

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.



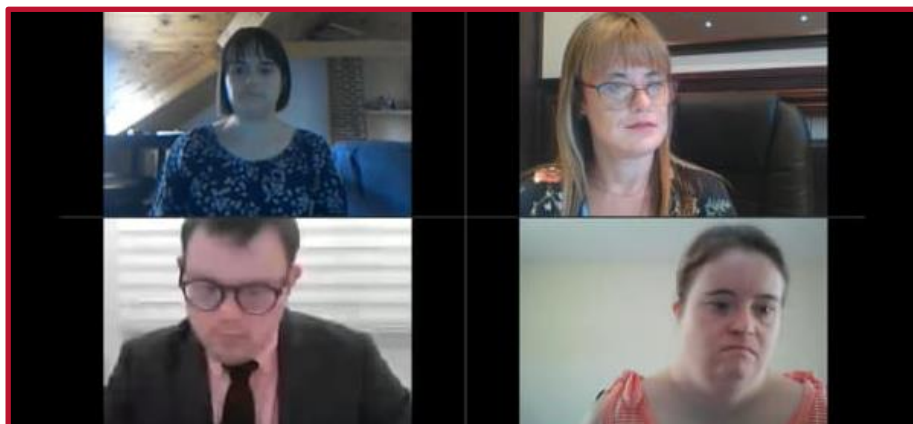
Working with self-advocates

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.

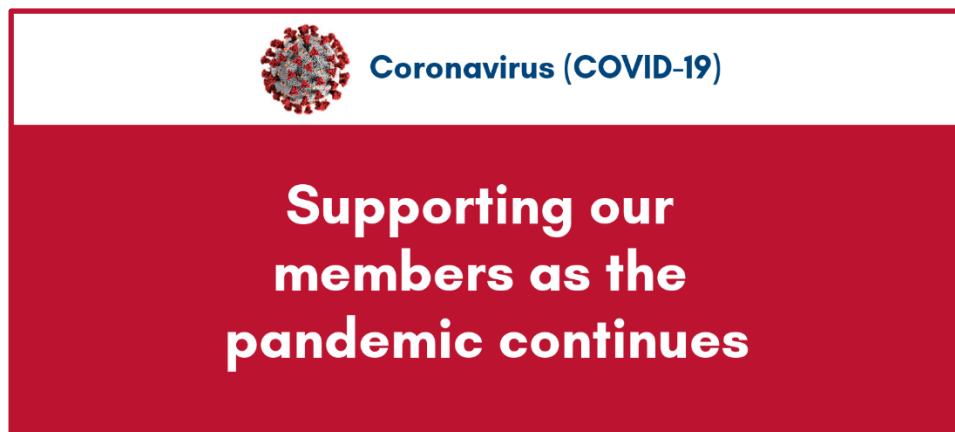
3. ADVOCACY AND CAMPAIGNING

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:

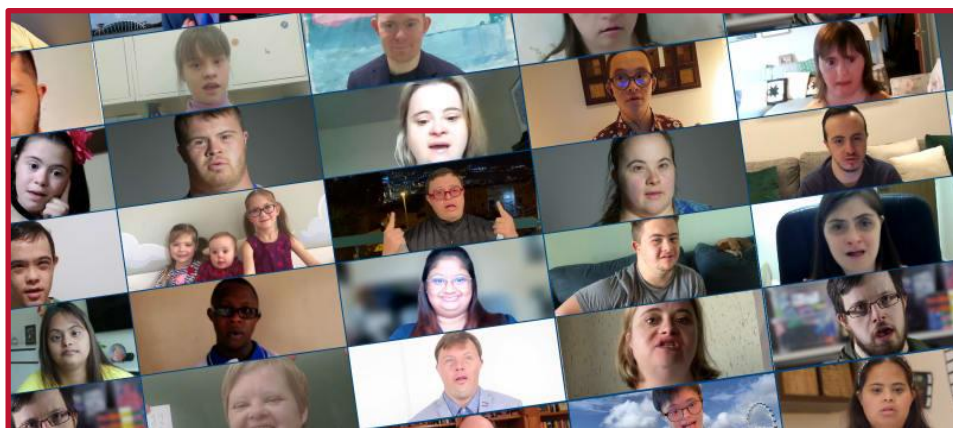
- our **12th annual WDS conference at United Nations (UN) HQ, New York**, held virtually on 21 March and
- our **6th annual, self-advocate led, side-event to the Committee on the Rights of Persons with Disabilities at UN Geneva**, held virtually on 21 March.

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

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2022**.

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:

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

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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.