

# **DOWN SYNDROME INTERNATIONAL (DSi)**



## **REPORT OF TRUSTEES (AND DIRECTORS) AND FINANCIAL STATEMENTS**

for the period from 1 April 2020 to 31 March 2021

## **Reference and administrative information**

<b>Company number</b>	04327941
<b>Country of incorporation</b>	United Kingdom
<b>Charity number</b>	1091843
<b>Country of registration</b>	England and Wales

### **Registered Office**

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

### **Operational Address**

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

### **Trustees**

The trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows:

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

### **Principal Staff**

A Boys	(Executive Director)
	(Company Secretary)

### **Principal Bankers**

HSBC  
16 King Street  
Covent Garden  
London  
WC2E 8JF

### **Solicitors**

Russell Cooke  
2 Putney Hill  
London  
SW15 6AB

## Introduction

The trustees present their report and independently examined financial statements for the year ended 31 March 2021. The financial statements cover a 12-month period since the previous statements for the year ended 31 March 2020.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with the current statutory requirements, Down Syndrome International's memorandum and articles of association and the Statement of Recommended Practice – Accounting and Reporting by Charities: SORP applicable to charities preparing their accounts in accordance with FRS 102. For a list of members, please refer to Annex 1.

For the year ended 31 March 2021 the organisation's income is greater than £25,000, therefore an independent examination of the financial statements is required.

## Objectives and activities

The charity objects of DSI, as stated in the memorandum and articles of association are:

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

DSi's published mission, aims and objectives seek to take DSI forward as a membership led organisation, providing support and advice, building on and disseminating its pool of information, knowledge and experience, undertaking training and build the capacity of its members, advocating for, representing and campaigning on behalf of the global Down syndrome community. DSI's work improves the understanding of Down syndrome, the capacity to support people with Down syndrome, champions basic rights and ultimately improves quality of life for people with Down syndrome.

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing its mission, aims and objectives and in planning its future activities. In particular, the trustees consider how planned activities will contribute to the mission, aims and objectives they have set. DSI is currently working on a new strategic plan which will build on this.

### **How our activities deliver public benefit**

The implementation of DSI's mission, aims and objectives and who it tries to help are described below. All its charitable activities focus on **enabling people with Down syndrome to live full and rewarding lives** and are undertaken to further its charitable purposes for the public benefit. DSI's mission, aims and objectives fully reflect the purposes the charity was set up to advance.

### **Who uses and benefits from our services?**

DSi is an international organisation of persons with disabilities (OPD), comprising a membership of individuals and organisations from 136 countries, engaging in national, world regional and international activities, all designed to improve lives and ensure basic rights for people with Down syndrome on a full and equal basis with others.

**DSi is the network that brings together the global Down syndrome community** and its services are available worldwide. The number of people with Down syndrome living worldwide is estimated at 7 million. Demand for DSi's services has grown substantially since it opened its international office in November 2009, providing a dedicated first point of contact for those requiring its services.

The trustees review the aims, objectives and activities of the charity each year. This report looks at what the charity has achieved and the outcomes of its work in the reporting period. The trustees report the success of each key activity and the benefits the charity has brought to those groups of people that it is set up to help. The review also helps the trustees ensure the charity's aims, objectives and activities remained focused on its stated purposes.

## **Achievements and performance**

The charity's main activities in 2020/21 and who we have tried to help are described immediately below in brief summary, based on 3 pillars. More information on each component then follows in this report:

### **1. Policy and practice, information, support and advice**

Played a lead or advisory role in a number of initiatives considering policies and practices on key issues affecting people with Down syndrome, worked with our members and partners to ensure provision of accurate, up to date information and provided advice and support on demand to members and others who needed it around the world.

### **2. Network development and training**

Strengthened our membership network through improving communications, developing alliances and networks of self-advocates, involving members more in our activities and through the delivery of training designed to build the capacity of national member organisations, people with Down syndrome, their families and other stakeholders.

### **3. Advocacy and campaigning**

Ran global campaigns and events and supported regional and national activities advocating for the rights of people with Down syndrome and participated actively in international disability and human rights forums, representing the global Down syndrome community.

In the following report, our thematic areas of focus will be prominent, namely:

- **Advocacy (and self-advocacy)**
- **Early development and parent support**
- **Education**
- **Employment**
- **Health**
- **Inclusive participation**
- **Organisation support**
- **Situations of risk and humanitarian action**

## 1. POLICY AND PRACTICE, INFORMATION, SUPPORT AND ADVICE

### POLICY AND PRACTICE

DSi and our network has a central role formulating and influencing national, regional and global policies and practices which specifically affect people with Down syndrome. 2020/21 saw a wide range of activities in this area.

#### Production of policy statements and guidelines

##### Education guidelines

In July 2020, DSi published the **International Guidelines for the Education of Learners with Down Syndrome**. Informed by research, practice and international stakeholder feedback, the document was written by experts in the field, with coordination and oversight from DSi.

The guidelines provide best-practice guidance for learners, teachers and managers in pre-school, school and post-school education settings to promote life-long learning. They are an important starting point in enabling people with Down syndrome to receive the educational support needed to achieve their full potential. They will provide a global reference point and a lobbying tool for education professionals, learners, families and supporters, commissioners of services, national Down syndrome organisations, managers and charities to encourage adoption of best practice in their countries.

Following publication, the guidelines are being disseminated via our global network, supported by toolkits, resources and training opportunities. The document has been translated into French and further official translations will follow. The guidelines will also comprise the **basis for DSi's upcoming Inclusive education advocacy project in United Kingdom** (see page 20 below) and all future projects in the area of education.

A quote from one of our international stakeholders - *"Situating all topics in scientific research conveys security and expands the possibility of deepening the subject. Anyone who reads it and puts it into practice can learn, make changes, and qualify its inclusive process."*



##### Cardiac consensus statement

As part of DSi's work in healthcare, we are collaborating with international clinical experts to create an up-to-date review and **expert consensus statement on cardiac disease in Down syndrome**.



This document will help health professionals around the world to better understand, diagnose, manage and care for people with Down syndrome with cardiac disease. The guidance will highlight best practice, but also acknowledge the differences that may exist between countries around the world.

A working group made up of 25 leading international specialists in cardiovascular disease and specialists in the treatment of people with Down syndrome, has been working together to write and review this work, following selection of key topic areas (supported by our membership network as stakeholders) and a systematic review of evidence. A consensus statement for each topic area will be prepared.

The original aim was to submit the statement for journal publication before the end of 2020. This has been delayed for a number of reasons, with submission now likely in late 2021. As a preparatory step, our team **published an article about the work we are doing in the Journal of Congenital Cardiology in January 2021.**

Once published, we anticipate this document will have a substantial and positive impact on the care provided by health professionals to people with Down syndrome with cardiac disease.



### **Thyroid guidelines (UK)**

In April 2020, a new UK health guideline **Thyroid Disorder in Children and Young People with Down Syndrome - Surveillance and When to Initiate Treatment**, developed by Down Syndrome Medical Interest Group UK and Ireland (DSMIG UK) was published. DSi was part of the Guideline Development Group.

A comprehensive process including expert and stakeholder input, a systematic review of evidence and robust recommendations was used to develop these guidelines, which are much needed to bring clarity for healthcare professionals in the UK working with children and young people with Down syndrome.

The guidelines have been endorsed by the Royal College of Paediatrics and Child Health (UK), the Royal College General Practitioners (UK), the Royal College of Nursing (UK), the Down's Syndrome Association (DSA - England, Wales and Northern Ireland) and Down's Syndrome Scotland. We hope that they will be a useful resource for medical professionals and improve the care and treatment of children and young people with Down syndrome with thyroid disorder.

### **Inclusive participation guidelines**

Throughout 2020/21, **DSi and Inclusion International have been working together on a project called #ListenIncludeRespect**, developing guidelines for inclusive participation.

Right now, there are more self-advocate leaders than ever working for change. But people with an intellectual disability are often still not included meaningfully in the work that affects them. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) guarantees the right to accessibility and participation for people with an intellectual disability.



We have heard from many organisations, who want to include people with intellectual disabilities in their work. But they need guidance to be more inclusive. While there are also lots of organisations already working with people with intellectual disabilities who do this very well, we can all do better.

So, we have come together to develop the **International Guidelines for Inclusive Participation**. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can take part in a meaningful way.

The guidelines will be used and endorsed by our members, development organisations, UN agencies and governments to become the international standard and will be a reference point to help organisations to know what they need to do to include self-advocates in their work.

Our activities in the last 12 months have included:

- creating and sharing a survey in 10 languages and in an easy-read format;
- members running around 50 consultation events with self-advocates, family members and professionals;
- receiving feedback through the events and survey from over 900 people in 80 countries;
- running a UN Conference of State Parties to the CRPD side-event, led by self-advocates (see “International human rights forums” on page 24 below);
- employing self-advocate consultants in Uganda and Argentina to support the Inclusion International and Down Syndrome International staff team's work and
- starting the first draft of the guidelines using the information and feedback we have collected.

### Production of best practice reports, studies and resources

#### **Inclusive employment case study and webinars**

In the second half of this year and moving into next year, we have been working on a **case study on best practices related to the employment of persons with Down syndrome and intellectual disabilities**, with a focus on Bangladesh. At the same time, we are also developing a **webinar series on inclusive employment of persons with intellectual disabilities**. Both projects are funded by Inclusive

Futures (Inclusion Works), a UK Aid-funded consortium of 16 disability and development organisations led by Sightsavers, working to create a future that is inclusive of people with disabilities.

We recruited a fellow in Bangladesh to lead the work on developing a case study on best practices related to the inclusive employment of persons with intellectual disabilities. He has undertaken a desk-based review and will go on to interview key stakeholders in Bangladesh, including jobseekers and employees with intellectual disabilities, family members, managers, co-workers, OPDs and NGOs working on employment programmes. Publication of the case study is scheduled for mid-2021.

As of the end of March 2021, we are about to recruit 5 self-advocates with intellectual disabilities from our member organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda to help us develop a webinar series on best practices related to inclusive employment of persons with intellectual disabilities. The self-advocates will lead the delivery of the webinars, scheduled for mid-2021.

### **World Down Syndrome Congress (WDSC)**

The WDSC is an opportunity to disseminate research, information and good practice to a captive audience, while bringing experts, professionals and key stakeholders together to advance knowledge and ensure policy and practice is kept accurate and up to date.

DSi oversees and selects hosts for the WDSC from among our national member organisations. We then work closely with the hosts, providing consultancy services (based on our knowledge and experience from previous events) and maintaining oversight on the event programme.

The next WDSC event was originally scheduled for Dubai, United Arab Emirates (hosted by Emirates Down Syndrome Association) in November 2020. However this had to be delayed due to the COVID-19 pandemic. As of March 2021, with the pandemic continuing to limit international travel and meetings, **the proposal is to hold the first ever virtual WDSC from Dubai in November 2021.**



Following this event, it has also been announced that the next WDSC in Brisbane, Australia (working with hosts Down Syndrome Australia), will be delayed from 2022 until 2024.

### **Advising on external projects related to Down syndrome and disability policy**

Throughout 2020/21, we have regularly contributed to the preparation of international policy statements and comments by the International Disability Alliance (IDA), the UN CRPD Committee, the UN Special Rapporteur on Disability and similar policy influencers. DSi is in Special Consultative (ECOSOC) Status with the United Nations (UN) Department of Economic and Social Affairs.



We continued to play an important role within IDA this year, with DSi represented on the IDA board, programme committee and on task groups. IDA's programme committee advises the IDA board and secretariat on various major disability development programmes, funded by international development agencies, with IDA and its members working on stand-alone programmes and in large consortium programmes with disability development organisations, including members of International Disability and Development Consortium (IDDC). IDA **plays a key role in the positioning of a number of these programmes**, focusing on disability policy, monitoring and development work, ensuring UN CRPD compliance and contribution to UN Sustainable Development Goals (SDGs) via meaningful engagement of persons with disabilities and their representative organisations. IDA has a key role in human rights policy making and disability development programming, giving the perspective of persons with disabilities.



[List of members:](#)



## INFORMATION

There is undoubtedly a great demand for up-to-date information resources and the latest research being undertaken and published, in key areas in the field of Down syndrome. There are information resources and research publications across the internet and the world. The extent to which they are provided free of charge, are accurate and evidence-based and are fully accessible (e.g. for people with disabilities, in different languages etc.), varies.

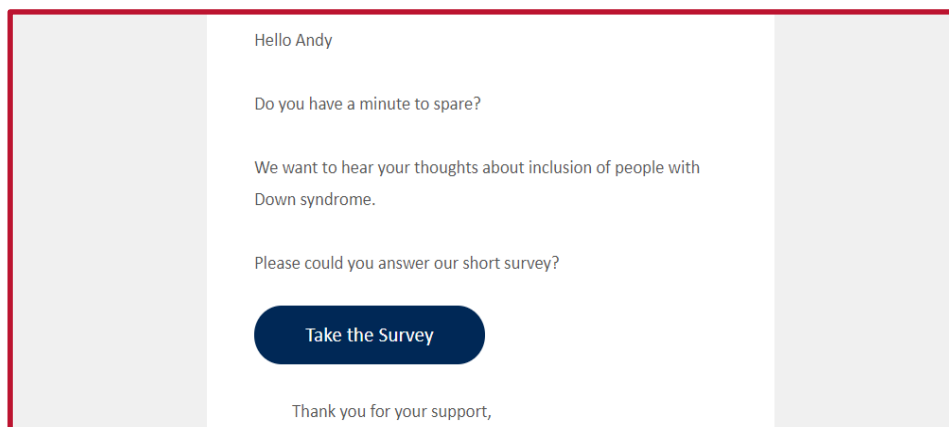
As of March 2021, we continue to work with our members and with key international partners to ensure that **free of charge, high quality and fully accessible information** and the **most important and highest quality research**, is promoted to the global Down syndrome community and beyond.

Our website currently provides information summaries in key areas and we regularly promote information resources and research initiatives to our members and on social media. Meanwhile, we are:

- exploring the production of DSi information resources;
- exploring the best way to promote external information resources and
- considering the most effective way to promote external research,

working with our members and partners including Trisomy 21 Research Society, NIH Down Syndrome Consortium, Alana Foundation, Lumind IDSC Foundation, International Association for the Scientific Study of Intellectual and Development Disabilities, DSMIG UK and DSMIG USA, among others.

**We send regular updates and e-newsletters to over 12,000 people** around the world including the latest news, updates, research and best practices related to people with Down syndrome.



### **COVID-19 response**

At the time of this report, the COVID-19 pandemic continues. **The pandemic has required an urgent and specific response from DSI**, in line with our commitment to support people with Down syndrome and their families in situations of humanitarian crises.

We have been working hard to respond to the evolving situation and support our members and the global Down syndrome community during these difficult times.

Our response over the last year has included:

#### **➤ Compiling and sharing information**

We have been compiling and sharing up-to-date and accurate information on COVID-19 and appropriate responses to it. We created a dedicated area on our website for information and resources related to people with Down syndrome and COVID-19, and via our Global Support blog, email campaigns and social media, we have ensured our community is kept up to date with all new developments and key issues, as they relate to people with Down syndrome and their families.

As of the end of March 2021, we are preparing **information and resources on COVID-19 vaccination advocacy** (see "COVID-19 response advocacy" on page 18 below).

#### **➤ Gathering experiences and evidence**

We have worked with our member organisations to gather experiences of people with Down syndrome, families and advocates and other evidence related to COVID-19 and its impact. This includes:

- the availability of information in accessible formats;
- how people with Down syndrome and their families are being included in pandemic responses;
- impact of quarantines on people with Down syndrome and their families;
- support available for people with Down syndrome and their families during the pandemic;
- provision of healthcare for people with Down syndrome affected by COVID-19;

- impact of the pandemic in key areas of life such as education and work and
- availability and prioritisation of vaccinations for people with Down syndrome.

#### ➤ **Support for member organisations**

We have been working with our member organisations to identify the challenges they are facing and the support they need in responding to the COVID-19 pandemic in their countries.

Early in the pandemic, we ran a **series of webinars with our member organisations** both to discuss the challenges and to deliver training on topics that could help them at that time. Subsequently, we are **assisting a number of our member organisations with funding, training and resources to deliver COVID-19 response advocacy activities** (see “COVID-19 response advocacy” on page 18 below).

#### ➤ **International collaboration**

We have been working with the international disability community and IDA to ensure a disability inclusive response to the COVID-19 pandemic. This has included advocating at various stages for action from global bodies, such as World Health Organization (WHO).



### **SUPPORT AND ADVICE**

We receive many enquiries for support and advice from around the world, particularly in Global South countries. This year again, we:

- responded to enquiries from many individuals around the world and
- had regular conference calls with and provided strategic and operational advice to more than 40 member organisations, primarily in Africa, Asia and South America.

We were also able to respond to specific support requests from our member organisations where the need was great and funding could be sourced (see “Member organisation support” on page 12 below).

## **2. NETWORK DEVELOPMENT AND TRAINING**

### **NETWORK DEVELOPMENT**

DSi is a global network made up of member organisations in 136 countries and over 1,000 individual members worldwide. We maintain close contact with our members to keep them informed on relevant research, best practices and strategies to advocate for the rights of people with Down syndrome. We

also seek regular feedback on our work and receive information from countries and regions, to help guide our strategy.



We are continuously:

- developing more effective ways to communicate with and be accountable to members;
- developing national and international advocacy networks of people with Down syndrome;
- supporting national and regional alliances of our members and making alliances with other partners in the Down syndrome and disability movement;
- developing opportunities to engage our members in our activities, ranging from stakeholder consultation in policy and practice activities to participation in our advocacy and campaigning activities and
- building the capacity of our national member organisations through the provision of support, advice, capacity assessment and training.

### Working with self-advocates

#### **Down Syndrome International Ambassadors**

We have a committee of national representatives with Down syndrome, which currently has members from 23 countries. They represent people with Down syndrome in their country and frequently give us input into our work. This year they were renamed the **DSi Ambassadors**.

This year, the DSi Ambassadors were actively involved in a lot of our work. They advised us at key times throughout the year, in particular in respect of the impact of COVID-19. The Ambassadors contributed to a number of our webinars. They **led a webinar on how they like to be supported** (aligned with our work on inclusive participation, see “Inclusive participation guidelines” on page 5 above) and **a webinar “What changed for us in 2020”**, as part of our World Down Syndrome Day 2021 advocacy campaign (see “2021 WDSD advocacy campaign” on page 20 below). The Ambassadors met with our Board of Trustees and discussed their contribution to the work of DSi. These are only some of the highlights and moving into next year, we will be seeking some crucial contributions from this group in our project work and strategic and operational planning.

#### **Inclusive participation with CAST**

Supported by a charity called CAST (Centre for Acceleration of Social Technology), throughout 2020/21 we have been running a project to look at and **find solutions for the key problem that people with Down syndrome are not involved enough in the work of organisations that represent them,**



something which has been exacerbated by the COVID-19 pandemic and the transition to online communications.

Working with self-advocates and DSi member organisations, the project has gone through some key consultation stages (“Explore” and “Definition”) to test the problem and find potential solutions. As of March 2021, the project continues, with 2 self-advocacy networks testing an application and an approach designed to deliver meaningful participation of people with Down syndrome. If successful, we hope this can be utilised by DSi member organisations and other organisations where representation is so important.

### **Other work with self-advocates**

Self-advocates with Down syndrome and intellectual disabilities have played a key role, leading and consulting on our inclusive participation guidelines project (see page 5 above) - on the staff team, leading high-level advocacy webinars and via global consultations.

In March 2021, self-advocates moderated and spoke in all of our World Down Syndrome Day 2021 advocacy campaign webinars (see “2021 WDSD advocacy campaign” on page 20 below).

We are also **working with self-advocates via most of our projects with member organisations** (see “Inclusive employment case study and webinars” on page 6 above, “Self-advocacy facilitation training” on page 16 below and “Other member organisation advocacy” on page 19 below).



### **Member organisation support**

We strongly believe that national Down syndrome organisations know their country best; what they need from DSi is support, to build their capacity and skills.

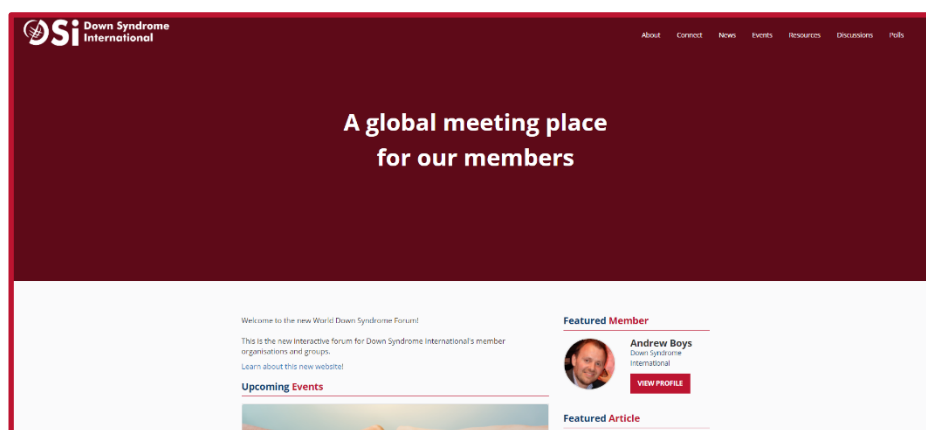
We **support national Down syndrome organisations with ongoing support, ad hoc strategic and operational advice**. We deliver training within the remit of specific funded projects (see “Training” on page 15 below). Where funding allows, we also support the development of member organisations through grant making and bespoke support, including to deliver advocacy activities (see “Other member organisation advocacy” on page 19 below).

Through all of this work, we are looking to develop members’ capacity to do their own work, develop their strategic and operational systems and evaluate the quality of activities delivered and the impact they have.



## World Down Syndrome Forum

In March 2021, we launched the **World Down Syndrome Forum**, a new web-based communication platform for our member organisations. This forum enables our members to connect more effectively with DSI, but crucially also to communicate directly with other DSI members. Via direct messaging, discussion forums, news and events posting and publication of resources, the forum is a global hub providing continuous learning opportunities for leaders and staff of DSI member organisations.



## Rwanda

We have been working in Rwanda for the last 4 years, **supporting the development of Rwanda Down Syndrome Organisation** (RDSO - the first Down syndrome specific OPD in Rwanda).

In Rwanda people with Down syndrome and their families are often isolated and lack important information about key issues affecting their lives. They struggle to participate in society due to negative attitudes and have limited access to basic healthcare and education.

In 2016, we supported the establishment of RDSO. As of March 2021, they are supporting in excess of 500 families, who previously had no support and often very little understanding of what Down syndrome was or how it might affect their child.

RDSO has had a major impact in the past year on the lives of people with Down syndrome, including:

- providing 27 free speech and language therapy and occupational therapy sessions for children with Down syndrome, who often need extra support to learn to speak, play and develop essential skills to become more independent;
- providing essential support and advice to parents of children and babies with Down syndrome, who often come to RDSO knowing nothing about Down syndrome and
- establishing Rwanda's first self-advocacy group for persons with Down syndrome, where young people and adults with Down syndrome learn to speak up for themselves and advocate for their rights (see "Self-advocacy facilitation training" on page 16 below).

## A success story

Joshua is a 5-year-old boy with Down syndrome from Kigali, Rwanda. When his mother first brought him to the RDSO office he could not walk and the physiotherapy sessions needed to help him learn were unaffordable. The RDSO team advocated for the local government authority to assist the family and in 2020 he received a month of physiotherapy sessions. Now he can walk independently and RDSO

staff are working with the family to find an adequate school and financial assistance to allow him to start attending.



#### Response to the pandemic

Despite the exceptionally difficult circumstances due to the COVID-19 pandemic and the restrictions imposed by it, RDSO has continued to provide its essential role supporting people with Down syndrome of all ages and their families in Rwanda.

The pandemic disrupted planned activities and many of the families that RDSO work with faced hunger and poverty due to lockdowns cutting off their sources of income. We supported them to respond dynamically, adapting how they delivered services and delivering support where possible to families.

While adapting their ways of working to respond to the pandemic they were also able to take major steps towards operating independently as an organisation.

#### Financial independence

With our support RDSO has taken the first steps towards financial independence. They are receiving their first international development funding through a project funded by the Norwegian Agency for Development Cooperation (NORAD - see “Employment-based advocacy projects in Africa and Bangladesh” on page 15 below) and are receiving capacity building support from Humanity and Inclusion. They have also started receiving some small donations and support from within Rwanda.

DSi will keep fundraising to support RDSO’s core running costs, while working with them to further reduce their reliance on this support. We are confident that RDSO will soon reach the stage where they can run without our support.

#### United Kingdom

Following DSi’s commission to:

- undertake a review of the website of the Down’s Syndrome Association (DSA – England, Wales and Northern Ireland);
- outline a new website structure for them and
- source a development team to build a new website,

DSA has spent this year developing their new website and working on content. They are **scheduled to launch their fantastic new website in June 2021**.

## TRAINING

### Employment-based advocacy project in Africa and Bangladesh

In 2020, DSi began a new 3-year project to advocate for access to employment for people with Down syndrome and intellectual disabilities.

The project, taking place in partnership with International Disability Alliance, with funding from Norwegian Agency for Development Cooperation (NORAD) and partly from Inclusive Futures (Inclusion Works - UK Aid), comprises the following:

- **technical human rights training and COVID-19 advocacy training** for our members organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda;
- **self-advocacy facilitation training** for our member organisations in Kenya, Rwanda and Uganda (following completion of similar training with Bangladesh and Nigeria last year) and
- **employment-based advocacy activities** from all 5 member organisations, led by self-advocacy groups (see “Other member organisation advocacy” on page 19 below).

### **Technical human rights training and COVID-19 advocacy training**

Over 6 weeks in 2020, this training was characterised by interaction, discussions and sharing of experiences between participants. The sessions were attended through a combination of live online workshops and resources and exercises to review and complete between sessions.

The well attended training drew participation from leadership and staff from Down Syndrome Society of Bangladesh, Down Syndrome Society of Kenya, Down Syndrome Foundation Nigeria, Rwanda Down Syndrome Organisation, Inclusion Uganda and Uganda Down Syndrome Association.

Topics covered included:

- an introduction to human rights and development;
- The UN Convention on the Rights of Persons with Disabilities (CRPD) and Sustainable Development Goals (SDGs);
- public policy and network building and
- organisations of persons with disabilities and inclusive participation.



### Self-advocacy facilitation training

As of end of March 2021, we are delivering self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda.

People with Down syndrome often have a limited voice in the decisions and changes that affect them. Decisions are often made without consideration of their opinions and preferences. As a result, their rights are frequently violated.

Prior to this year, we have trained 71 self-advocacy group facilitators from our member organisations in 5 countries: Turkey, Nigeria, Bangladesh, United Arab Emirates and Kosovo. These facilitators have started 8 self-advocacy groups so far with a total of 73 self-advocates with Down syndrome.

**The groups support people with Down syndrome to learn about human rights and build their self-advocacy skills**, enabling them to engage in a variety of advocacy activities.

Participation in the self-advocacy groups has also had a very positive impact on the individuals with Down syndrome. This has included increased confidence, more positive attitudes towards having Down syndrome, and better ability to express opinions and advocate for their rights.

These projects are based on the following methodology:

- initial visit to train self-advocacy group facilitators and work with our member organisation on general understanding of self-advocacy;
- trained facilitators empower self-advocates to start groups and meet regularly over a 10 month period, during which time group discussions lead to advocacy activities;
- DSi returns for a follow up training and monitoring visit 6 months after initial training;
- DSi provides structured support and advice to the facilitators over full 12 months of project;
- After 12 months, the projects are completed, with a report prepared to review success and outcomes;
- member organisations continue and look to build on the project going forward, supported by DSi.

Due to the COVID-19 pandemic and travel restrictions, the delivery of the projects in Kenya, Rwanda and Uganda has partly moved online, but still with good results and this training has been well supported by a project fellow employed in Uganda. See “Other member organisation advocacy” on page 19 below for some example advocacy activities undertaken by the groups.



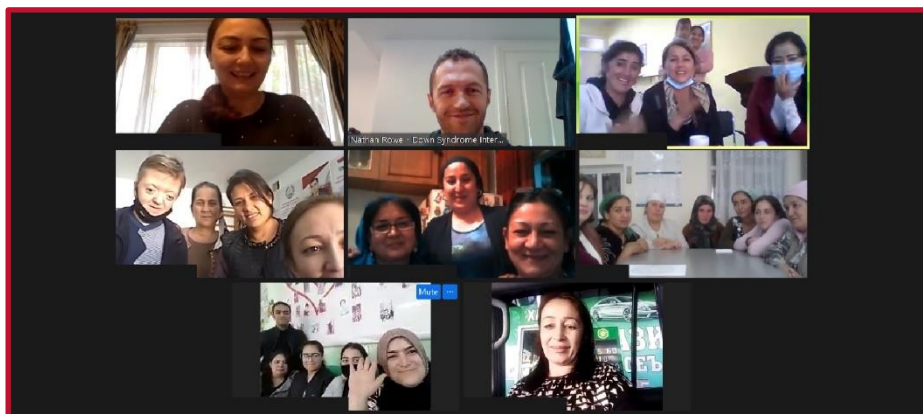
Through these ground-breaking projects, it is an absolute pleasure to see the increase in confidence of self-advocates. We are incredibly proud of each of the self-advocates and all that they have achieved and we look forward to working with them and their organisations to bring about positive change for people with Down syndrome and intellectual disabilities.

### **Rights-based advocacy training for people with Down syndrome**

DSi also works directly with self-advocates with Down syndrome in various international forums, developing their rights-based advocacy skills so they have the tools to speak out. See “Working with self-advocates” on page 11 above.

### **Human rights training in Tajikistan**

This year, as part of a larger advocacy project led by Nazari Digar, our member organisation in Tajikistan, we ran 2 days of online human rights training with parents and family members in Tajikistan and 2 days training with organisations representing people with Down syndrome and their families.



### **Training for parents and family members**

The training included parents and family members from across Tajikistan and one from Russia, with children of varying ages. The participants shared their experiences raising children with Down syndrome and some of the difficulties they faced. Many of their children had faced discrimination and bullying and they had difficulties accessing services they needed. There were also common issues related to education, including rejection from mainstream schools, and requirements to travel long distances or board at special schools.

We provided **training on the rights that persons with Down syndrome have**, including the right to non-discrimination, healthcare, and inclusive education.

### **Training for organisations representing persons with Down syndrome**

The training included organisations representing persons with Down syndrome from across Tajikistan. The issues raised by these representatives were similar to those raised by parents. We provided a **more in-depth advocacy training** for them, focusing on:

- The UN human rights system;
- The UN Convention on the Rights of Persons with Disabilities;
- The Sustainable Development Goals and
- international accountability mechanisms.



As of the end of March 2021, we are now supporting Nazari Digar and the other organisations in the training to plan an advocacy project, focusing on the key issues they identified. They have already conducted interviews with over 100 family members in the country to better understand the issues their children with Down syndrome face and provide good data to support their advocacy work.

As a part of this project we also delivered some basic training to the same representative group on DSI's recently published **International Guidelines for the Education of Learners with Down Syndrome** (see "Education guidelines" on page 4 above).

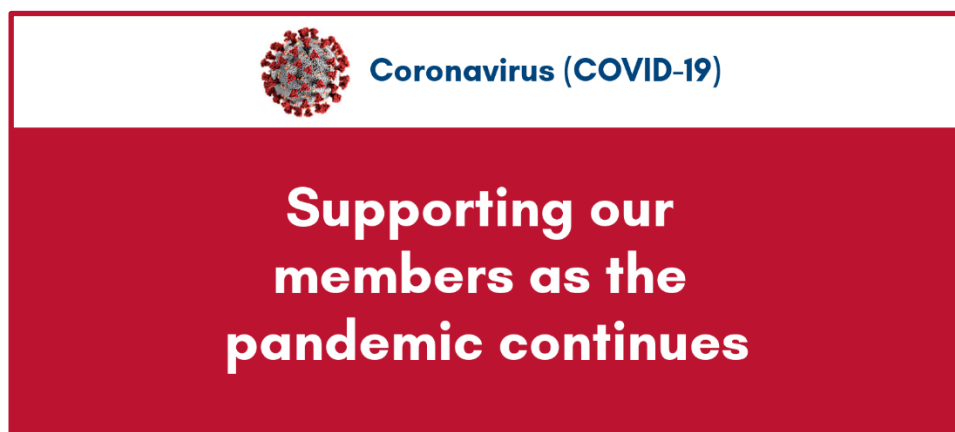
### 3. ADVOCACY AND CAMPAIGNING

A key part of DSI's role is to **advocate for the rights of people with Down syndrome in line with the UN CRPD**. We do this at national, regional and international levels, working with our members and partners, participating in disability and human rights forums and campaigning to raise awareness in wider society.

#### COVID-19 response advocacy

Advocating for the rights of people with Down syndrome where the pandemic has had an impact and required responses (see "COVID-19 response" on page 9 above) has been a key focus this year.

We have worked with international partners to undertake global advocacy (see "International collaboration" on page 10 above), we have worked with and supported our national member organisations to deliver crucial advocacy activities and we have supported the global Down syndrome community, providing tools and resources for individuals and families to ensure people with Down syndrome are included in pandemic responses.



**In March 2021, we provided grants to 5 of our national member organisations for COVID-19 specific advocacy activities.** We will be supporting these members - Down Syndrome Albania Foundation, Asociacion Sindrome de Down de la Republica Argentina (ASDRA), Federacao Brasileira das Associacoes Sindrome de Down, Indonesia Down Syndrome Care Foundation (YAPESDI) and Down Syndrome South Africa – as they prepare and deliver these crucial interventions.

These activities are funded by UK Aid via the COVID-19 Pooled Fund and DSI will be providing more support, resources and training related to COVID-19 response advocacy for other member organisations later in 2021.

As of the end of March 2021, we are preparing **information and advocacy resources on COVID-19 vaccination prioritisation** for people with Down syndrome, with a global campaign planned for mid-2021. This follows a number of previous COVID-19 related global campaigns and distribution of information and resources throughout 2020 (see “COVID-19 response” on page 9 above).

### Other member organisation advocacy

#### **Employment-based advocacy project in Africa and Bangladesh**

Following our technical human rights training, COVID-19 advocacy training and self-advocacy facilitation training for our members organisations in Bangladesh, Kenya, Nigeria, Rwanda and Uganda (see “Employment-based advocacy project in Africa and Bangladesh” on page 15 above), later in 2021 we will be supporting **employment-based advocacy activities from all 5 member organisations, led by their self-advocacy groups.**

In fact, the self-advocacy groups have been active this year in terms of advocacy as follows:

#### **In Nigeria**

The self-advocacy group visited the Nigerian Institute of Medical Research (NIMR) to advocate for free COVID-19 testing for people with intellectual disabilities. The NIMR agreed to offer free testing for people with intellectual disabilities and their supporters. In addition, NIMR delivered training for people with Down syndrome and their families about COVID-19 and the vaccine, including the effects and benefits for people with Down syndrome.

Nigeria’s self-advocates visited the local Government Chairman of Ifako-Ijaiye to advocate for free face masks, hand sanitiser and a mechanical hand wash machine, as well as free vaccines for people with Down syndrome. The Chairman agreed and is distributing these items via our member organisation.

Nigeria’s self-advocates visited the Kings Seed School in Iju Fagba to speak about inclusion. The self-advocates invited the school to participate in their 'Ring The Bell' campaign to raise awareness of the need to include people with disabilities.



#### **In Uganda**

Self-advocates spent time talking about their general wellbeing both at home and in the community. This helped build their confidence to speak up, express their views and learn that their contribution matters and has the power to impact their lives and those around them.

#### In Rwanda

Self-advocates met with staff from Rwanda Biomedical Center (RBC) to participate in COVID-19 testing. RBC offered to deliver training to the group about COVID-19 and the vaccine so they can make informed decisions.

#### In Kenya

Down Syndrome Society of Kenya worked with self-advocates to produce easy read materials explaining social distancing, hand washing and mask wearing. These were distributed to people with Down syndrome and their families using WhatsApp.

#### **Inclusive education advocacy project in United Kingdom**

Also planned for 2021, DSI will begin a project, working in partnership with our member Down's Syndrome Association (DSA - England, Wales and Northern Ireland), **advocating for inclusive education in United Kingdom**. Through this project, we will:

- use our International Guidelines for the Education of Learners with Down Syndrome (see "Education guidelines" on page 4 above) as a basis to prepare a comprehensive series of information and training resources;
- train and work with the Down syndrome community to advocate for full inclusion in education and
- analyse where key interventions can be made at the policy level and in the UK education system to deliver inclusive education and plan for future activities.

This project has the potential to make a big impact and provide a template for DSI to work with other member organisations on education in countries where our support is needed.

#### World Down Syndrome Day

DSi brings together the global Down syndrome community on and around **21 March each year** for World Down Syndrome Day (WDSD). We coordinate a range of activities, all designed to advocate for the rights of people with Down syndrome and campaign to raise awareness.



Activities for WDSD in March 2021, included:

#### **2021 WDSD advocacy campaign**

Our annual WDSD international advocacy campaign, was based on the theme **"#CONNECT"**:

### ***“Why #CONNECT?”***

*In 2020 around the world, we all had to adapt the ways we connect with each other. It was a big challenge and many people have been left behind. But it was an opportunity to find new ways to connect. This can be a positive outcome from the COVID-19 pandemic.*

*For WSDS 2021 we want to focus on improving connections to **ensure that all people with Down syndrome can CONNECT and participate on an equal basis with others.***

*WSDS is a unique annual opportunity for the global Down syndrome community to connect.*

*We CONNECT so that we can:*

- *share ideas, experiences and knowledge;*
- *empower each other to advocate for equal rights for people with Down syndrome, and*
- *reach out to key stakeholders to bring about positive change.*

*From now, up to 21 March 2021, Down Syndrome International (DSi) will encourage the global community to CONNECT.*

### ***What can you do?***

*Every year we encourage people with Down syndrome, families, advocates, professionals and organisations to observe WSDS with your own activities.*

*We want to see this again, more than ever in 2021. So:*

- *go ahead and plan whatever is possible and safe to do;*
- *advocate for equal rights for people with Down syndrome in your activities and*
- *if you can, include ideas about #CONNECT into your activities.”*

Through this campaign we worked with people with Down syndrome and those who support and work with them to empower them to advocate for opportunities to #CONNECT.

A wide variety of campaigning resources were used by our members and many other advocates throughout the global community. The campaign was popular around the world and, notwithstanding the continued restrictions of the COVID-19 pandemic, many organised their own campaigns, activities and events, mostly online.



## 2021 UN conferences and other events

Following the UN declaration of WDS in December 2011, DSI has organised advocacy events in New York and Geneva. In March 2021, the following events took place:

- our **10<sup>th</sup> annual WDS conference at United Nations (UN) HQ, New York**, held virtually from 17-19 March and
- our **5<sup>th</sup> annual, self-advocate led, side-event to the Committee on the Rights of Persons with Disabilities at UN Geneva**, held virtually on 19 March.

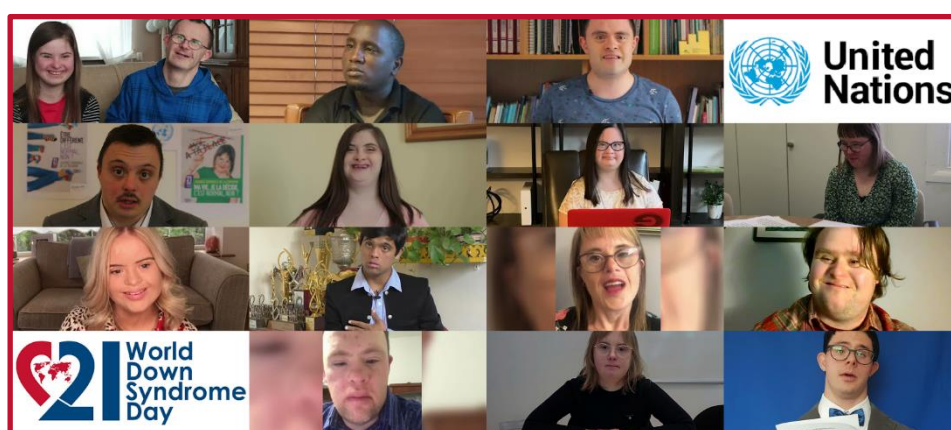
Our New York conference explored the importance of connecting for people with Down syndrome, inclusion and connection in education and barriers and solutions for connecting, all in the context of the COVID-19 pandemic. Moderated by our DSI Ambassadors (see page 11 above), the event comprised 3 webinars and was also broadcast on UN Web TV and Facebook.

Our Geneva side-event was led by self-advocates reaching out to key stakeholders to ensure all people with Down syndrome can #CONNECT and participate on an equal basis with others, particularly during the COVID-19 pandemic. The event comprised a webinar and was broadcast on UN Web TV and Facebook.

This year, DSI also organised the following WDS events:

- **“What changed for us in 2020”** – a webinar in which the DSI Ambassadors (see page 11 above) shared stories from over 100 people with Down syndrome from 14 countries;
- our **1<sup>st</sup> side-event to the Organization of American States (OAS)**, via webinar and live on Facebook on 16 March, held in Spanish on the subject of “Connect to Include” and
- **#CONNECT for World Down Syndrome Day in Africa** - Africa Down Syndrome Network and partner organisations, including African Union, African Disability Alliance and DSI connected virtually to explore the impact of COVID-19 on people with Down syndrome.

These events were all very well attended and received and we are grateful to all of our event sponsors and fantastic speakers, many of whom were self-advocates.



## Videos

Once again, **we worked with Down TV, a global portal for videos related to Down syndrome**. We encouraged people all over the world to upload videos to Down TV’s WDS hub - videos highlighting activities, making a statement or in many cases saying what WDS means to them.



Following the cancellation in 2020 of the annual video campaign organised by our member CoorDown (Italy), we were delighted to work with them again to **launch "The Hiring Chain", featuring a video with an original song performed by 17-time Grammy award winning artist Sting**. The campaign message:

*"The message to employers all over the world is that hiring a person with Down syndrome not only changes the life of the person concerned but can trigger a virtuous cycle of new opportunities for everyone. The punchy, joyful lyrics come to life on screen and bear witness to the "virtuous" chain of inclusion in the workplace.*

*On World Down Syndrome Day 2021, CoorDown takes up the challenge of the pandemic and the social crisis to affirm that job inclusion is not only a right to be guaranteed now more than ever for every person, but it brings benefits in the workplace and in society at large.*

*Employers inspired by this video should visit [hiringchain.org](https://hiringchain.org) to find contact details for organisations around the world that can provide information, support and encouragement to get people with Down syndrome into their workplace."*



The Hiring Chain campaign, designed to find employers and other stakeholders willing to employ people with Down syndrome and advocate for their employment, was a success, with substantial positive feedback. Plans are now being put in place for later in 2021 for **DSi, its members and other partners to develop employment resources, forums and training opportunities** for those interested in this area.

#### **#LotsOfSocks awareness campaign and merchandise**

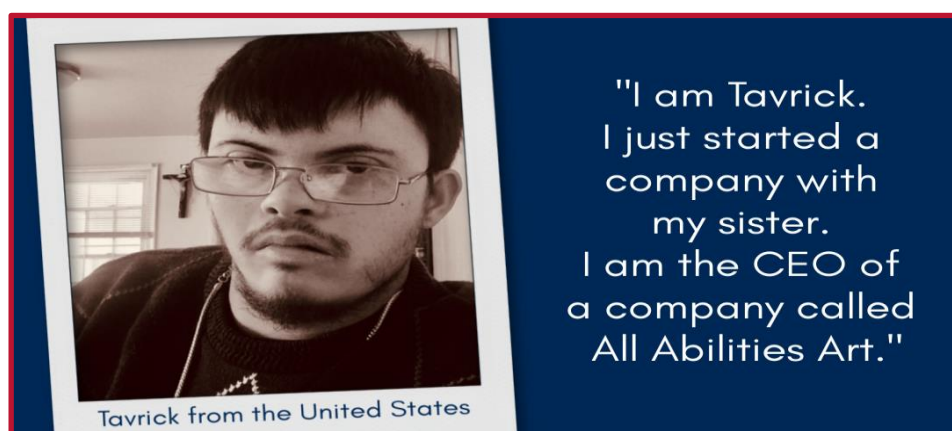
For the 9<sup>th</sup> year for WSDS 2021, DSi launched the #LotsOfSocks campaign, with the stated aim of asking people across the world to wear socks that draw attention on 21 March 2021, wherever they were, to get people talking.

The campaign was again successful, **generating substantial support on social media**. The DSi office received lots of requests for information, many committed to raise funds, we sold and distributed socks and worked with many organisations, global companies, influencers and the global community to generate global reach on 21 March.

#### **WSDS website**

The WSDS website [worlddownsyndromeday.org](https://worlddownsyndromeday.org) (and associated social media channels) is a global hub for promoting WSDS events and activities, coordinated by DSi. For WSDS 2021, we relaunched the website with some new features, designed to be useful for the global Down syndrome community and

the wider public. In addition to key information about Down syndrome and WDS, our website now features a growing list of stories shared by people with Down syndrome from around the world and includes a wide range of ideas and resources to enable people to participate and take action on WDS.



### Other advocacy activities

#### **International human rights forums**

In July 2020, DSI was represented at the High-Level Political Forum on Sustainable Development in New York (HLPF) in July, as a part of IDA's Stakeholder Group of Persons with Disabilities for Sustainable Development. In December 2020, DSI participated in the annual Conference of States Parties to the CRPD at UN, New York (COSP), including joint coordination of a side-event with Inclusion International, led by self-advocates, focusing on our **Inclusive participation guidelines** (see "Inclusive participation guidelines" on page 5 above).

### Raising funds

As the demand for the charity's services is increasing year on year, **it is imperative to maintain sufficient funding for DSI to operate.**

**Income from restricted sources, including trusts, foundations and development agencies increased in 2020/21** with significant projects in the pipeline and this trend looks set to continue in 2021/22. The challenge we have is our ability to generate sufficient restricted funding to carry out all of our charitable activities, but with corresponding programme management income and non-programme attributable (operational) income to cover the costs of carrying out those activities. As of March 2021, a significant proportion of our unrestricted income is used to fund our programme and operational management functions. DSI needs to generate more restricted funds to meet the rising demand for services, while making sure we receive the corresponding programme and operational management income needed to complete our activities successfully. This is something we analyse in detail in our financial forecasting and in our strategy to raise funds.

**The income generated from unrestricted sources decreased slightly in 2020/21**, but we have been able to fund our activities as described above. Going forward though, DSI needs to generate more unrestricted income and use it primarily to improve our unrestricted reserves position.

DSI's overall strategy for raising funds continues to develop as our activities increase year on year. In 2020/21 we looked for new funding opportunities while also focusing on the sustainability of existing funding channels. A thorough **fundraising strategy review also took place in 2020/21**, supported by

Joffe Charitable Trust, following which **we published a comprehensive fundraising strategy for the next 3 years and were able to appoint a new fundraising officer** to help us deliver this strategy - again thanks to the support of Joffe Charitable Trust.



### **Financial review**

Down Syndrome International's **total income in 2020/21 was £411,852** (2020: £283,036). This increase was due mainly to receiving substantially more restricted funding for charitable activities. We received various instalments of grants from IDA (onward granted from UK AID and Norwegian Agency for Development Cooperation) for employment, self-advocacy, COVID-19 response and inclusive participation projects. We received the 2<sup>nd</sup> instalment of a grant from Actelion Pharmaceuticals to fund the production of our upcoming cardiac consensus statement. We received 2 grants from Centre for Acceleration of Social Technology (CAST) for our project finding digital solutions for people with Down syndrome to participate. We also received significant unrestricted donations from the Joffe Charitable Trust, The National Lottery Community Fund and the Down's Syndrome Association (DSA).

**Total expenditure in 2020/21 was £382,291** (2020: £305,597). This increase reflects substantially higher restricted project expenditure in line with the increase in restricted project income.

Overall there was a **surplus in the 12 month period of £29,560** (2020: deficit £22,561). This surplus, combined with funds brought forward from 2019/20 of £27,841, resulted in **total funds available on 31 March 2021 of £57,402**. Of this, £18,323 is restricted, leaving unrestricted funds available on 31 March 2021 of £39,079.

The above indicates a stronger financial position at the end of 2020/21 compared to the previous year, but **DSi still has insufficient free reserves as required by our reserves policy**. Furthermore, we will require more operational capacity going forward in order to fulfil activities. So careful financial management, combined with a robust strategy to move towards a position of financial sustainability, will be required.

### **Reserves policy and going concern**

The reserves policy states that the unrestricted funds not committed or invested in tangible fixed assets and stocks ('the free reserves') held by the charity should be between 3 to 6 months of the resources expended. That equates to between £95,573 and £191,146 in general funds, based on this year's costs.

At this level the trustees feel that they would be able to continue the current activities of the charity in the event of a significant drop in funding. The trustees are aware that should this occur, consideration would need to be given to how such funding would be replaced or the activities changed.

Currently the free reserves available equate to £39,079, **equivalent to just over 1 month of the resources expended**. It should be noted that gifts in kind totalling approximately £43,370 (based on this year's costs) would not necessarily need to be replaced or change DSI's current activities if they were not received. But even with this allowed for, the current free reserves available are equivalent to less than 3 months of the resources expended.

It should be noted that DSI has an informal "overdraft" agreement with one of its creditors, the Down's Syndrome Association (DSA). DSA acts as a payroll agency for DSI and recovers the salary costs from DSI on a quarterly basis. Under the agreement, DSA allows an informal "overdraft" facility to DSI, up to a maximum of £35,000, to help cover cashflow troughs, should a quarterly invoice not be able to be paid immediately on request.



## **Risk management**

As part of our risk management framework, **major risk reviews are carried out periodically** by the trustees. Top down and bottom up risks are considered, ranked in order of likelihood and impact, those risks needing attention are prioritised and responsibility is allocated for managing each risk. Those responsible provide updates to the trustees on their progress against action plans designed to manage the risks identified. Some of the major risk areas are described below:

**Funding:** DSI needs to ensure that the services we offer are relevant to beneficiaries, while providing sustainable income. A sudden loss of funding is a major risk for DSI right now, with limited reserves in place. In order to mitigate this, we have a fundraising strategy designed to strengthen and diversify our existing income streams and develop new means of generating both unrestricted and restricted income.

**Leadership:** The trustees and executive director recognise the importance of ensuring strong direction, motivation of purpose and continuity of leadership. The trustees have reviewed DSI's leadership, have considered the risks of leadership changes and are satisfied with progress, albeit this needs to remain under regular review.

**Core activities:** High quality and efficient delivery of DSI's core activities are key to its success. Delivery is monitored closely by the executive director and trustees, supplemented by engagement of staff and

stakeholders. The trustees are aware that better systems will be required going forwards, as our activities increase, to improve accountability and monitor progress.

**Staff:** Staff need to feel engaged and have a stake in the organisation. Their engagement is currently monitored by the president and executive director via staff reviews. Going forwards, staff satisfaction surveys, an organisational health check and new HR policies will be required.

**Operational systems:** It is critical that operational systems support our core activities, ensuring that the DSI office is run efficiently and effectively. In the last 3 years, DSI has undertaken a lot of work to improve our management, communication, finance, data and storage operational systems, introducing standard operating procedures, automating tasks and ensuring compliance with statutory requirements such as GDPR. This work will continue, with systems undergoing regular testing and review.

**Reputation:** The retention of confidence of members, stakeholders and donors is key to DSI's effectiveness. Any external facing work needs to be relevant and robust and internal support needs to be well managed. DSI is putting a lot of focus on engaging with stakeholders and this will be built upon going forwards.



## Plans for the future

2021/22 will see some significant activities, including:

### **Policy and practice, information, support and advice**

- Continued dissemination of our **international education guidelines** via our global network, including development of further complementary toolkits, resources and training opportunities, making the document accessible in more languages and formats and its playing a key role in all of DSI's future education projects.
- Publication of our **expert consensus statement on cardiac disease in Down syndrome**, followed by post-launch activities to engage with member organisations and the global community and a review of DSI's priorities for health going forward.
- Further development of the **International Guidelines for Inclusive Participation**, working jointly with Inclusion International to draft, consult again and publish the final document.
- Via the Inclusive Futures project, **publish a case study on best practices related to the employment of persons with Down syndrome and intellectual disabilities**.
- Also via the Inclusive Futures project, **support self-advocates to deliver a webinar series on inclusive employment of persons with intellectual disabilities**.



- **Working closely with the hosts of the next WDSC** to organise the first ever virtual WDSC from Dubai in November 2021.
- **Working as a member of IDA** supporting its work and its role in major international disability development programmes, including Inclusive Futures.
- **Continuing to developing our COVID-19 response**, compiling and sharing information, gathering experiences and evidence, collaborating with international partners and supporting our member organisations with specific COVID-19 response advocacy activities.



### Network development and training

- Continuing to develop systems which deliver more **effective member communications**, making us more responsive and accountable.
- Working in more depth with the **DSi Ambassadors**, who will assist us delivering training and other project work and will support an internal inclusive participation review, among other activities.
- Continuing to **progress the CAST project**, testing and hopefully promoting an approach designed to include people with Down syndrome in the work of organisations that represent them.
- Continuing to **support national member organisations to develop their capacity**, via the new World Down Syndrome Forum, ad hoc support and advice from DSi and other support resources planned.
- Continuing to **support our member in Rwanda** as they deliver more impact and move towards financial sustainability.
- Completing **self-advocacy facilitation training projects** with our members in Kenya, Rwanda and Uganda.
- Providing more **rights-based advocacy training for people with Down syndrome** via various international forums.
- Following up with our member organisation in Tajikistan as **they develop and execute advocacy activities**.

### Advocacy and campaigning

- Supporting our members in Albania, Argentina, Brazil, Indonesia and South Africa **to prepare and deliver crucial COVID-19 response advocacy activities**.
- Launching a **global advocacy campaign on COVID-19 vaccination prioritisation**.

- Supporting **employment-based advocacy activities from 5 member organisations in Africa and Bangladesh**, led by their self-advocacy groups.
- Delivering a **new inclusive education advocacy project in United Kingdom**.
- **Delivery of WDS 2022 activities**, including the launch of the 2022 WDS advocacy campaign, delivery of our WDS UN conferences in New York and Geneva (whether they are in-person or virtual), other WDS events, WDS video projects, “Lots of Socks” awareness campaign and merchandise sales and coordinating the WDS website and social media.
- **Participation in international human rights forums** such as COSP and HLPF.



### Raising funds

- Seeking to **increase income from restricted sources**, including trusts, foundations and development agencies, to cover the operational costs of carrying out activities.
- Seeking to **increase income from unrestricted sources**, via general donations, events and merchandise sales, to improve our unrestricted reserves position.
- Overall, looking for new opportunities while **maintaining focus on the sustainability** of existing funding.

2021/22 will also be a very important year as we finalise a new strategy for the next few years. With a new fundraising strategy now in place and a new communications strategy in progress, we have been reviewing our programme activities, purpose, resources, our environment and seeking feedback from our stakeholders ahead of publishing new strategic and operational plans. Given our increased activity levels, increased funding and our need to manage risks, this work will be crucial for DSi to set a clear path to a sustainable future.

### Structure, governance and management

The organisation is a charitable company limited by guarantee, registered as a charity on 1 May 2002 and incorporated on 23 November 2001.

The organisation was established under a Memorandum and Articles of Association, which set out the objects and powers of the organisation.

The trustees operate under a Code of Governance, which sets out the basis of board and staff responsibilities, conduct and procedure and a specific procedure for the constitution of the board of trustees to ensure an equitable cross-section of persons and countries.

All of the trustees give their time voluntarily and receive no benefits from the charity. Any expenses reclaimed from the charity are minimal and are set out in note 7 of the accounts.

### **Appointment of trustees**

The Articles of Association state that **the charity has members who all have one vote at general meetings**. The members are the trustees and a member stops being such if he/she ceases to be a trustee.

The trustees can establish other classes of membership as they see fit and the board may admit and remove such members in accordance with regulations made by them, notwithstanding that such members are not members of the charity for the purposes of the Articles of Association or the Companies Act. For the avoidance of doubt, **DSi currently has 2 such classes of membership** – representative membership and affiliate membership.

The **board of trustees manages the business of the charity** and as of 31 March 2021 consists of 9 members, elected by the charity members. The Articles of Association allow for not less than 5 and no more than 21 trustees.

At each annual general meeting one third of the trustees must retire but are all eligible for re-election. Those board members who must retire are decided upon on a rotation basis so that a different third retire each year and an individual will not therefore be required to retire any more frequently than once in every 3-year period.

The board of trustees may co-opt additional members provided that the rules as to the total number of board members and its make-up are not transgressed. Such appointed or co-opted board members should be appointed for a specific purpose and their appointment is subject to a board vote in the usual manner. Such co-opted board members will hold office until the next annual general meeting. They will then be eligible for re-election and to vote at the meetings of the board.



### **Recruitment, selection and induction of trustees**

The Articles of Association require that the board use reasonable endeavours to ensure that there is a wide geographical representation on its board.

The Code of Governance includes a full policy on recruitment, selection and induction of trustees. The board must use open and transparent methods, with posts filled by the person most likely to fill the requirements of DSi as determined by a skills audit, but with reference to a number of recruitment and

selection procedures. Existing trustees must examine the charity's purpose and aims and their duties and responsibilities as trustees, so that they can explain this to new trustees. The board must ensure that they, rather than staff, retain overall responsibility for the process. Trustees must also be aware of the legal rules on eligibility and should consider conflicts of interest.

The board is first required to consider suitable candidates from among DSI's representative members. In the unlikely event that a suitable candidate cannot be found from there, the board may then consider affiliate members and applications from the wider international community.



Notwithstanding the search for candidates with the required skills, the board must be aware of the following key requirements for its composition in their decision-making process:

- 55% of the board must be **persons with Down syndrome or family members** of persons with Down syndrome;
- a maximum of 2 people from any country can be board members at the same time;
- the board will use best endeavours to ensure there is a widespread geographical representation from around the World and there should be at least 1 person from Europe, North America, South America, Africa, Asia and Australia (continent) on the board at all times and
- the board will use best endeavours to ensure that **at least 25% of its members are from "developing economies"** according to the International Monetary Fund's World Economic Outlook Report, April 2015."

On induction, the board provides all trustees with induction material (including governing documents, annual reports, meeting minutes, strategy and management documents) to allow them to understand their charitable purposes, financial position and current issues.

### **Related parties and connected organisations**

DSi has good links with a large number of Down syndrome, disability and international development organisations worldwide.

We have a close working relationship with the Down's Syndrome Association (DSA), which has led to the location of our registered office in Teddington, information and resource sharing and funding.

Other notable members include Down Syndrome Ireland, Down Syndrome South Africa, Down Syndrome Foundation Nigeria, Down Syndrome Society of Bangladesh, Down Syndrome Federation of India, Down Syndrome Association Singapore, Down Syndrome Australia, Federacao Brasileira das



Associacoes Sindrome de Down (Brazil), Down's Syndrome Scotland, Emirates Down Syndrome Association (United Arab Emirates), National Down Syndrome Society (United States), Down España (Spain) and Trisomie 21 France among many others.

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

DSi is in special consultative status with the Economic and Social Council of the United Nations (UN), is a member of International Disability Alliance (IDA) and we work closely with Inclusion International.



### **Remuneration policy**

DSi is committed to ensuring a proper balance between paying our staff and others who work for us fairly so that we attract and retain the best people for the job and careful management of our charity funds. In so doing we will ensure the greatest effectiveness in delivering our charitable objectives and meeting the needs of our beneficiaries.

When determining the salary for a newly created post, we will collect information about comparable roles in other organisations, preferably within the voluntary sector. We will use this information to benchmark our own salaries, normally aiming to set it at a level that appears to represent the market average. We will also seek advice from colleagues within other organisations, if applicable, when we know they employ people in similar roles.

All DSi staff will be entitled to an annual pay increase in line with the cost of living in their country of residence. For DSi staff working in the UK, this would normally be 3% per annum unless there are significant monetary reasons why this should not happen. Any variance to the annual cost of living increase as stated above must be agreed by the Board of Trustees. Individual staff may be entitled to an annual pay increase over and above the cost of living increase in exceptional circumstances, which must be agreed by the Board of Trustees. Annual pay increases are paid from the beginning of the financial year.

The board as a whole is responsible for appraising the executive director and deciding on a remuneration package annually, with principles to be observed including a package which is sufficient to attract, retain and motivate, while providing for full disclosure all elements of the package, with any performance-related elements linked to the achievement of specific and measurable targets which are reviewed annually.



## Fundraising

We regularly review all our fundraising processes and procedures to ensure that we adhere to the relevant codes of practice and that we are dealing with supporters or potential supporters in a way which aligns with our values.

Vulnerable people are protected as we never share personal data, never put any of our supporters under undue pressure, always seek consent for contact and anyone can opt out of hearing from us at any time.

We do not work with any commercial participators or professional fundraisers. We have never received any complaints related to our fundraising. All fundraising activities are reported on regularly and reviewed by the executive director and trustees.



## Statement of responsibilities of the trustees

The trustees (who are also directors of Down Syndrome International for the purposes of company law) **are responsible for preparing the trustees' annual report and the financial statements** in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to **prepare financial statements for each financial year** which give a true and fair view of the state of affairs of the charitable company and group and of the incoming resources and application of resources, including the income and expenditure, of the charitable company and group for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and group and enable them to

ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditor is unaware and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Members of the charity guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 March 2021 was 9 (2020: 9). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

#### **Independent examiner**

The company has taken advantage of the small companies' exemption in preparing the report above.

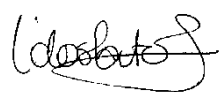
The following person was appointed to carry out an independent examination of these accounts:

Mr Luke Burns

Fellow Member of the Association of Chartered Certified Accountants (ACCA)

1 Century Drive, Reading, RG7 1PE, UK.

The trustees' annual report has been approved by the trustees on 25 August 2021 and signed on their behalf by:



**Vanessa dos Santos**  
**President**  
**Board of Trustees**



Section A

Independent Examiner's Report

Report to the  
trustees/directors/  
members of

Down Syndrome International

On accounts for the year  
ended

31 March 2021

Charity no.:

1091843

Company no.:

04327941

Responsibilities and  
basis of report

I report to the charity trustees on my examination of the accounts of the Company for the year ended **31/03/2021**.

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

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

Independent  
examiner's statement

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

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

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

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

Signed:

Date:

08/08/2021

**Name:** Luke Burns

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

Fellow of the Association of Chartered Certified Accountants (ACCA)

**Address:**

1 Century Drive

Reading

RG7 1PE

## Section B

### Disclosure

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

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

No material matters to note.

## **Annex 1: Membership**

### **Organisation members in Africa**

#### **Botswana**

*Representative Organisation*

Down's Syndrome Association of Botswana

#### **Cameroon**

*Representative Organisation*

Aidrikings Foundation

#### **Congo**

*Affiliate Organisation*

Lenire Asbl

#### **Eritrea**

*Affiliate Organisation*

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

#### **Ethiopia**

*Affiliate Organisation*

Ethiopian National Association on Intellectual  
Disabilities

#### **Ghana**

*Representative Organisation*

Robb Foundation

*Affiliate Organisation*

Inclusion Ghana

#### **Kenya**

*Representative Organisation*

Down Syndrome Society of Kenya

#### **Liberia**

*Affiliate Organisation*

My Heart's Appeal Inc

#### **Libya**

*Representative Organisation*

Libyan Down Syndrome Association

#### **Madagascar**

*Representative Organisation*

Down Syndrome Madagascar

#### **Mauritius**

*Representative Organisation*

Down Syndrome Association Mauritius

#### **Morocco**

*Representative Organisation*

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

#### **Nigeria**

*Representative Organisation*

Down Syndrome Foundation Nigeria

*Affiliate Organisations*

Larger Than I Developmental Foundation

Moyinoluwa Rainbow Foundation

#### **Rwanda**

*Representative Organisation*

Rwanda Down Syndrome Organisation (RDSO)

#### **South Africa**

*Representative Organisation*

Down Syndrome South Africa

#### **Tanzania**

*Representative Organisation*

Pearl of People with Down Syndrome Foundation

*Affiliate Organisation*

Elimisha

Morogoro Saving the Poor Organization

#### **Togo**

*Representative Organisation*

APAPE - Down Syndrome Togo



**Tunisia***Affiliate Organisation*

AMED (Association Mon Enfant est Different)

**Uganda***Representative Organisation*

The Uganda Down Syndrome Association (TUDSA)

*Affiliate Organisation*

Angel's Center for Children with Special Needs

EmbraceKulture

**Zimbabwe***Representative Organisation*

Zimbabwe Down Syndrome Association

**Organisation members in Asia Pacific****Australia***Representative Organisation*

Down Syndrome Australia

*Affiliate Organisation*

e.motion 21

**Bangladesh***Representative Organisation*

Down Syndrome Society of Bangladesh

*Affiliate Organisation*

Bangladesh Down Syndrome Association

**Bhutan***Affiliate Organisation*

Ability Bhutan Society

**China***Representative Organisation*

Macau Down Syndrome Association

*Affiliate Organisation*

Shanghai Hope Star Public Welfare Development Center

**Hong Kong, S.A.R, China***Representative Organisation*

Hong Kong Down Syndrome Association

**India***Representative Organisation*

Down Syndrome Federation of India

*Affiliate Organisation*

ALAN T21 Welfare Trust

**Indonesia***Representative Organisation*

Indonesia Down Syndrome Care Foundation (YAPESDI)

*Affiliate Organisation*

Ikatan Sindroma Down Indonesia (ISDI)

**Japan***Representative Organisation*

Japan Down Syndrome Society (JDS)

*Affiliate Organisation*

DSIJ

**Malaysia***Affiliate Organisation*

Kiwanis Down Syndrome Foundation

**Maldives***Representative Organisation*

Beautiful Eyes Down Syndrome Association

**Mongolia***Representative Organisation*

Down Syndrome Association Mongolia (DSAM)

**Myanmar***Representative Organisation*

Myanmar Down Syndrome Association

**Nepal***Representative Organisation*

Down's Syndrome Association of Nepal (DSAN)

Down Syndrome Society Nepal

#### **New Zealand**

*Representative Organisation*

New Zealand Down Syndrome Association

#### **Pakistan**

*Representative Organisation*

Karachi Down Syndrome Program

Pakistan Down Syndrome Association (PDSA)

#### **Philippines**

*Affiliate Organisation*

Down Syndrome Association of the Philippines, Inc.

#### **Singapore**

*Representative Organisation*

Down Syndrome Association Singapore

#### **South Korea**

*Representative Organisation*

Korea Down Syndrome Society

#### **Sri Lanka**

*Representative Organisation*

Jinendhi Resource Centre for Down Syndrome

*Affiliate Organisation*

Jinendhi Resource Centre for Down Syndrome

Kosala Dullewa Foundation for Children with Special Needs

Soulink Lanka

#### **Vietnam**

*Affiliate Organisation*

My Future

#### **Organisation members in Central Asia**

#### **Armenia**

*Representative Organisation*

Sun Children

#### **Georgia**

*Representative Organisation*

Georgian Down Syndrome Association

#### **Kazakhstan**

*Affiliate Organisation*

Solnechnyi Mir

#### **Kyrgyzstan**

*Representative Organisation*

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

*Affiliate Organisation*

Luch Dobra (The Ray of Kindness)

#### **Russia**

*Representative Organisation*

Downside Up

*Affiliate Organisation*

Regional public organization "Time of Changes"

#### **Tajikistan**

*Representative Organisation*

Nazari Digar

*Affiliate Organisation*

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

Public Organisation Open Hearts

#### **Turkey**

*Representative Organisation*

Down Turkiye Down Sendromu Dernegi

#### **Ukraine**

*Representative Organisation*

Ukrainian Charitable Organization "Down Syndrome"

#### **Uzbekistan**

*Representative Organisation*

Downside Sport Uzbekistan



## Organisation members in Europe

### **Regional**

#### *Affiliate Organisation*

European Down Syndrome Association (EDSA)

### **Albania**

#### *Representative Organisation*

Down Syndrome Albania Foundation

Jonathan Center

### **Austria**

#### *Representative Organisation*

Down-Syndrom Österreich

### **Belgium**

#### *Representative Organisation*

Down Syndrome Foundation Belgium

#### *Affiliate Organisation*

APEM T21

Downsyndroom Vlaanderen

Inclusion ASBL

### **Bosnia & Herzegovina**

#### *Representative Organisation*

Udruzenje Zivot Sa Down Syndromom

### **Bulgaria**

#### *Representative Organisations*

Association of the Parents of Children with Down Syndrome

Life with Down Syndrome

### **Croatia**

#### *Representative Organisation*

Croatian Down Syndrome Association

### **Cyprus**

#### *Representative Organisation*

Pan Cyprian Down Syndrome Association

### **Denmark**

#### *Representative Organisation*

Landsforeningen Downs Syndrom

### **Estonia**

#### *Representative Organisation*

Downi Sundroomi Uhing / Down Syndrome Association Estonia

### **France**

#### *Representative Organisation*

Trisomie 21 France

### **Germany**

#### *Representative Organisation*

Deutsches Down-Syndrom InfoCenter

### **Gibraltar**

#### *Representative Organisation*

Down's Syndrome Support Group Gibraltar (DSSGG)

### **Greece**

#### *Representative Organisation*

Down Syndrome Association of Greece

### **Hungary**

#### *Affiliate Organisation*

Down Egyesület

### **Ireland**

#### *Representative Organisation*

Down Syndrome Ireland

#### *Affiliate Organisation*

The Down Syndrome Centre (Ireland)

### **Italy**

#### *Representative Organisation*

Associazione Italiana Persone Down

#### *Affiliate Organisation*

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

**Kosova***Representative Organisation*

Down Syndrome Kosova

**Lithuania***Representative Organisation*

Down Syndrome Lithuania

**Macedonia***Affiliate Organisation*

Trisomija 21 - Skopje

**Malta***Representative Organisation*

Down Syndrome Association Malta

**Malta***Affiliate Organisation*

Inspire

**Netherlands***Affiliate Organisation*

Stichting Down Syndroom (SDS)

**Norway***Representative Organisation*

Norsk Nettverk for Down Syndrom (NNDS)

**Poland***Affiliate Organisations*

Ja Tez

Jeden Swiat

Legnickie Stowarzyszenie Rodzin i Przyjaciół Dzieci z  
Zespołem Downa Otworzyć Serce

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

Zespoldowna.info

**Portugal***Affiliate Organisation*

Pais21

**Romania***Affiliate Organisation*

Asociatia Down Bucuresti

Asociatia Ioana-Maria

European Centre for the Rights of Children with  
Disabilities

**Russia***Representative Organisation*

Downside Up

*Affiliate Organisation*

Regional public organization "Time of Changes"

**Slovakia***Representative Organisation*

Spoločnosť Downovho Syndromu na Slovensku

**Spain***Representative Organisation*

Down Espana

*Affiliate Organisation*

ASNIMO

**Sweden***Representative Organisation*

Svenska Downforeningen

**Switzerland***Representative Organisation*

Insieme 21

*Affiliate Organisation*

Light for Sight Foundation

**Turkey***Representative Organisation*

Down Türkiye Down Sendromu Derneği

**Ukraine***Representative Organisation*

Ukrainian Charitable Organization "Down Syndrome"

## **United Kingdom**

### *Representative Organisation*

Down's Syndrome Association (UK)

Down's Syndrome Scotland

### *Affiliate Organisation*

Cheshire Down's Syndrome Support Group

Down Syndrome Extra 21

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

Down Syndrome Research Foundation UK

Down's Heart Group

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

## **Organisation members in Middle East**

### **Iran**

#### *Representative Organisation*

Aseman Nili Down Syndrome Association

### **Iraq**

#### *Representative Organisation*

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

### **Israel**

#### *Representative Organisation*

Yated Down Syndrome Parents Association

### **Jordan**

#### *Representative Organisation*

Jasmine Association for Children with Down Syndrome

### **Lebanon**

#### *Representative Organisation*

Lebanese Down Syndrome Association

#### *Affiliate Organisation*

National Rehabilitation and Development Center (NRDC)

### **Oman**

#### *Representative Organisation*

Oman Down Syndrome Association

### **Palestinian Territory**

#### *Representative Organisation*

Al-Raheem (Down Syndrome Friends) Association

#### *Affiliate Organisation*

Right to Live Society

### **Qatar**

#### *Representative Organisation*

HOPE Qatar Center for children with special needs

### **Saudi Arabia**

#### *Affiliate Organisation*

Werathah

Help Center

### **United Arab Emirates**

#### *Representative Organisation*

Emirates Down Syndrome Association

### **Yemen**

#### *Representative Organisation*

Yemeni Down Syndrome Society (YDSS)

## **Organisation members in North America**

### **Bahamas**

#### *Representative Organisation*

The Bahamas Down Syndrome Association and Center

### **Bermuda**

#### *Representative Organisation*

Bermuda Down Syndrome Support Group

### **Canada**

#### *Representative Organisation*

Canadian Down Syndrome Society

#### *Affiliate Organisation*

Down Syndrome Resource Foundation

T21 Association Ouest Africaine



## **Dominican Republic**

### *Representative Organisation*

Asociacion Dominicana de Sindrome de Down

## **Grenada**

### *Representative Organisation*

Grenada Down Syndrome Association

## **Jamaica**

### *Representative Organisation*

Jamaica Down's Syndrome Foundation

## **Trinidad and Tobago**

### *Representative Organisation*

Down Syndrome Family Network

## **United States**

### *Representative Organisation*

National Down Syndrome Society (NDSS)

### *Affiliate Organisation*

Alexander's Angels, Inc.

LuMind IDSC Foundation

National Down Syndrome Congress (NDSC)

San Diego Down Syndrome Organisation

Down Syndrome Affiliates in Action

## **Organisation members in South and Central America**

## **Argentina**

### *Representative Organisation*

Asociacion Sindrome de Down de la Republica Argentina (ASDRA)

## **Brazil**

### *Affiliate Organisation*

Federacao Brasileira das Associacoes Sindrome de Down

Instituto Alana

MetaSocial Institute

Movimento Down

## **Chile**

### *Representative Organisation*

Fundacion down 21 Chile

### *Affiliate Organisation*

Pro Inclusion Rayos de Sol

## **Colombia**

### *Representative Organisation*

Fundacion Sindrome de Down del Caribe (Fundown Caribe)

## **Costa Rica**

### *Representative Organisation*

Fundacion El Futuro es de Todos

## **El Salvador**

### *Representative Organisation*

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

## **Guatemala**

### *Representative Organisation*

Asociacion Guatemalteca para el Sindrome de Down

### *Affiliate Organisation*

Fundacion Margarita Tejada Para Sindrome Down

## **Honduras**

### *Representative Organisation*

Integrar, Fundacion Sindrome de Down, Honduras

### *Affiliate Organisation*

Centro de Educacion Activa

## **Mexico**

### *Representative Organisation*

Fundacion John Langdon Down

### *Affiliate Organisation*

Comunidad Educativa Incluyente

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

Trisomia 21 A.C.

## **Nicaragua**

### *Affiliate Organisation*

Fundacion 21 Sindrome de Down Nicaragua

## **Panama**

### *Affiliate Organisation*

Fundacion Down Panama

SD Padres en Accion

## **Paraguay**

### *Affiliate Organisation*

Asociacion de Padres de Personas con Sindrome de Down de Itapua

Fundacion Saraki

## **Peru**

### *Representative Organisation*

Sociedad Peruana de Sindrome Down (SPSD)

### *Affiliate Organisation*

Asociacion Proyecto Yannick

## **Venezuela**

### *Representative Organisation*

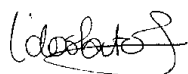
Asociacion Venezolana para el Sindrome de Down (AVESID)

<b>Down Syndrome International</b>					
<b>Consolidated statement of financial activities (incorporating and income and expenditure account)</b>					
<b>For the year ended 31 March 2021</b>					
	Note	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
<b>Income from:</b>					
Donations and legacies	2	190,589	-	<b>190,589</b>	156,518
Charitable activities					
1. Policy and practice, information, advice and support	3	-	60,396	<b>60,396</b>	18,965
2. Network development and training	3	1,976	93,192	<b>95,168</b>	34,728
3. Advocacy and campaigning	3	-	40,735	<b>40,735</b>	4,670
Other trading activities	4	24,964	-	<b>24,964</b>	68,155
<b>Total income</b>		217,529	194,323	<b>411,852</b>	283,036
<b>Expenditure on:</b>					
Raising funds	5	52,240	-	<b>52,240</b>	82,612
Charitable activities					
1. Policy and practice, information, advice and support	5	52,631	60,812	<b>113,443</b>	64,487
2. Network development and training	5	40,243	87,045	<b>127,288</b>	92,981
3. Advocacy and campaigning	5	47,212	42,108	<b>89,320</b>	65,517
<b>Total expenditure</b>		192,327	189,964	<b>382,291</b>	305,597
<b>Net income/(expenditure) for the year</b>		25,202	4,358	<b>29,560</b>	(22,561)
<b>Net movement in funds</b>		25,202	4,358	<b>29,560</b>	(22,561)
<b>Reconciliation of funds:</b>					
Total funds brought forward		13,877	13,965	<b>27,841</b>	50,402
<b>Total funds carried forward</b>		39,079	18,323	<b>57,402</b>	27,841
All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 11 to the financial statements.					

Down Syndrome International – Balance Sheet - As at 31 March 2021			
	Note	2020/21 £	2019/20 £
<b>Fixed assets:</b>			
Tangible assets		-	-
Investments		-	-
<b>Total fixed assets:</b>		-	-
<b>Current assets:</b>			
Stock		-	-
Debtors		36,739	11,683
Short-terms deposits		-	-
Cash at bank and in hand		65,801	64,486
<b>Total current assets</b>		<b>102,539</b>	76,169
<b>Liabilities:</b>			-
Creditors: amounts falling due within one year		45,138	48,328
<b>Net current assets (liabilities):</b>		<b>57,402</b>	27,841
<b>Total net assets (liabilities):</b>		<b>57,402</b>	27,841
<b>Funds:</b>	11		-
Restricted income funds		18,323	13,965
Unrestricted income funds		39,079	13,877
<b>Total funds:</b>		<b>57,402</b>	27,841

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

Approved by the trustees on 25 August 2021 and signed on their behalf by\*:



**Vanessa dos Santos – President, Board of Trustees**

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

<b>Down Syndrome International</b>			
<b>Consolidated statement of cash flows</b>			
<b>For the year ended 31 March 2021</b>			
	Note	<b>2020/21 £</b>	<b>2019/20 £</b>
<b>Cash flows from operating activities:</b>			
Net cash used in operating activities		<b>1,315</b>	(17,721)
<b>Cash flows from investing activities:</b>		-	-
Net cash used in investing activities		-	-
<b>Change in cash and cash equivalents in the year</b>		<b>1,315</b>	(17,721)
Cash and cash equivalents at the beginning of the year		<b>64,486</b>	82,207
Cash and cash equivalents at the end of the year		<b>65,801</b>	64,486



**Down Syndrome International**  
**Notes to the financial statements**  
**For the year ended 31 March 2021**

**1. Accounting policies**

**a) Statutory information**

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

**b) Basis of preparation**

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

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

**c) Public benefit entity**

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

**d) Going concern**

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

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

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

**e) Income**

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

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

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

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

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

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

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

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

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

**f) Donations of gifts, services and facilities**

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

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

**g) Interest receivable**

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

**h) Fund accounting**

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

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

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

**i) Expenditure and irrecoverable VAT**

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

Expenditure is classified under the following activity headings:

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

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

**j) Allocation of support costs**

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

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

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

• Cost of raising funds	25%
• Policy and practice, information, support and advice	25%
• Network development and training	25%
• Advocacy and campaigning	25%

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

**k) Operating leases**

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

**l) Tangible fixed assets**

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

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

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

**m) Listed investments**

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

**n) Stocks**

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

resale, are recognised at fair value which is the amount the charity would have been willing to pay for the items on the open market.

**o) Debtors**

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

**p) Short term deposits**

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

**q) Cash at bank and in hand**

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

**r) Creditors and provisions**

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

**s) Financial instruments**

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

**t) Pensions**

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

## 2. Income from donations and legacies

	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Gifts	143,098	-	143,098	121,450
Legacies	-	-	-	-
Donated services	47,491	-	47,491	35,067
<b>Total income from donations and legacies</b>	<b>190,589</b>	<b>-</b>	<b>190,589</b>	<b>156,518</b>

### 3. Income from charitable activities

Down Syndrome International - Income from charitable activities				
For the year ended 31 March 2021				
	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Actelion Pharmaceuticals	-	15,965	15,965	15,965
Emirates Down Syndrome Association	-	-	-	3,000
International Disability Alliance (via Inclusion Works Consortium - UK Aid)		14,831	14,831	-
International Disability Alliance (Inclusive Participation Guidelines)	-	29,600	29,600	-
<b>Sub-total for Policy and Practice, Information, Support and Advice</b>	-	60,396	60,396	18,965
Emirates Down Syndrome Association	-	-	-	1,500
Down Syndrome Kosova	-	-	-	1,858
W F Southall Trust	-	-	-	3,000
Down's Syndrome Association	-	-	-	6,750
Nazari Digar	1,976	-	1,976	-
Cente for Acceleration of Social Technology (CAST)	-	10,000	10,000	-
International Disability Alliance (via UK Aid Catalyst project)	-	-	-	21,620
International Disability Alliance (via Norwegian Agency for Development Cooperation - NORAD)	-	83,192	83,192	-
<b>Sub-total for Network Development and Training</b>	1,976	93,192	95,168	34,728
Other project related income	-	-	-	115
International Disability Alliance (via UK Aid Catalyst project)	-	-	-	4,555
International Disability Alliance (via COVID-19 Pooled Fund - UK Aid)	-	29,465	29,465	-
International Disability Alliance (via Inclusion Works Consortium - UK Aid)	-	11,270	11,270	-
<b>Sub-total for Advocacy and Campaigning</b>	-	40,735	40,735	4,670
<b>Total income from charitable activities</b>	1,976	194,323	196,299	58,364



#### 4. Income from other trading activities

	Unrestricted funds £	Restricted funds £	2020/21 total funds £	2019/20 total funds £
Fundraising events	-	-	-	6,641
Trading	24,964	-	<b>24,964</b>	61,514
<b>Total income from other trading activities</b>	<b>24,964</b>	-	<b>24,964</b>	68,155

5. Analysis of expenditure		Charitable activities						
	Cost of Raising Funds £	Policy and Practice, Information, Support and Advice £	Network Development and Training £	Advocacy and Campaigning £	Governance Costs £	Support Costs £	2020/21 Total £	2019/20 Total £
Staff costs (Note 7)	20,865	43,019	39,255	22,583	12,460	20,926	159,109	156,733
Cost of operating online shop	6,399	-	-	-	-	-	6,399	31,489
Fundraising event and other fundraising costs	5,713	-	-	-	-	-	5,713	6,013
Advertising, marketing and publicity	4,956	15,676	15,676	15,676	-	-	51,983	34,422
Grant making for projects and activities	-	8,623	52,298	33,833	-	-	94,754	5,642
Spending on projects and activities	-	30,107	5,611	1,806	-	-	37,524	34,800
Office running costs and equipment	-	-	-	-	-	9,203	9,203	10,312
Consultants and professional fees	-	-	-	-	548	500	1,048	1,099
Rent, insurance and maintenance	-	1,570	-	975	-	6,931	9,476	9,953
Travel, meetings and conferences	-	141	141	141	-	-	422	11,220
Management, communications, finance, data and storage operational Systems	-	-	-	-	-	6,662	6,662	3,914
<b>Sub-total</b>	37,933	99,136	112,981	75,013	13,008	44,221	382,291	305,597
Support costs	11,055	11,055	11,055	11,055	-	(44,221)		
Governance costs	3,252	3,252	3,252	3,252	(13,008)			
<b>Total expenditure 2020/21</b>	<b>52,240</b>	<b>113,443</b>	<b>127,288</b>	<b>89,320</b>			<b>382,291</b>	

## 6. Grant making

	2020/21 total funds £	2019/20 total funds £
<b>Cost</b>		
Rwanda Down Syndrome Organisation	17,840	2,557
Asociacion Guatemalteca para el Sindrome de Down	-	3,085
Down Syndrome Society of Kenya	18,536	-
Down Syndrome Foundation Nigeria	4,250	-
Inclusion Uganda	20,295	-
Down Syndrome Society of Bangladesh	9,843	-
Down Syndrome Albania Foundation	4,550	-
Asociacion Sindrome de Down de la Republica Argentina (ASDRA)	3,735	-
Federacao Brasileira das Associacoes Sindrome de Down	5,715	-
Indonesia Down Syndrome Care Foundation (YAPESDI)	5,050	-
Down Syndrome South Africa	4,940	-
At the end of the year	94,754	5,642

## 7. Analysis of staff costs, trustee remuneration/expenses and cost of key management personnel

Staff costs were as follows:

	2020/21 total funds £	2019/20 total funds £
Salaries and wages	140,254	137,599
Social security costs	12,258	12,281
Employer's contribution to defined pension schemes	4,520	4,913
Total	157,032	154,793

No employee earned more than £60,000 during the year (2019/20: £nil). The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £59,197 (2019/20: £59,174).

The charity trustees were neither paid nor received any other benefits from employment with the charity in the year (2019/20: £nil). No charity trustee received payment for professional or other services supplied to the charity (2019/20: £nil).

Trustees' expenses represent the payment or reimbursement of travel, accommodation and subsistence costs totalling £0 (2019/20: £6,564) incurred by 0 (2019/20: 8) members relating to participation in project activities and governance meetings.

## 8. Staff numbers

The average numbers of employees (head count based on number of staff employed) during the year was as follows:

	2020/21 No.	2019/20 No.
Raising funds	1	1
Charitable activities	7	2
Support	3	2
Governance	1	1
<b>Total</b>	<b>12</b>	<b>6</b>

## 9. Related party transactions

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

Membership fee transactions have taken place during the year with many members of Down Syndrome International. Membership requires a fee and in exchange basic support and advice is provided, members participate as partners or stakeholders in our activities and we promote our members' work. The maximum annual fee charged for membership is £240. Some DSI members purchase merchandise from our shop related to World Down Syndrome Day for sale or distribution in their own countries. DSI also makes grants to certain members, as set out in note 6 of these notes to the accounts.

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

General donations and restricted grants are given by DSA to DSI to support our work. DSI contributes 50% of the staff costs for a shared community fundraiser, employed by DSA (agreement ended April 2020). Donations for certain events and activities organised by this fundraiser (and others) are shared equally with DSA.

<b>DSA made the following payments to DSi during the year:</b>	<b>2020/21 £</b>	<b>2019/20 £</b>
Donations and grants	<b>55,000</b>	64,565
Membership fee	<b>240</b>	240
Income from providing new website advice and support services	-	6,750
Income from shared donations and fundraising activities	-	6,287
Merchandise	-	-
<b>Total</b>	<b>55,240</b>	77,842

<b>DSi made the following payments to DSA during the year:</b>	<b>2020/21 £</b>	<b>2019/20 £</b>
Staff costs for shared community fundraiser	<b>813</b>	8,787
Income from shared donations and fundraising activities	-	1,666
<b>Total</b>	<b>813</b>	10,453

DSi received funds from 3 other members in 2020/21 - £1,976 from our member Nazari Digar for human rights and education advocacy training; a general grant of £260 from Cheshire Down's Syndrome Support Group and a general grant of £2,175 from Alexander's Angels, Inc.

DSi received separate grants of £26,101, £83,192, £29,465 and £29,600 in 2020/21 from International Disability Alliance (IDA – onward granted from UK Aid and Norwegian Agency for Development Cooperation). DSi is a member of IDA.

## 10. Taxation

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



## 11. Movement in funds

Down Syndrome International - Movement in funds (current year) - For the year ended 31 March 2021					
	At the start of the year £	Incoming resources and gains £	Outgoing resources and funds £	Transfers £	At the end of the year £
<b>Restricted funds:</b>					
Inclusion Works – employment and COVID-19 advocacy Bangladesh, case study and webinar series	-	26,101	29,174	-	(3,073)
CAST - finding digital communication solutions for people with Down syndrome	-	10,000	10,000	-	-
NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa	-	83,192	77,045	-	6,147
COVID-19 Pooled Fund - COVID-19 advocacy in Albania, Argentina, Brazil, Indonesia and South Africa	-	29,465	29,465	-	-
International guidelines for inclusive participation of people with intellectual disabilities	-	29,600	27,668	-	1,932
Consensus statement on cardiac disorders in people with Down syndrome	13,965	15,965	16,613	-	13,317
<b>Total restricted funds</b>	<b>13,965</b>	<b>194,323</b>	<b>189,964</b>	<b>-</b>	<b>18,323</b>
<b>Unrestricted funds:</b>					
<b>Designated funds:</b>					
The National Lottery Community Fund - COVID-19 response	-	10,000	10,000	-	-
The Joffe Charitable Trust - Fundraising strategy research and fundraising staff resources	-	32,560	9,643	-	22,917
University of Exeter - Access to Internship scheme	-	1,300	1,300	-	-
Nazari Digar - Human rights and education advocacy training	-	1,976	1,976	-	-
<b>Total designated funds</b>	<b>-</b>	<b>45,836</b>	<b>22,919</b>	<b>-</b>	<b>22,917</b>
<b>General funds:</b>	<b>13,877</b>	<b>171,693</b>	<b>169,408</b>	<b>-</b>	<b>16,163</b>
<b>Total unrestricted funds:</b>	<b>13,877</b>	<b>217,529</b>	<b>192,327</b>	<b>-</b>	<b>39,079</b>
<b>Total funds</b>	<b>27,841</b>	<b>411,852</b>	<b>382,291</b>	<b>-</b>	<b>57,402</b>

### Purposes of restricted funds

#### Inclusion Works - employment and COVID-19 advocacy Bangladesh, case study and webinar series

Supporting our member in Bangladesh to deliver employment and COVID-19 related advocacy. Preparing a case study on best practices in employment and preparation for self-advocate led webinar series on inclusive employment of persons with intellectual disabilities.

**CAST - finding digital communication solutions for people with Down syndrome**

Running a project to look at and find solutions for the key problem that people with Down syndrome are not involved enough in the work of organisations that represent them, something which has been exacerbated by the COVID-19 pandemic and the transition to online communications.

**NORAD - self-advocacy training and employment and COVID-19 advocacy in Africa**

Technical human rights training and COVID-19 advocacy training for our members organisations in Kenya, Nigeria, Rwanda and Uganda and self-advocacy facilitation training for our member organisations in Kenya, Rwanda and Uganda.

**COVID-19 Pooled Fund - COVID-19 advocacy in Albania, Argentina, Brazil, Indonesia and South Africa**

Providing grants to 5 of our national member organisations for COVID-19 specific advocacy activities. Supporting Down Syndrome Albania Foundation, Asociacion Sindrome de Down de la Republica Argentina (ASDRA), Federacao Brasileira das Associacoes Sindrome de Down, Indonesia Down Syndrome Care Foundation (YAPESDI) and Down Syndrome South Africa.

**International guidelines for inclusive participation of people with intellectual disabilities**

Developing the International Guidelines for Inclusive Participation, jointly with Inclusion International. The guidelines will enable organisations to make their work inclusive, so that people with an intellectual disability can take part in a meaningful way.

**Consensus statement on cardiac disorder in people with Down syndrome**

Progressing a project to publish a consensus statement on cardiac disorder in people with Down syndrome, following a process which includes systematic evidence review, detailed advice from world leading experts in this field and structured input from international stakeholders.

**Purposes of designated funds****The National Lottery Community Fund - COVID-19 response**

Undertaking vital work addressing the ongoing negative impact of the COVID-19 pandemic on people with Down syndrome and their families in the UK and around the world – including provision of information and resources and advocating for fully inclusive responses.

**The Joffe Charitable Trust - Fundraising strategy research and fundraising staff resources**

Undertaking detailed research of key areas of fundraising, publishing a new fundraising strategy for DSI and employing a new fundraising officer to deliver this strategy and improve DSI's financial sustainability.

**University of Exeter - Access to Internship scheme**

Employing an intern for 1 month in 2020 to support the programme team.

**Nazari Digar - human rights and education advocacy training**

Running 2 days of online human rights training with parents and family members in Tajikistan and 2 days training with organisations representing people with Down syndrome and their families.

**12. Legal status of the charity**

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