome Medical Interest Group UK and Ireland (DSMIG-UK)

Down Syndrome Research Foundation UK

Down's Heart Group

Sports Union for Athletes with Down Syndrome (SU-DS)

Organisation members in Middle East

Iran

Representative Organisation

Aseman Nili Down Syndrome Association

Iraq

Representative Organisation

Down Syndrome Association of Iraq (Hiba Centre for Down Syndrome)

Israel

Representative Organisation

Yated Down Syndrome Parents Association

Jordan

Representative Organisation

Jasmine Association for Children with Down Syndrome

Lebanon

Representative Organisation

Lebanese Down Syndrome Association

Affiliate Organisation

National Rehabilitation and Development Center (NRDC)

Oman

Representative Organisation

Oman Down Syndrome Association

Palestinian Territory

Representative Organisation

Al-Raheem (Down Syndrome Friends) Association

Affiliate Organisation

Right to Live Society

Qatar

Representative Organisation

HOPE Qatar Center for children with special needs

Saudi Arabia

Affiliate Organisation

Werathah

Help Center

United Arab Emirates

Representative Organisation

Emirates Down Syndrome Association

Yemen

Representative Organisation

Yemeni Down Syndrome Society (YDSS)

Organisation members in North America

Bahamas

Representative Organisation

The Bahamas Down Syndrome Association and Center

Bermuda

Representative Organisation

Bermuda Down Syndrome Support Group

Canada

Representative Organisation

Canadian Down Syndrome Society

Affiliate Organisation

Down Syndrome Resource Foundation

T21 Association Ouest Africaine

Dominican Republic

Representative Organisation

Asociacion Dominicana de Sindrome de Down

Grenada

Representative Organisation

Grenada Down Syndrome Association

Jamaica

Representative Organisation

Jamaica Down's Syndrome Foundation

Trinidad and Tobago

Representative Organisation

Down Syndrome Family Network

United States

Representative Organisation

National Down Syndrome Society (NDSS)

Affiliate Organisation

Alexander's Angels, Inc.

LuMind IDSC Foundation

National Down Syndrome Congress (NDSC)

San Diego Down Syndrome Organisation

Down Syndrome Affiliates in Action

Organisation members in South and Central America

Argentina

Representative Organisation

Asociacion Sindrome de Down de la Republica Argentina (ASDRA)

Brazil

Affiliate Organisation

Federacao Brasileira das Associacoes Sindrome de Down

Instituto Alana

MetaSocial Institute

Movimento Down

Chile

Representative Organisation

Fundacion down 21 Chile

Affiliate Organisation

Pro Inclusion Rayos de Sol

Colombia

Representative Organisation

Fundacion Sindrome de Down del Caribe (Fundown Caribe)

Costa Rica

Representative Organisation

Fundacion El Futuro es de Todos

El Salvador

Representative Organisation

Fundacion Club de Amigos Especiales a Distancia de El Salvador (FUNCAEDES)

Guatemala

Representative Organisation

Asociacion Guatemalteca para el Sindrome de Down

Affiliate Organisation

Fundacion Margarita Tejada Para Sindrome Down

Honduras

Representative Organisation

Integrar, Fundacion Sindrome de Down, Honduras

Affiliate Organisation

Centro de Educacion Activa

Mexico

Representative Organisation

Fundacion John Langdon Down

Affiliate Organisation

Comunidad Educativa Incluyente

Taller de Expresion y Desarrollo Integral A.C. (TEDI)

Trisomia 21 A.C.

Nicaragua

Affiliate Organisation

Fundacion 21 Sindrome de Down Nicaragua

Panama

Affiliate Organisation

Fundacion Down Panama

SD Padres en Accion

Paraguay

Affiliate Organisation

Asociacion de Padres de Personas con Sindrome de Down de Itapua

Fundacion Saraki

Peru

Representative Organisation

Sociedad Peruana de Sindrome Down (SPSD)

Affiliate Organisation

Asociacion Proyecto Yannick

Venezuela

Representative Organisation

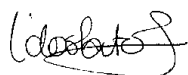
Asociacion Venezolana para el Sindrome de Down (AVESID)

Down Syndrome International					
Consolidated statement of financial activities (incorporating and income and expenditure account)					
For the year ended 31 March 2021					
	Note	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Income from:					
Donations and legacies	2	190,589	-	190,589	156,518
Charitable activities					
1. Policy and practice, information, advice and support	3	-	60,396	60,396	18,965
2. Network development and training	3	1,976	93,192	95,168	34,728
3. Advocacy and campaigning	3	-	40,735	40,735	4,670
Other trading activities	4	24,964	-	24,964	68,155
Total income		217,529	194,323	411,852	283,036
Expenditure on:					
Raising funds	5	52,240	-	52,240	82,612
Charitable activities					
1. Policy and practice, information, advice and support	5	52,631	60,812	113,443	64,487
2. Network development and training	5	40,243	87,045	127,288	92,981
3. Advocacy and campaigning	5	47,212	42,108	89,320	65,517
Total expenditure		192,327	189,964	382,291	305,597
Net income/(expenditure) for the year		25,202	4,358	29,560	(22,561)
Net movement in funds		25,202	4,358	29,560	(22,561)
Reconciliation of funds:					
Total funds brought forward		13,877	13,965	27,841	50,402
Total funds carried forward		39,079	18,323	57,402	27,841
All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 11 to the financial statements.					

Down Syndrome International – Balance Sheet - As at 31 March 2021			
	Note	2020/21 £	2019/20 £
Fixed assets:			
Tangible assets		-	-
Investments		-	-
Total fixed assets:		-	-
Current assets:			
Stock		-	-
Debtors		36,739	11,683
Short-terms deposits		-	-
Cash at bank and in hand		65,801	64,486
Total current assets		102,539	76,169
Liabilities:			-
Creditors: amounts falling due within one year		45,138	48,328
Net current assets (liabilities):		57,402	27,841
Total net assets (liabilities):		57,402	27,841
Funds:	11		-
Restricted income funds		18,323	13,965
Unrestricted income funds		39,079	13,877
Total funds:		57,402	27,841

- The company was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small companies.
- The members have not required the company to obtain an audit in accordance with section 476 of Companies Act 2006.
- The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.
- These accounts have been prepared in accordance with the provisions applicable to small companies subject to the small companies regime and in accordance with FRS102 SORP.

Approved by the trustees on 25 August 2021 and signed on their behalf by*:



Vanessa dos Santos – President, Board of Trustees

* this is also the signature of a director authenticating accounts being sent to Companies House.

Down Syndrome International			
Consolidated statement of cash flows			
For the year ended 31 March 2021			
	Note	2020/21 £	2019/20 £
Cash flows from operating activities:			
Net cash used in operating activities		1,315	(17,721)
Cash flows from investing activities:		-	-
Net cash used in investing activities		-	-
Change in cash and cash equivalents in the year		1,315	(17,721)
Cash and cash equivalents at the beginning of the year		64,486	82,207
Cash and cash equivalents at the end of the year		65,801	64,486

Down Syndrome International
Notes to the financial statements
For the year ended 31 March 2021

1. Accounting policies

a) Statutory information

Down Syndrome International is a charitable company limited by guarantee and is incorporated in England. The registered office address is Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS. The principal place of business is 7/9 Chapel Street, Exmouth, Devon, EX8 1HR.

b) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (August 2014) and the Companies Act 2006.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

c) Public benefit entity

The charitable company meets the definition of a public benefit entity under FRS 102.

d) Going concern

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

There are no key judgements that the charitable company has made which have a significant effect on the accounts.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

e) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

Income generated from the supply of goods or services is included in the statement of financial activities in the period in which the supply is made.

Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when received.

Revenue grants are credited to the statement of financial activities when received or receivable whichever is earlier.

Where unconditional entitlement to grants receivable is dependent upon fulfilment of conditions within the charity's control, the incoming resources are recognised when there is sufficient evidence that conditions will be met. Where there is uncertainty as to whether the charity can meet such conditions, the incoming resource is deferred.

Membership income is included in full in the statement of financial activities when received.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of the provision of a specified service is deferred until the criteria for income recognition are met.

f) Donations of gifts, services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item or received the service, any conditions associated with the donation have been met, the receipt of economic benefit from the use by the charity of the item is probable and that economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), volunteer time is not recognised so refer to the trustees' annual report for more information about their contribution.

On receipt, donated gifts, professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

g) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

h) Fund accounting

Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular purposes.

i) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Expenditure is classified under the following activity headings:

- Costs of raising funds relate to the costs incurred by the charitable company in inducing third parties to make voluntary contributions to it, as well as the cost of any activities with a fundraising purpose;
- Expenditure on charitable activities includes the costs of delivering services and campaigning undertaken to further the purposes of the charity and their associated support costs;

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

j) Allocation of support costs

Resources expended are allocated to the particular activity where the cost relates directly to that activity. However, the cost of overall direction and administration of each activity, comprising the salary and overhead costs of the central function, is apportioned on the following basis which are an estimate, based on staff time, of the amount attributable to each activity.

Where information about the aims, objectives and projects of the charity is provided to potential beneficiaries, the costs associated with this publicity are allocated to charitable expenditure.

Support and governance costs are re-allocated to each of the activities on the following basis which is an estimate, based on staff time, of the amount attributable to each activity:

• Cost of raising funds	25%
• Policy and practice, information, support and advice	25%
• Network development and training	25%
• Advocacy and campaigning	25%

Governance costs are the costs associated with the governance arrangements of the charity. These costs are associated with constitutional and statutory requirements and include any costs associated with the strategic management of the charity's activities.

k) Operating leases

Rental charges are charged on a straight-line basis over the term of the lease.

l) Tangible fixed assets

Items of equipment are capitalised where the purchase price exceeds £1,000. Depreciation costs are allocated to activities on the basis of the use of the related assets in those activities. Assets are reviewed for impairment if circumstances indicate their carrying value may exceed their net realisable value and value in use.

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

• Leasehold improvements	5 years
• Fixtures and fittings	5 years
• Computer equipment	3 years

m) Listed investments

Investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the balance sheet date using the closing quoted market price. Any change in fair value will be recognised in the statement of financial activities and any excess of fair value over the historic cost of the investments will be shown as a fair value reserve in the balance sheet. Investment gains and losses, whether realised or unrealised, are combined and shown in the heading "Net gains/(losses) on investments" in the statement of financial activities. The charity does not acquire put options, derivatives or other complex financial instruments. Investments in subsidiaries are at cost.

n) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks. Donated items of stock, held for distribution or

resale, are recognised at fair value which is the amount the charity would have been willing to pay for the items on the open market.

o) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

p) Short term deposits

Short term deposits include cash balances that are invested in accounts with a maturity date of between 3 and 12 months.

q) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account. Cash balances exclude any funds held on behalf of service users.

r) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

s) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

t) Pensions

Payments to the stakeholder pension scheme are charged as an expense as they fall due.

2. Income from donations and legacies

	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Gifts	143,098	-	143,098	121,450
Legacies	-	-	-	-
Donated services	47,491	-	47,491	35,067
Total income from donations and legacies	190,589	-	190,589	156,518

3. Income from charitable activities

Down Syndrome International - Income from charitable activities				
For the year ended 31 March 2021				
	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Actelion Pharmaceuticals	-	15,965	15,965	15,965
Emirates Down Syndrome Association	-	-	-	3,000
International Disability Alliance (via Inclusion Works Consortium - UK Aid)		14,831	14,831	-
International Disability Alliance (Inclusive Participation Guidelines)	-	29,600	29,600	-
Sub-total for Policy and Practice, Information, Support and Advice	-	60,396	60,396	18,965
Emirates Down Syndrome Association	-	-	-	1,500
Down Syndrome Kosova	-	-	-	1,858
W F Southall Trust	-	-	-	3,000
Down's Syndrome Association	-	-	-	6,750
Nazari Digar	1,976	-	1,976	-
Cente for Acceleration of Social Technology (CAST)	-	10,000	10,000	-
International Disability Alliance (via UK Aid Catalyst project)	-	-	-	21,620
International Disability Alliance (via Norwegian Agency for Development Cooperation - NORAD)	-	83,192	83,192	-
Sub-total for Network Development and Training	1,976	93,192	95,168	34,728
Other project related income	-	-	-	115
International Disability Alliance (via UK Aid Catalyst project)	-	-	-	4,555
International Disability Alliance (via COVID-19 Pooled Fund - UK Aid)	-	29,465	29,465	-
International Disability Alliance (via Inclusion Works Consortium - UK Aid)	-	11,270	11,270	-
Sub-total for Advocacy and Campaigning	-	40,735	40,735	4,670
Total income from charitable activities	1,976	194,323	196,299	58,364

4. Income from other trading activities

	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Fundraising events	-	-	-	6,641
Trading	24,964	-	24,964	61,514
Total income from other trading activities	24,964	-	24,964	68,155

5. Analysis of expenditure		Charitable activities						
	Cost of Raising Funds £	Policy and Practice, Information, Support and Advice £	Network Development and Training £	Advocacy and Campaigning £	Governance Costs £	Support Costs £	2020/21 Total £	2019/20 Total £
Staff costs (Note 7)	20,865	43,019	39,255	22,583	12,460	20,926	159,109	156,733
Cost of operating online shop	6,399	-	-	-	-	-	6,399	31,489
Fundraising event and other fundraising costs	5,713	-	-	-	-	-	5,713	6,013
Advertising, marketing and publicity	4,956	15,676	15,676	15,676	-	-	51,983	34,422
Grant making for projects and activities	-	8,623	52,298	33,833	-	-	94,754	5,642
Spending on projects and activities	-	30,107	5,611	1,806	-	-	37,524	34,800
Office running costs and equipment	-	-	-	-	-	9,203	9,203	10,312
Consultants and professional fees	-	-	-	-	548	500	1,048	1,099
Rent, insurance and maintenance	-	1,570	-	975	-	6,931	9,476	9,953
Travel, meetings and conferences	-	141	141	141	-	-	422	11,220
Management, communications, finance, data and storage operational Systems	-	-	-	-	-	6,662	6,662	3,914
Sub-total	37,933	99,136	112,981	75,013	13,008	44,221	382,291	305,597
Support costs	11,055	11,055	11,055	11,055	-	(44,221)		
Governance costs	3,252	3,252	3,252	3,252	(13,008)			
Total expenditure 2020/21	52,240	113,443	127,288	89,320			382,291	

6. Grant making

	2020/21 total funds £	2019/20 total funds £
Cost		
Rwanda Down Syndrome Organisation	17,840	2,557
Asociacion Guatemalteca para el Sindrome de Down	-	3,085
Down Syndrome Society of Kenya	18,536	-
Down Syndrome Foundation Nigeria	4,250	-
Inclusion Uganda	20,295	-
Down Syndrome Society of Bangladesh	9,843	-
Down Syndrome Albania Foundation	4,550	-
Asociacion Sindrome de Down de la Republica Argentina (ASDRA)	3,735	-
Federacao Brasileira das Associacoes Sindrome de Down	5,715	-
Indonesia Down Syndrome Care Foundation (YAPESDI)	5,050	-
Down Syndrome South Africa	4,940	-
At the end of the year	94,754	5,642

7. Analysis of staff costs, trustee remuneration/expenses and cost of key management personnel

Staff costs were as follows:

	2020/21 total funds £	2019/20 total funds £
Salaries and wages	140,254	137,599
Social security costs	12,258	12,281
Employer's contribution to defined pension schemes	4,520	4,913
Total	157,032	154,793

No employee earned more than £60,000 during the year (2019/20: £nil). The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £59,197 (2019/20: £59,174).

The charity trustees were neither paid nor received any other benefits from employment with the charity in the year (2019/20: £nil). No charity trustee received payment for professional or other services supplied to the charity (2019/20: £nil).

Trustees' expenses represent the payment or reimbursement of travel, accommodation and subsistence costs totalling £0 (2019/20: £6,564) incurred by 0 (2019/20: 8) members relating to participation in project activities and governance meetings.

8. Staff numbers

The average numbers of employees (head count based on number of staff employed) during the year was as follows:

	2020/21 No.	2019/20 No.
Raising funds	1	1
Charitable activities	7	2
Support	3	2
Governance	1	1
Total	12	6

9. Related party transactions

There are no donations from or to related parties which are outside the normal course of business.

Membership fee transactions have taken place during the year with many members of Down Syndrome International. Membership requires a fee and in exchange basic support and advice is provided, members participate as partners or stakeholders in our activities and we promote our members' work. The maximum annual fee charged for membership is £240. Some DSI members purchase merchandise from our shop related to World Down Syndrome Day for sale or distribution in their own countries. DSI also makes grants to certain members, as set out in note 6 of these notes to the accounts.

The Down's Syndrome Association (DSA) is a member of DSI. DSI uses office space at DSA's headquarters. The Chief Executive of DSA, Carol Boys, is a trustee of Down Syndrome International. DSI's Executive Director, Andrew Boys, is Carol's son. DSA is the payroll agency for DSI.

General donations and restricted grants are given by DSA to DSI to support our work. DSI contributes 50% of the staff costs for a shared community fundraiser, employed by DSA (agreement ended April 2020). Donations for certain events and activities organised by this fundraiser (and others) are shared equally with DSA.

DSA made the following payments to DSi during the year:	2020/21 £	2019/20 £
Donations and grants	55,000	64,565
Membership fee	240	240
Income from providing new website advice and support services	-	6,750
Income from shared donations and fundraising activities	-	6,287
Merchandise	-	-
Total	55,240	77,842

DSi made the following payments to DSA during the year:	2020/21 £	2019/20 £
Staff costs for shared community fundraiser	813	8,787
Income from shared donations and fundraising activities	-	1,666
Total	813	10,453

DSi received funds from 3 other members in 2020/21 - £1,976 from our member Nazari Digar for human rights and education advocacy training; a general grant of £260 from Cheshire Down's Syndrome Support Group and a general grant of £2,175 from Alexander's Angels, Inc.

DSi received separate grants of £26,101, £83,192, £29,465 and £29,600 in 2020/21 from International Disability Alliance (IDA – onward granted from UK Aid and Norwegian Agency for Development Cooperation). DSi is a member of IDA.

10. Taxation

The charity is exempt from corporation tax. All its income is charitable and is applied for charitable purposes.

11. Movement in funds

Down Syndrome International - Movement in funds (current year) - For the year ended 31 March 2021					
	At the start of the year £	Incoming resources and gains £	Outgoing resources and funds £	Transfers £	At the end of the year £
Restricted funds:					
Inclusion Works – employment and COVID-19 advocacy Bangladesh, case study and webinar series	-	26,101	29,174	-	(3,073)
CAST - finding digital communication solutions for people with Down syndrome	-	10,000	10,000	-	-
NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa	-	83,192	77,045	-	6,147
COVID-19 Pooled Fund - COVID-19 advocacy in Albania, Argentina, Brazil, Indonesia and South Africa	-	29,465	29,465	-	-
International guidelines for inclusive participation of people with intellectual disabilities	-	29,600	27,668	-	1,932
Consensus statement on cardiac disorders in people with Down syndrome	13,965	15,965	16,613	-	13,317
Total restricted funds	13,965	194,323	189,964	-	18,323
Unrestricted funds:					
Designated funds:					
The National Lottery Community Fund - COVID-19 response	-	10,000	10,000	-	-
The Joffe Charitable Trust - Fundraising strategy research and fundraising staff resources	-	32,560	9,643	-	22,917
University of Exeter - Access to Internship scheme	-	1,300	1,300	-	-
Nazari Digar - Human rights and education advocacy training	-	1,976	1,976	-	-
Total designated funds	-	45,836	22,919	-	22,917
General funds:	13,877	171,693	169,408	-	16,163
Total unrestricted funds:	13,877	217,529	192,327	-	39,079
Total funds	27,841	411,852	382,291	-	57,402

Purposes of restricted funds

Inclusion Works - employment and COVID-19 advocacy Bangladesh, case study and webinar series

Supporting our member in Bangladesh to deliver employment and COVID-19 related advocacy. Preparing a case study on best practices in employment and preparation for self-advocate led webinar series on inclusive employment of persons with intellectual disabilities.

CAST - finding digital communication solutions for people with Down syndrome

Running a project to look at and find solutions for the key problem that people with Down syndrome are not involved enough in the work of organisations that represent them, something which has been exacerbated by the COVID-19 pandemic and the transition to online communications.

NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa

Technical human rights training and COVID-19 advocacy training for our members organisations in Kenya, Nigeria, Rwanda and Uganda and self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda.

COVID-19 Pooled Fund - COVID-19 advocacy in Albania, Argentina, Brazil, Indonesia and South Africa

Providing grants to 5 of our national member organisations for COVID-19 specific advocacy activities. Supporting Down Syndrome Albania Foundation, Asociacion Sindrome de Down de la Republica Argentina (ASDRA), Federacao Brasileira das Associacoes Sindrome de Down, Indonesia Down Syndrome Care Foundation (YAPESDI) and Down Syndrome South Africa.

International guidelines for inclusive participation of people with intellectual disabilities

Developing the International Guidelines for Inclusive Participation, jointly with Inclusion International. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can take part in a meaningful way.

Consensus statement on cardiac disorder in people with Down syndrome

Progressing a project to publish a consensus statement on cardiac disorder in people with Down syndrome, following a process which includes systematic evidence review, detailed advice from world leading experts in this field and structured input from international stakeholders.

Purposes of designated funds**The National Lottery Community Fund - COVID-19 response**

Undertaking vital work addressing the ongoing negative impact of the COVID-19 pandemic on people with Down syndrome and their families in the UK and around the world – including provision of information and resources and advocating for fully inclusive responses.

The Joffe Charitable Trust - Fundraising strategy research and fundraising staff resources

Undertaking detailed research of key areas of fundraising, publishing a new fundraising strategy for DSI and employing a new fundraising officer to deliver this strategy and improve DSI's financial sustainability.

University of Exeter - Access to Internship scheme

Employing an intern for 1 month in 2020 to support the programme team.

Nazari Digar - human rights and education advocacy training

Running 2 days of online human rights training with parents and family members in Tajikistan and 2 days training with organisations representing people with Down syndrome and their families.

12. Legal status of the charity

The charity is a company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £10.