



**Down's Syndrome
Association**

A Registered Charity No. 1061474

About the Down's Syndrome Association



Report and financial statements

For the year ended 31 March 2020

Company number: 3310024
Charity Number: 1061474

A Down's Syndrome Association publication

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For the year ended 31 March 2020

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Trustees' annual report

For the year ended 31 March 2020

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| Company number | 3310024 |
| Country of incorporation | United Kingdom |
| Charity number | 1061474 |
| Country of registration | England |
| Registered office and operational address | Down's Syndrome Association Langdon Down Centre 2a Langdon Park Teddington, Middlesex TW11 9PS |

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

| | |
|-----------------|-------------------|
| Georgie Hill | Chair |
| Sarah Leggat | Vice Chair |
| Anyia Souza | |
| Ertan Tanner | (resigned Sep 19) |
| Trevor Pearcy | |
| Gerry Coghlan | |
| Robert Stirling | |
| Darren Warkcup | Treasurer |

| | | |
|---------------------------------|-----------------------|--------------------------------|
| Key management personnel | Carol Boys | Chief Executive |
| | Sharon Gordon-Roberts | Finance & Fundraising Director |
| | Gillian Bird | Services Director |

| | |
|----------------|---|
| Bankers | Royal Bank of Scotland St Paul's Branch, 9-13 Paternoster Row London EC4M 7EH |
|----------------|---|

| | |
|-------------------|--|
| Solicitors | Russell Cooke 2 Putney Hill London, SW15 6AB |
|-------------------|--|

| | |
|----------------|---|
| Auditor | Sayer Vincent LLP Chartered Accountants and Statutory Auditor Invicta House, 108-114 Golden Lane London EC1Y 0TL |
|----------------|---|

The trustees present their report and the audited financial statements for the year ended 31 March 2020.

Reference and administrative information set out on page 3 forms part of this report. The financial statements comply with current statutory requirements, the 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.

Objectives and activities

Purposes and aims

Objects of the charity

The objects of the Association, as stated in its memorandum and articles of association, are:

- To create and develop the conditions which will enable people with Down's syndrome to attain their full potential.
- To undertake any other charitable activities in connection with Down's syndrome.

In furtherance of these objectives, the Association offers information and support to people with Down's syndrome, their parents and carers, interested professionals and the general public. It also champions the rights of people with Down's syndrome and works to improve knowledge and understanding of the condition. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing our aims and objectives and in planning our future activities. In particular, the trustees consider how planned activities will contribute to the aims and objectives we have set.

Mission

Our mission is to benefit the public by creating and maintaining the conditions that will enable all people with Down's syndrome to live full and rewarding lives. In working towards this we train and educate the professionals who work with people with Down's syndrome to promote best practice and new initiatives. We carry out research into various health issues and campaign to change policy and service provision. Most importantly, we provide information and support directly to families and carers on all aspects of living with and supporting people with Down's syndrome throughout their lives.

Aims

- To campaign for the rights of people with Down's syndrome.
- To be the centre for information and training in relation to people with Down's syndrome throughout their lives.
- To involve adults with Down's syndrome in the work of the DSA and to gather and represent their views.
- To increase and retain the membership of the organisation.
- To develop the organisation's sources of funding, working within the annual budget and managing risk.

- To encourage and monitor research into health and education.
- To develop and maintain links with learning disability and other relevant organisations.

How our activities deliver public benefit

The implementation of our aims and those we try to help are described below. All of our charitable activities focus on enabling people with Down's syndrome to live full and rewarding lives and are undertaken to further our charitable purposes for the public benefit. Our aims fully reflect the purposes the charity was set up to advance.

Who uses and benefits from our services?

The services we provide are available throughout England, Wales and Northern Ireland. Demand for our services is growing and our helpline, which is usually our first point of contact with those requiring our services, is provided free of charge to everyone.

Equal access to our services is an important issue to us and we monitor the ethnic diversity of our members and proactively try to reach underrepresented ethnic and social groups.

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.

Strategic report

Achievements and performance in the year to 31 March 2020

The charity's main activities and who it serves are described below. All its charitable activities are undertaken to further the Down's Syndrome Association's charitable purposes for the public benefit.

Information, training and assessments

Objective 1: To continue to develop and provide information, advice and support

In 2019 - 2020, our information officers and specialist advisors provided advice, information and advocacy for 4,054 parents, family members, professionals and people with Down's syndrome through phone calls and emails, as well as support for 3,800 members of our private Facebook groups.

Helpline service: phone calls and emails

We provided support for 4,054 individuals on a wide range of topics divided into the following broad categories:

31% services and rights

(service provision, housing and support, leisure, employment, sex and relationships)

19% welfare benefits including appeals

18% education and development

(including speech, language and communication advice and transition)

14% physical and mental health

(including dual diagnoses, complex needs and behaviour)

5% pre-natal and new born support

1% ageing issues

12 % general information

(about Down's syndrome and other topics)

Helpline service: closed Facebook groups

We supported 3,800 members of nine private DSA discussion forums. Each of our closed Facebook groups has a unique focus: children from birth to 11 years; young people 12 - 25 years; adults 25 years and older; children and adults with complex needs and/or autism; young adults experiencing a type of mental regression; maternity professionals; health care professionals; Down's syndrome and dementia and affiliated support group leaders.

Information: resources

This year we published a comprehensive relationships and sex education training package to educate and support adults with Down's syndrome, as well as resources for teaching teenagers about relationships and sex.

We created a new Helpline postcard and NIPT Factchecker information to support parents and practitioners through the pre-natal period. We updated information already in our range for expectant parents and maternity health practitioners, including Top Tips and Management of Pregnancy. We sent multiple copies of the new Helpline postcards to every maternity service in England and Wales with a DSA leaflet holder.

We updated two titles in the Health series, Thyroid and Neck instability, and created accessible information in Easy Read for three health topics (gastrointestinal, thyroid, neck instability).

We co-produced new online information with NHS digital about Down's syndrome (NHS Health A to Z).

In early 2020 we established Our Voice as a vehicle to operate across all of our services, including information, enabling us to dynamically co-produce accessible information as part of our inclusive participation strategy. We responded quickly to the urgent need for accessible information as the coronavirus epidemic developed.

We published films to complement our speech, language and communication resources to help children and families to home educate.

We created new information resources to support the emotional wellbeing of children, adults and their carers, to be published from April onwards.

Information: campaigns

We continued to publicise our 'It's My Life' (adult support and social care), Health Alert! (health inequalities) and 'Tell It Right' (maternity services) campaigns.

We responded to changes in the law relating to the coronavirus period, including direct communications with the Department of Health and Social Care about healthcare guidance for people who have Down's syndrome.

We supported a letter to the Department of Children and Families in collaboration with other organisations to address our education concerns and the urgent need to progress the SEND review.

Information: consultations

We submitted the following responses to consultations and submission requests:

- Mandatory learning disability training for health and care professionals, Department of Health and Social Care.
- NICE topic engagement of top themes for dementia services
- Older people with a learning disability
- Ante-natal screening Wales standards and protocols
- Reducing restrictive practices for people with a learning disability
- Department of Work and Pensions engaging with disabled people
- School transport consultation
- Additional Learning Wales Code of Practice

We were invited to join the Wales government ministerial advisory group for people with learning disabilities.

Objective 2: To continue to deliver a series of national training events that meet the needs of professionals and families

We offer training to support individuals at every stage of their lives. From our Royal College of Midwives accredited 'Tell It Right'® study days, to workshops and online training on education and development, positive behaviour support, adolescence and puberty, complex needs and autism, support for adults in the community, Down's syndrome awareness, and ageing and dementia.

In January 2020 we added Family Advice days to our range of training events. 50 families heard expert advice on vision and hearing, and our specialists met their children in order to advise on sensory, speech and language and other early development needs.

We began to develop new online training services from March 2020 in response to restrictions on training events.

In 2019 - 2020, 2,400 people attended 76 DSA training events including:

- 22 'Tell it Right® Start it Right' study days
- 2 Family Advice days
- 30 Education, Supporting behaviour and Puberty and adolescence training days
- 7 Complex needs and/or autism meeting

- 3 Supporting adult needs training events
- 12 Ageing and dementia training days

Objective 3: To develop assessment and education consultancy services

Our psychologists, teacher and speech and language therapist advocated for 36 individuals in need through individual assessments, written reports and school visits. Our speech and language therapist provided assessments at offices in Teddington and Belfast.

Beneficiary projects and services

Northern Ireland

New parents

All maternity units in hospitals in Northern Ireland receive our new parent packs. We also have a team of volunteers, parents who have training in counselling skills, who are able to support the hospitals. We remain the first point of contact for new families. All new parents are also offered the opportunity to attend our new parents' day where they can access experts in counselling, physiotherapy, speech and language, Makaton and get to know what the DSA has to offer.

Members' projects

Every Monday to Thursday we offer a range of opportunities for members with Down's syndrome. These include a music, exercise and mental health project; our choir which rehearses weekly and also performs at events; two youth groups (on Wednesday and Thursday each week); and regular social activities. These are held on alternate Tuesdays and involve trips to local places of interest as well as trips to the cinema, theatre, bowling and eating out.

On alternate Saturdays we run our dance troupe, Entertainment Factory, who learn new dances each year and put on a show for parents, families and friends. Our show is in May each year with almost 300 guests attending. This is a great showcase for the work we do.

Makaton

The Makaton lessons and support we provide continues to be in demand from parents and professionals. All of our volunteers in Northern Ireland are trained in Makaton.

We offer one to one Makaton sessions for parents where a child or their parents have become a bit 'stuck'. The sessions give the family new strategies and tools they can use to move forward.

We also offer group training to new parents and enhanced training to professionals who work regularly with people with Down's syndrome.

We are also now training government staff at Stormont as the interest in and knowledge of Makaton has increased. In local government we have recently given training to all council staff in Craigavon, Armagh and Portadown.

We have recently developed a relationship with the Police Service of Northern Ireland. We delivered Makaton training to officers from across Northern Ireland. We hope to build on this relationship as we hope to engage the police service further.

Training

We provide training when asked in nurseries and primary schools. We also give talks to schools, youth groups and companies when required.

Volunteers

Volunteers continue to be a great source of support to our work in Northern Ireland. We have volunteers of all ages (17-64 years) and all professions. The volunteers provide such a rich and valuable resource in their skills and knowledge. Volunteers work in all our projects.

Advice and support

We offer support on a daily basis via telephone calls, emails and face-to-face when people drop in at the office. We give advice, support and can sign post our members to other local agencies if we cannot help.

Membership

Membership is a continuing priority for the organisation as 'the more members we have, the stronger our voice'. The team has put the following strategies in place to retain and grow membership:

- Successful integration between the website and Salesforce database – streamlining joining and renewal process. Will be promoting this method to all.
- Gathered more email addresses so renewals can be sent out digitally rather than through traditional mail method
- Continue to promote membership in all training, conference and any other events
- Digitalise membership pack so easier to send out more efficiently and in a more cost effective way.
- Make it compulsory for trustees of the regional groups to be members in order to benefit from our insurance cover.

WorkFit® - Connecting Employers with Employees who have Down's syndrome

Objectives: To provide training, information and resources to employers to support them to offer employment opportunities to people who have Down's syndrome. To develop employment opportunities for people who have Down's

syndrome and provide advice and support to enable them to embrace the exciting challenges that lie ahead on the journey to fulfilling their career ambitions. To provide ongoing support to employers and candidates at all stages of the programme.

During 2019-20 the WorkFit programme engaged with 196 employers, trained 101 employers (631 staff were present at the training sessions) and developed 109 employment opportunities across England and Wales. Since the project launch in 2012, WorkFit has secured 417 employment opportunities for people who have Down's syndrome. Placements would have exceeded 430, however, opportunities have had to be deferred due to the Covid-19 pandemic.

The project continues to grow significantly. Since 2011, over 1,120 people who have Down's syndrome have registered with the WorkFit programme, with candidate registrations last year exceeding 150. This has been a result of the fidelity of the WorkFit model, a targeted marketing approach and the success of candidates across an expanding range of industry sectors. It is clear that people's aspirations have been raised with more family members now seeing permanent, paid work as a realistic and sustainable outcome for their relative who has Down's syndrome.

'Our WorkFit officer met the team and made taking on someone with Down's syndrome so much easier and took away the worry.' WorkFit Employer, North East

'I had a great time at my new job I enjoyed making sandwiches and getting to know where things are stored. I had fun getting to know them and they are amazing I am happy and I can't think of anything different I love working with them - they are like family already' Victoria, WorkFit candidate, North East

'Ffion may have Down's syndrome, but she has the same rights as everyone else. She may need support and encouragement, but it's her right to have that. There are employers out there who could provide work experience and permanent employment for Ffion. Finding them is difficult, almost impossible for a parent, but with the support provided by WorkFit there is no reason why more people with Down's syndrome cannot be gainfully employed'. Parent of a WorkFit candidate, Wales

The profile of WorkFit has grown in part thanks to the social media presence and a further round of WorkFit films that highlight the skills and abilities of our candidates. A new WorkFit leaflet has also been produced to encompass the key messages of the programme.

WorkFit Wales continues to progress with funding from Welsh Government recently secured for the next 3 years. Funding for the six of the nine regions of England that are currently operational is less certain although applications are constantly being made by Fundraising to secure the ongoing provision of the service.

In November 2019, one of our employers – XPO Logistics - triumphed in the Best Employer Practice category at the British Association of Supported Employment (BASE) Awards. The BASE awards are considered the most prestigious awards in this sphere and this is an unprecedented fourth consecutive year that a WorkFit employer has been successful in this category. XPO Logistics have provided ten employment opportunities for WorkFit candidates, offering permanent paid work in a varied range of operational

and administrative roles in their supply chain and recycling operations. They plan to offer significantly more in the coming months.

We have hosted three regional WorkFit conferences in the North East, South West and the North West. Unfortunately the Yorkshire & Humberside conference, planned for April 2020, had to be postponed due to the Covid-19 pandemic. At all of the events we welcomed WorkFit members, employers, professionals and practitioners from a range of services including education and social care. Feedback from the events was very positive and it was helpful to have the perspectives of a range of stakeholders. James (pictured) and his manager were special guest speakers at the WorkFit North Regional Conference in October 2019.

'James has added value to our business. We want to be an inclusive garden centre. We want everyone to feel welcome. James puts people at ease straight away.' WorkFit Employer, Yorkshire and Humberside

'A local garden centre, who also have a cafe, were advertising for staff so I applied for a job and together with Alison from the Workfit Programme, we got in touch with them and they said they would like me to start an eight week work experience and if everything was ok they would give me a job with pay. Well, I have been working at Fields Kitchen for a few months now. I love working with my Buddy, Charlotte. I love working with all my teammates and they have shown me the ropes. I also like meeting new people and giving good customer service with a smile.' WorkFit Candidate, Yorkshire and Humberside



New World Trading Company is one of a number of examples of how WorkFit is successfully developing multiple opportunities with large employers across a national network of sites. The company have offered six permanent paid opportunities to date in their bar/restaurants with plans to expand the number of sites involved. Isaac and his manager were special guest speakers at the WorkFit North Regional Conference in October 2019.



'Isaac recently started working for us at The Botanist (NWTC) and has really fitted in well with the team. His role is to help set up the restaurant and to make sure that cutlery is polished. During shift Isaac is responsible for making sure that all tables are clean and helping out the guys where they need it. All the team love working with him and they all get on with him. We are really pleased to have Isaac as a member of our team and look forward to working with him in the future.' Employer, NWTC Newcastle upon Tyne

Securing paid work has made a huge difference to the lives of James, Isaac and almost fifty other WorkFit candidates in the last year alone. Along with developing paid work we have also secured work experience, volunteering and supported apprenticeships securing 109 potentially life-changing opportunities for people who have Down's syndrome. We have seen our candidates grow in confidence, develop skills, expand their social circle and enjoy the self-esteem of being part of a team where their contribution is valued.

At all stages of the WorkFit programme our dedicated Employment Development Officers (EDO's) support the process and activities are underpinned by the expertise, resources and experience of WorkFit and the wider Down's Syndrome Association. We will be

working towards Disability Confident Level 3 status (awarded by Department of Work and Pensions) in recognition of our commitment to employing and supporting colleagues who have disabilities.

DSActive

Objective 1: To provide sporting activities for people aged 5 and over with Down's syndrome to play sport and be physically active

The main aim of the DSActive programme is to ensure that people with Down's syndrome have opportunities to be active, be healthy and play sport. We have successfully added athletics to the DSActive portfolio, and we have sessions launching in 3 new sports in the next financial year.

| Sports | Number of sessions | Number of participants |
|--------------|--------------------|------------------------|
| Football | 45 | 919 |
| Tennis | 28 | 100 |
| Athletics | 4 | 30 |
| Cricket | 1 | 15 |
| Rugby | 1 | 15 |
| Total | 79 | 1,079 |

Objective 2: Festivals

The DSActive team have been busy running festivals throughout the year. Our National Football Festival attracted over 100 participants. We also ran our summer camps last year across 6 weeks. We've also run many football, tennis and athletics festivals, either as promotional events or to get participants used to competition. In total 411 participants attended.

Objective 3: Coach education

The DSActive team have been able to open up our Coach Education workshop to more sports. We've been able to train a total of 331 coaches.

Objective 4: Coachability

We have supported players with Down's syndrome to achieve level 1 coaching qualifications in tennis and athletics. We are also working with World Snooker and British Gymnastics to ensure they have coaching pathways available for people with Down's syndrome.

Objective 5: Nutrition campaign

Due to the success of our nutrition campaign, we were able to secure funding from the Department of Digital, Culture, Media and Sport to develop a nutrition app for people

with Down's syndrome. The app was launched in the summer of 2019 and has been downloaded more than 1,000 times with some very positive feedback.

Objective 6: Leisure and fitness

We have now finished writing our workshop for the leisure and fitness industry and have started delivering it within the industry. The initial feedback has been positive and we hope to continue to gain momentum behind the workshop.

Wales

Objective 1: We will submit an application for project funding to The Welsh Government's Sustainable Social Services Grant scheme

We are delighted to report that we were successful in being awarded a 3-year grant from Welsh Government to support our activities in Wales. This will provide partial funding for our WorkFit Wales project, our DSActive project and enable us to expand our information, advocacy and training services across Wales.

Objective 2: We will continue to offer a range of training opportunities to families of individuals with Down's syndrome and the professionals who support them

Training continues to be a major focus of our activities in Wales, reaching 435 delegates. We facilitated:

- 6 Tell it Right Training sessions for maternity units and universities in Wales
- 2 Dementia training days
- 6 training sessions for schools
- 1 behaviour training sessions for families
- 1 complex needs day

Objective 3: We will develop a new training course on meeting the health needs of adults with Down's syndrome, pilot this and evaluate its impact

The content for this training day has been developed and was delivered (as a pilot) in a location outside of Wales in July 2019. A further day was scheduled to take place in March in Wales, but was postponed, due to the outbreak of coronavirus in the UK. We will be looking at ways of delivering this session as a virtual learning opportunity in the interim period.

Objective 4 :We will continue to engage with Public Health Wales with regard to the offer of antenatal screening in Wales and provide the lived experience of individuals with Down's syndrome and their families in the delivery of training for relevant health professionals.

This has continued to be a major focus of our work in Wales. During 2019/20, our Services Development Manager has attended meetings of Antenatal Screening Wales

Steering Group and the Wales NIPT Evaluation Group. This work will continue in 2020-21.

Campaigning

Objective 1: Involve adults with Down's syndrome in the work of the DSA and to gather and represent their views

We continue to promote and share the stories and voices of people with Down's syndrome.

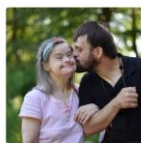
Working with our members, supporters and our colleagues we have created and shared their stories via all our communications channels throughout the year.

New content



The second series of our Shifting Perspectives podcast released

The second series of our podcast included interviews with two young people who are living their lives to the full; two brothers creating a film about what it's like to have a sibling with Down's syndrome; and two parents.



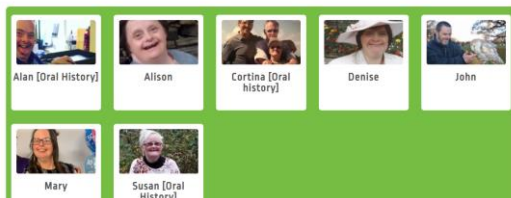
Throughout 2020, we will be celebrating our 50th anniversary by hearing from people over 50 and their families, to learn about their life and memories over the past 50 years.

So stay tuned and follow us on social media to get updated when a new story is available.



50th Anniversary Memories & Stories Project

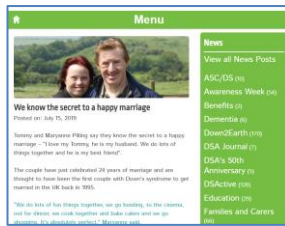
Giving older people who have Down's syndrome, and their families, an opportunity to highlight their stories during our anniversary year. Three oral histories were produced before lockdown, and other written stories were also shared in the first three months of 2020.



We Decide Celebrating the theme of World Down Syndrome Day

Thanks to contributions from our members we created a simple but powerful illustration of the global theme.

Blogs and social media posts



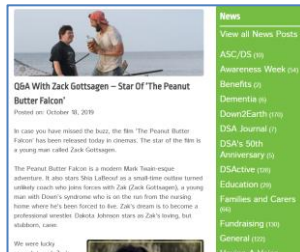
Tommy and Maryanne Pilling, who celebrated their 24th wedding anniversary in the summer of 2019 share their secret to a happy marriage.

- 2,527 page views
- 33,920 people reached on Facebook
- 41,494 impressions on Twitter



George Webster talks about his role in a forthcoming film, S.A.M., his acting career and his involvement in his local Parkrun.

- 743 page views
- 12,373 people reached on Facebook
- 8,942 impressions on Twitter



We were lucky enough to have the opportunity to ask Zack Gottsagen, the star of The Peanut Butter Falcon, a few questions.

- 691 page views
- 20,020 people reached on Facebook
- 12,173 impressions on Twitter



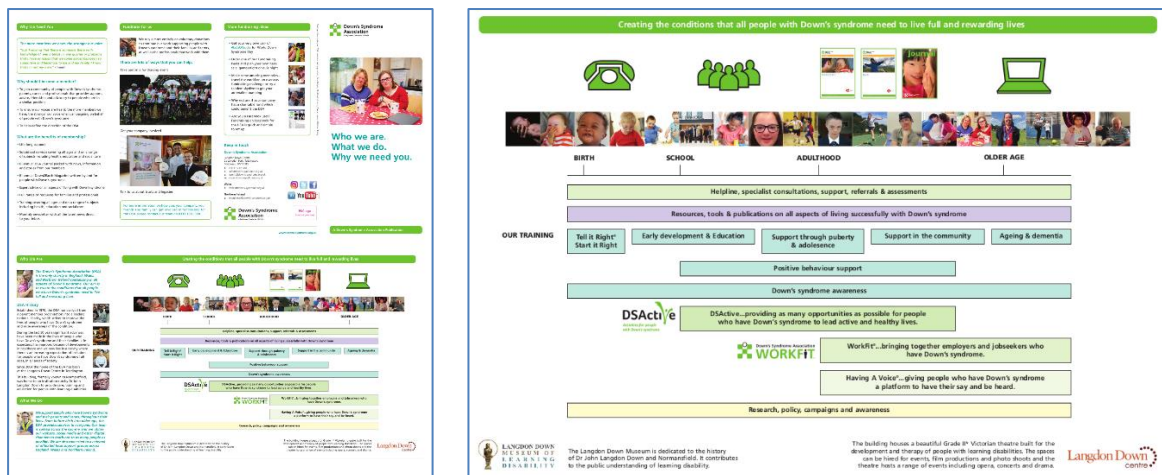
The fabulous Sara Pickard was nominated to attend the Women of the Year awards where she got to meet lots of celebrity guests. She wrote a blog for us about the experience.

- 594 page views
- 49,079 people reached on Facebook
- 9,787 impressions on Twitter

Objective 2: Continue to raise awareness of our existence and our work

We continue to increase awareness of all aspects of the DSA's work through films, social media and press, supporting our colleagues in the Fundraising, Training & Information, WorkFit® and DSActive teams.

We updated our Who We Are leaflet to focus on the breadth of the support we offer.



Together with Training & Information we have added significantly to the Tell it Right® resources and campaigning materials.



We sent copies of this two-sided postcard-sized flyer with a holder to maternity units across England, Wales and Northern Ireland. The flyer has a simple message directing people to our Helpline.



We published a short factsheet that fact-checked some of the statistics associated with non-invasive prenatal testing (NIPT) for Down's syndrome.

Other new publications included:

- Tell it Right top tips
- Management of pregnancy
- Ante, neo and post-natal care – a guide for healthcare practitioners

We published the findings of our Health Alert! campaign and added three new titles to the Health Series: Thyroid, Leukaemia and Inflammatory Arthritis.

The Let's Talk About Relationships and Sex training resource was launched.

Supported the launch of the HealthSwap App.

Worked with Elaine, Ollie and Cameron Scougal to create a one-off WorkFit film promoting the concept of the presumption of employment and encouraging parents of younger children to support the WorkFit® programme.



In March 2020, in response to the coronavirus pandemic, we created and published a suite of information and resources to inform and support the Down's syndrome community. This work continues and develops as the situation changes.

Key statistics April 2019 to March 2020

Website

483,564 users
641,054 sessions
1,375,199 page views
14% returning visitors

Social Media

Facebook page: 221,094 Likes
Twitter: 17,874 followers
YouTube: 41,167 views
LinkedIn: 1,989 followers
Instagram: 6,899 followers

Research

Objective 1: To identify new areas of research that should be undertaken

We continue to record and monitor the experiences of callers to our Helpline. This information, along with our knowledge of current research, allows us to identify potential new avenues for study that may lead to practical outcomes for people who have Down's syndrome and their families. We are then able to communicate this knowledge to interested researchers who are looking for ideas to inform the direction of their research.

Objective 2: To support other organisations or people who are conducting research that may be of benefit to people with Down's syndrome

The DSA has worked with a number of researchers this year, advising on the development of projects and project materials, finding participants and raising awareness of the work of researchers through our website, social media channels, blogs and Journal articles. Below are some of the projects we are involved with at an advisory level or have supported:

More information about all research projects (ongoing, new and completed) can be found on our website at www.downs-syndrome.org.uk/research/

Ongoing support 2019 to 2020

- Fractures in people with intellectual disabilities, University of Oxford
- Defeating Dementia in Down's syndrome, University of Cambridge
- Feeding and Autoimmunity in Down's syndrome Evaluation Study (FADES), Bristol University
- Respiratory Tract Infections in Children with Down's syndrome, University College London
- Paediatric facial analysis for spectacle wear, Aston University Birmingham
- Cognitive, Genetic and Cellular Study of Alzheimer's Disease in Down's syndrome - London Down Syndrome Consortium

New studies registered 2019 to 2020

- The impact of mental regression in adults with Down's syndrome, University of Cambridge
- Investigating if the eye structures involved in focusing on close work are different between young adults with and without DS, Aston University Birmingham
- Parent carer views on technology and digital communication, Canterbury Christ Church University
- The Impact of Positive Reappraisal Coping on the Wellbeing of Caregivers of those with Down's Syndrome, University of South Wales
- What works to support school placements for children and young people with Down's syndrome, University College London
- Understanding the mainstream secondary experience of Children with Down's Syndrome, from a parents' perspective, Oxford Brookes University
- Stay Calm Project – The development and evaluation of an emotional outburst questionnaire, University of Birmingham
- Measuring mainstream teachers' attitudes towards the inclusion of students with Down's Syndrome, University of Cardiff
- Neurodegeneration in Aging Down Syndrome (NiAD) – A Longitudinal Study of Cognition and Biomarkers of Alzheimer's Disease, University of Cambridge
- Socio-emotional wellbeing in young individuals with developmental disorders, University College London
- Adult Sibling Survey, University of Warks
- Face processing ability in Down's syndrome and Williams syndrome, Birkbeck University, London
- COVID19 Crisis Response Survey for families of Individuals with Special Needs, University College London
- Validating a Novel Visual Processing Questionnaire for Children with Neurodevelopmental Disorders, Kings College London
- Exploring the impact and contextual pathways of emotional outbursts, University of Birmingham
- Survey of experience of Covid-19 crisis of people with a learning disability or autistic spectrum disorders, University of Cardiff
- Risks and associated clinical outcomes related to COVID 19 for people who have Down's syndrome, T21 Research Society
- Improving Continence for Children and Young People with Neurodisability (ICoN), University of Exeter

Completed studies reported 2019 to 2020

- How parents and primary carers experience the adjustment to the dual diagnosis of Down's syndrome and Autism Spectrum Disorders – A narrative analysis, University of Surrey
- Parental perspectives of foot-care and footwear in children and young people with learning disabilities, University of Brighton
- Transition from school to adult services: Transition Voices – Navigating Change, University of Edinburgh

Raising funds

Objective 1: To maintain sufficient funding for the DSA

We had a fantastic year in fundraising, with total income ending the year over budget.

In the next year we face new and sometimes unknown challenges but the team is ensuring that we stay alert and aware of what they are and react accordingly

Objective 2: To increase unrestricted fundraising

General donations were boosted by Facebook in the last year and we had a positive year with legacies that also contribute to the unrestricted pot of funds.

Objective 3: Ensure the fundraising structure complements the economic environment

The fundraising team has diversified specialities to ensure that all major income streams have a specialised focus. We have specialists in trust, corporate, community and events fundraising.

Financial review

The Down's Syndrome Association income was £2.3m (2019: £2.2m). This increase from the previous year was largely due to an increase in legacy income and general donations, including new streams e.g. donations via Facebook. We were very grateful to have received grant funding during the year from the Department of Digital, Culture, Media and Sport (for our DSActive nutrition app project) and from the EU and Big Lottery Fund, to support our WorkFit® project in Wales and the North of England.

Total expenditure increased from the previous year to £2.4m (2019: £2.2m). The increase was largely due to spending restricted grant funding and expanding and strengthening the size and expertise of our Information and Training team.

The amount of money spent on raising funds represented 17% (2019: 18%) of total expenditure (or 17p in every £1 spent).

Overall there was a planned deficit in the year of £68,000 (2018: surplus £26,000). This deficit was less than budgeted due to the legacy income received during the year.

Down's Syndrome Trading Ltd

This is the subsidiary trading company of the Down's Syndrome Association. Its principal activity is the sale of Christmas cards, socks, t-shirts and books. 'The Lots of Socks' campaign was incredibly popular during Awareness Week. The company made a gross profit of £10,596 (2019 - £9,867) and after administrative expenses the company made an operating profit of £3,508. The company did not gift aid any profits to its parent undertaking, the Down's Syndrome Association in this year but will do after the year end. (2019 - £0).

Principal risks and uncertainties

Risk management

As part of their ongoing strategic planning work, the trustees carry out a formal risk review each year to examine the major risks facing the charity. The review considers both top down and bottom up risks and ranks them in order of likelihood and impact. Responsibility for each risk is allocated either to a member of the senior management team or to the trustees. The senior management team provide updates to the trustees each quarter on their progress against action plans designed to manage the risks identified. The risk register was most recently reviewed and updated by the trustees in March 2020.

The main risks facing the Association have been identified as a loss of funding and the possibility of members leaving. In order to mitigate against these risks a fundraising strategy has been established which strengthens and diversifies our income streams. Additionally an adequate reserves policy has been established to ensure security through any dips in certain income streams.

Strong relationships are developed with our members through frequent and regular communication utilising various channels, including social media. This ensures that all members have a sense of “belonging” and that all members are aware of our latest news and any developments and that they are confident that the organisation is stronger because they are a part of it. Any lapses in membership are followed up and any reasons for lapses are addressed.

Reserves policy and going concern

Reserves are needed to bridge the gap between the spending and receiving of income and to cover any unplanned or emergency expenditure. 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 three to six months of the resources expended. That equates to between £0.6m and £1.2m in general funds, based on the budget for 2020-21. 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. The free reserves currently available equate to just over six months running costs and amount to £1.3m.

Our consolidated balance sheet remains strong. The trustees have reviewed the circumstances of the Down’s Syndrome Association and consider that adequate resources continue are available to fund the activities of the Association for the foreseeable future. The trustees are of the view that the Association is a going concern.

Plans for the future

Information, training and assessments

- We will continue to develop inclusive participation with people who have Down’s syndrome.
- We will create content for the new DSA website, to include accessible information.

- We will continue to offer helpline support and information for expectant and new parents.
- We will publish new information resources to support the emotional wellbeing of children, adults and carers.
- We will provide evidence-informed guidance about the role of the speech and language therapist with recommendations for effective speech, language and communication practice for children at different ages.
- We will produce resources for primary age children on growing up, relationships and sex education.
- We will continue to extend our range of online training and support services for parents, professionals and people with Down's syndrome on education, health, adult support and complex needs topics.
- We will continue to inform, raise awareness and campaign about the health, support, education and employment needs of people who have Down's syndrome and their right to equitable opportunities, healthcare and support.
- We will continue to campaign for people with Down's syndrome and their families.
- As key stakeholders, we will submit evidence for government consultations in Wales, England and Northern Ireland. We will continue to advise on the Wales ministerial advisory group and to feedback on NICE clinical guidance.

Campaigns, policy and research

- We will ensure that the support we offer our community during the course of the coronavirus pandemic is as accessible and effective as possible.
- We will refocus on our postponed 50th anniversary celebrations
- We will support the work of the Our Voice project and continue to provide a direct channel for the voices of people with Down's syndrome in the communications output of the DSA.
- we will continue to encourage more engagement with our members and their families through life-stories and include people of all ages, backgrounds and abilities to ensure a wide range of life experience is shown.

Beneficiary projects and services

WorkFit®

The demand for the programme continues to grow significantly both from people who have Down's syndrome who want to start or develop their careers and from employers who wish to partner with us to offer opportunities, with 152 candidates and 93 employers registering in the last financial year. We now have over 1,100 candidates registered who are on various stages of their employment journey, some of whom have not yet had the opportunity to meet with their EDO and are on the waiting list due to the demand. We continue to expand our reach beyond the traditional sectors of catering, retail and hospitality, placing people in roles in Arts & Heritage, Construction, Finance & Law, Warehouse & Distribution and a range of public sector bodies including the Emergency Services.

We will continue to work with affiliated groups to encourage adults who have Down's syndrome to explore employment opportunities, source employer contacts and share job

vacancies. We will continue to work with colleges, supported employment agencies and employers, and will deliver further employer training to support linking more people to work opportunities.

Beneficiary projects and services

DSActive

Participation

The DSActive team is using the opportunity of the current crisis and the halting of all of our activities for a time to re-evaluate the programme, which has grown significantly since its conception. We will form a strategy which will allow it to expand its reach and grow and develop into a programme promoting healthy, holistic lifestyles for all people who have Down's syndrome.

Coach Education

We are looking to increase the number of coaches trained to support people with Down's syndrome, including ensuring all our existing DSActive clubs are trained. We will also continue to work with other National Governing Bodies to offer our coach education workshop.

Leisure and Fitness workshop

We want to continue to expand our work within the leisure and fitness industry which is currently not always inclusive for people with disabilities. We want to ensure that people with Down's syndrome have the opportunities to use their local facilities to be active.

Beneficiary projects and services

Wales

- In the immediate period from April 2020 onwards, we will give a particular focus to supporting individuals with Down's syndrome and their families in Wales cope with new ways of living following the COVID-19 crisis. This will involve provision of information, accessible resources and advocacy
- We will deliver on the performance indicators of our Welsh Government's Sustainable Social Services Grant
- We will continue to offer a range of training opportunities to families of individuals with Down's syndrome and the professionals who support them and move these to an online format, whilst social-distancing rules mean that face to face training events will not be possible
- We will continue to engage with Public Health Wales with regard to the offer of antenatal screening in Wales and provide the lived experience of individuals with Down's syndrome and their families in the delivery of training for relevant health professionals.
- We will be active members of the Welsh Ministerial Advisory Group in Learning Disability, which meets quarterly

Raising funds

Trusts

- Fundraising from trusts has had a good run in the last few years, however, the last quarter of 2019-20 was impacted by the then-ensuing Covid-19 pandemic, the effects of which are likely to last for a while, depending on Trusts' own income generation, budgeting and in some cases shifting priorities.
- Many leading local and national Trusts have pooled their resources together to help the third sector, and the DSA has been prompt in applying to these. Results of many of these applications is pending.
- The DSA will continue to provide, and if needed improve, on its stewardship of those trusts that have been its supporters over the years (we have a portfolio of about 20 trusts who regularly donate money).
- We will explore the major donor route for Trusts.

Events

- The main focus for the Events is to make sure we are aware of the changing climate surrounding them due to Covid-19. Events cannot currently take place like they have in the past, and so the team must be aware of and act accordingly for any changes that are made.
- Focus on virtual events that enable us to keep a steady income coming into the charity. MAYrathon has been successful and is something we would look to do next May too. We are also looking into other virtual events as well – Run for Charity for example (we already have a partnership with them).
- Over the last year we have streamlined our events offer. Moving away from most third party events that require large upfront payments by the charity, we now have places in London Marathon, Great North Run and events linked to Run for Charity. This is saving the charity a huge amount of money each year. Depending on what changes are made due to Covid-19, we will streamline and adapt our third party challenge offer further.
- Following on from last year's aims, we will continue to add to our ever-growing fundraising materials that we offer on our website. Race training plans have been created and added to the website with the help of the DSAActive specialists.

Community

- We will expand the current online offer of community fundraising resources
- We will create more fundraising resources that can be used in community fundraising – both online and hard copy
- We will get resources printed so that we can send these out in our fundraising pack – focussing on an 'insert theme', so we can cater to each fundraiser and personalise their pack
- we will use Health Swap App recipes in partnership with baking/cooking themed community fundraising

- We will run community fundraising themed competitions to bring in income – we received a good amount of interest from the short story competition and hope to run a colouring competition

Corporates

- We will capitalise on the success of 2019-20 support from corporates and strengthen relationships with existing companies from Mastercard to Simplyhealth, AXA XL and London Stock Exchange, and secure a cross section of quality grants from corporates for DSA's work on Covid-19
- We will work with pharmaceutical companies including Pfizer, Roche, Smith & Nephew to gain £10,000 plus grants for DSA work for long term support
- We will secure calibre celebrities as ambassadors for DSA and work with BGC to get the charity selected for BGC Charity Day 2020.
- We will work to bring on board new companies to support DSA for long term support

Legacies

- few will follow up communication from the legacy appeal at the end of 2019
- we will run another legacy appeal in 2020/21
- We will promote legacies through events (the new leaflet is given to event attendees as LDC)

Other

- Government and Lottery funding: We will continue to pursue these funding streams.
- Social Media: we will ensure we are up to date with social media trends and reacting accordingly.
- We will explore new fundraising channels such as 'twitching' (fundraising through gaming)

Merchandise

- we will efficiently monitor stock levels and not over order socks, Christmas cards etc. in order to maximise revenue vs spend.

Structure, governance and management

The organisation started as a parent support group in 1970. It was registered as a charitable company limited by guarantee, registered as a charity on 11 June 1973 and incorporated on 30 January 1997.

The organisation was established under a memorandum of association which set out the objects and powers of the organisation and is governed under its articles of association.

All trustees give their time voluntarily and receive no benefits from the charity. Any expenses reclaimed from the charity are set out in note 8 to the accounts.

Appointment of trustees

The board of trustees consists of up to eight Full Members elected by the Full Members together with any persons appointed or co-opted.

To be eligible for election, a Member must have been a Full Member of the Association for at least three years immediately prior to the election.

At each Annual General Meeting, one third of the elected trustees must retire by rotation, but all are eligible for re-election. Once trustees have served for a term of three years they are required to stand down from the Board but are eligible to stand again for election.

Trustee induction and training

New trustees undergo orientation to brief them on their legal obligations under charity and company law, the Charity Commission guidance on public benefit and inform them of the content of the memorandum and articles of association, the committee and decision-making processes, the business plan and recent financial performance of the charity. Trustees are encouraged to attend appropriate external training events where these will enhance their skills for their role.

Related parties and relationships with other organisations

The Association continues its close links with Down's Syndrome Scotland, Down's Syndrome Ireland and the Down's Heart Group. The DSA regularly works with other national organisations such as Mencap, Early Support and the National Autistic Society. It belongs to the Care and Support Alliance, a group of national charities who campaign for improvements in social care, as well as Disability Rights UK and the Special Education Consortium. The DSA is a member of Down Syndrome International and supports the organisation financially.

The DSA works in collaboration with a number of Universities, and is currently involved with Cambridge, Cardiff, Kingston, Newcastle, Suffolk, Birmingham and Middlesex Universities, working together on specific projects.

Remuneration policy for key management personnel

The Down's Syndrome Association is committed to ensuring a proper balance between (i) paying our staff and others who work for us fairly so that we attract and retain the best people for the job and (ii) 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.

Salary banding

Salaries for all current posts, other than the Chief Executive, will fall within a salary band, based on the skills required for the role, the responsibility of the role and the experience of the person.

Normally, in April each year, the trustees will consider awarding a cost of living adjustment for all staff when setting the following year's annual budget. This increase is to reflect changes in the cost of living and is entirely at the discretion of the trustees.

The trustees' considerations will begin with an assumption that salaries should be adjusted to match inflation (specifically the Consumer Price Index) over the preceding 12 months. They will also take into account economic forecasts for the rate of inflation in the year ahead. They will then determine whether this is appropriate in the context of the charity's financial situation and the charity's performance.

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 at the senior management team and trustees.

Statement of responsibilities of the trustees

The trustees (who are also directors of Down's Syndrome Association 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 or 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
- 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 proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company 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
- 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 £1 to the assets of the charity in the event of winding up. The total number of such guarantees at 31 March 2020 was 7 (2019: 8). The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditors

Sayer Vincent LLP were re-appointed as the charitable company's auditor during the year and have expressed their willingness to continue in that capacity.

The trustees' annual report has been approved by the trustees on 11 July 2020 and signed on their behalf by

Georgie Hill
Chair of Trustees

Independent auditor's report to the members of Down's Syndrome Association

Opinion

We have audited the financial statements of Down's Syndrome Association (the 'parent charitable company') and its subsidiary (the 'group') for the year ended 31 March 2020 which comprise the consolidated statement of financial activities, the group and parent charitable company balance sheets, the consolidated statement of cash flows and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- Give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 March 2020 and of the group's incoming resources and application of resources, including its income and expenditure, for the year then ended
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice
- Have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities Act 2011

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the group financial statements section of our report. We are independent of the group and parent charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- The trustees' use of the going concern basis of accounting in the preparation of the group financial statements is not appropriate; or
- The trustees have not disclosed in the group financial statements any identified material uncertainties that may cast significant doubt about the group's or the parent charitable company's ability to continue to adopt the going concern basis of

accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the trustees' annual report, including the strategic report, other than the group financial statements and our auditor's report thereon. Our opinion on the group financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the group financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the group financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the group financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the trustees' annual report including the strategic report, for the financial year for which the financial statements are prepared is consistent with the financial statements
- The trustees' annual report including the strategic report, has been prepared in accordance with applicable legal requirements

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the parent charitable company and their environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report including the strategic report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and Charities Act 2011 require us to report to you if, in our opinion:

- Adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- The parent charitable company financial statements are not in agreement with the accounting records and returns; or

- Certain disclosures of trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the statement of responsibilities of the trustees set out in the trustees' annual report, the trustees (who are also the directors of the parent charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the parent charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the parent charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed auditor under the Companies Act 2006 and section 151 of the Charities Act 2011 and report in accordance with those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the group's and parent company's internal control
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees

- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the group's or the parent charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the group or the parent charitable company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation
- Obtain sufficient appropriate audit evidence regarding the financial information of the entities or business activities within the group to express an opinion on the consolidated financial statements. We are responsible for the direction, supervision and performance of the group audit. We remain solely responsible for our audit opinion.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Use of our report

This report is made solely to the charitable company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 144 of the Charities Act 2011 and regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Helen Elliott (Senior statutory auditor)

10 September 2020

for and on behalf of Sayer Vincent LLP, Statutory Auditor

Invicta House, 108-114 Golden Lane, LONDON, EC1Y 0TL

Sayer Vincent LLP is eligible to act as auditor in terms of section 1212 of the Companies Act 2006

For the year ended 31 March 2020

| | Note | Unrestricted £ | Restricted £ | 2020 Total £ | Unrestricted £ | Restricted £ | 2019 Total £ |
|--|------|-------------------|------------------|--------------------|-------------------|------------------|--------------------|
| Income from: | | | | | | | |
| Donations and legacies | 2 | 1,431,779 | 82,919 | 1,514,698 | 1,437,291 | 71,141 | 1,508,432 |
| Charitable activities | | | | | | | |
| Information, Training and Assessments | 3 | 43,691 | 72,616 | 116,307 | 31,620 | 101,108 | 132,728 |
| Beneficiary Projects and Services | 3 | – | 548,114 | 548,114 | – | 405,899 | 405,899 |
| Campaigning and Research | 3 | – | 7,959 | 7,959 | – | 28,741 | 28,741 |
| Other trading activities | 4 | 148,732 | 1,160 | 149,892 | 157,567 | 123 | 157,690 |
| Investments | | 9,947 | – | 9,947 | 9,166 | – | 9,166 |
| Total income | | 1,634,150 | 712,767 | 2,346,917 | 1,635,644 | 607,012 | 2,242,656 |
| Expenditure on: | | | | | | | |
| Raising funds | 5 | 410,496 | 4,926 | 415,422 | 387,316 | 4,790 | 392,106 |
| Charitable activities | 5 | | | | | | |
| Information, Training and Assessments | 5 | 490,048 | 156,600 | 646,648 | 477,494 | 116,821 | 594,315 |
| Beneficiary Projects and Services | 5 | 270,906 | 649,101 | 920,007 | 239,279 | 616,251 | 855,530 |
| Campaigning and Research | 5 | 381,015 | 51,258 | 432,273 | 319,619 | 54,631 | 374,249 |
| Total expenditure | | 1,552,465 | 861,885 | 2,414,350 | 1,423,708 | 792,493 | 2,216,201 |
| Net income / (expenditure) before net gains / (losses) on investments | | 81,685 | (149,118) | (67,433) | 211,936 | (185,481) | 26,455 |
| Net gains / (losses) on investments | | (185) | – | (185) | (68) | – | (68) |
| Net income / (expenditure) for the year | 7 | 81,500 | (149,118) | (67,618) | 211,868 | (185,481) | 26,387 |
| Transfers between funds | | (83,769) | 83,769 | – | (65,453) | 65,453 | – |
| Net movement in funds | | (2,269) | (65,349) | (67,618) | 146,415 | (120,028) | 26,387 |
| Reconciliation of funds: | | | | | | | |
| Total funds brought forward | | 1,526,860 | 1,195,753 | 2,722,613 | 1,380,445 | 1,315,781 | 2,696,226 |
| Total funds carried forward | | 1,524,591 | 1,130,404 | 2,654,995 | 1,526,860 | 1,195,753 | 2,722,613 |

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 21 to the financial statements.

Balance sheets

www.downs-syndrome.org.uk

As at 31 March 2020

| | | The group | | The charity | |
|--|------|------------------|------------------|------------------|------------------|
| | Note | 2020 | 2019 | 2020 | 2019 |
| | | £ | £ | £ | £ |
| Fixed assets: | | | | | |
| Tangible assets | 12 | 1,090,483 | 1,096,414 | 1,090,483 | 1,096,414 |
| Investments | 13 | 92 | 277 | 94 | 279 |
| | | <u>1,090,575</u> | <u>1,096,691</u> | <u>1,090,577</u> | <u>1,096,693</u> |
| Current assets: | | | | | |
| Stock | 16 | 12,546 | 12,295 | 8,536 | 7,520 |
| Debtors | 17 | 81,604 | 90,067 | 80,019 | 90,064 |
| Short-term deposits | | 852,701 | 846,379 | 852,701 | 846,379 |
| Cash at bank and in hand | | 737,889 | 875,755 | 733,073 | 861,576 |
| | | <u>1,684,740</u> | <u>1,824,496</u> | <u>1,674,329</u> | <u>1,805,539</u> |
| Liabilities: | | | | | |
| Creditors: amounts falling due within one year | 18 | (120,320) | (198,574) | (136,943) | (203,163) |
| | | <u>1,564,420</u> | <u>1,625,922</u> | <u>1,537,386</u> | <u>1,602,376</u> |
| Net current assets | | | | | |
| | | <u>2,654,995</u> | <u>2,722,613</u> | <u>2,627,963</u> | <u>2,699,069</u> |
| Total net assets | | | | | |
| | | <u>2,654,995</u> | <u>2,722,613</u> | <u>2,627,963</u> | <u>2,699,069</u> |
| Funds: | 21 | | | | |
| Restricted income funds | | 1,130,404 | 1,195,753 | 1,130,404 | 1,195,753 |
| Unrestricted income funds: | | | | | |
| Designated funds | | 228,363 | 151,432 | 228,363 | 151,432 |
| General funds | | 1,269,196 | 1,351,884 | 1,269,196 | 1,351,884 |
| Non-charitable trading funds | | 27,032 | 23,544 | – | – |
| | | <u>1,524,591</u> | <u>1,526,860</u> | <u>1,497,559</u> | <u>1,503,316</u> |
| Total unrestricted funds | | | | | |
| | | <u>1,524,591</u> | <u>1,526,860</u> | <u>1,497,559</u> | <u>1,503,316</u> |
| Total funds | | <u>2,654,995</u> | <u>2,722,613</u> | <u>2,627,963</u> | <u>2,699,069</u> |

Approved by the trustees on 11 July 2020 and signed on their behalf by

Darren Warkcup
Treasurer

| | Note | 2020 £ | £ | 2019 £ | £ |
|--|------|-----------|----------------|-----------|----------------|
| Cash flows from operating activities | 22 | | | | |
| Net cash used in operating activities | | | (89,906) | | 127,224 |
| Cash flows from investing activities: | | | | | |
| Dividends and interest from investments | | 9,947 | | 9,166 | |
| Purchase of fixed assets | | (51,586) | | (7,841) | |
| Movement in short-term deposits | | (6,322) | | (6,787) | |
| Net cash used in investing activities | | | (47,961) | | (5,462) |
| Change in cash and cash equivalents in the year | | | (137,866) | | 121,762 |
| Cash and cash equivalents at the beginning of the year | | | 875,755 | | 753,993 |
| Cash and cash equivalents at the end of the year | | | <u>737,889</u> | | <u>875,755</u> |

1 Accounting policies

a) Statutory information

Down's Syndrome Association is a charitable company limited by guarantee and is incorporated in England. The registered office address and principal place of business is Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS.

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.

These financial statements consolidate the results of the charitable company and its wholly-owned subsidiary Down's Syndrome Trading Limited on a line by line basis. Transactions and balances between the charitable company and its subsidiary have been eliminated from the consolidated financial statements. Balances between the two companies are disclosed in the notes of the charitable company's balance sheet. A separate statement of financial activities, or income and expenditure account, for the charitable company itself is not presented because the charitable company has taken advantage of the exemptions afforded by section 408 of the Companies Act 2006.

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.

1 Accounting policies (continued)

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.

Membership income is treated as donation income and recognised when received.

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, campaigning and research 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.

1 Accounting policies (continued)

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 | 15% |
| ● Information, Training and Assessments | 29% |
| ● Beneficiary Projects and Services | 41% |
| ● Campaigning and Research | 14% |

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:

| | |
|----------------------------|----------------------------|
| ● Freehold Property | 2% straight line basis |
| ● Long Leasehold Premises | 2% straight line basis |
| ● Improvements to Property | 10% reducing balance basis |
| ● Pullen Exhibition Assets | 10% straight line basis |
| ● Fixtures & Fittings | 25% straight line basis |
| ● Computer Equipment | 33% straight line basis |

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.

1 Accounting policies (continued)

Investments in subsidiaries

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 includes 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.

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.

s) Pensions

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

2a Income from donations and legacies (current year)

| | Unrestricted £ | Restricted £ | 2020 total Total £ | 2019 Total £ |
|---|-------------------|-----------------|--------------------------|--------------------|
| Gifts | 1,017,351 | 64,106 | 1,081,457 | 1,102,071 |
| Legacies | 409,907 | 18,813 | 428,720 | 385,229 |
| Donated services | 4,521 | – | 4,521 | 21,132 |
| Total income from donations and legacies | 1,431,779 | 82,919 | 1,514,698 | 1,508,432 |

2b Income from donations and legacies (prior year)

| | Unrestricted £ | Restricted £ | 2019 total Total £ | 2018 Total £ |
|---|-------------------|-----------------|--------------------------|--------------------|
| Gifts | 1,050,930 | 51,141 | 1,102,071 | 930,299 |
| Legacies | 385,229 | – | 385,229 | 278,835 |
| Donated services | 1,132 | 20,000 | 21,132 | 18,496 |
| Total income from donations and legacies | 1,437,291 | 71,141 | 1,508,432 | 1,227,630 |

At the end of the year, we have been notified that we are entitled to funds from a total of 4 (2019: 4) residual legacies. However, as at 31 March 2020, we had not been notified as to the final value of our entitlement or when this would be received. As such we are not able to recognise these funds in the financial statements for the year. We currently estimate of the value of the legacies will be approximately £500,000.

3a Income from charitable activities (current year)

| | Unrestricted £ | Restricted £ | 2020 Total £ | 2019 Total £ |
|--|-------------------|-----------------|--------------------|--------------------|
| Charitable Trusts & Foundations | | 58,455 | 58,455 | 80,723 |
| Companies | | 10,776 | 10,776 | 17,945 |
| Big Lottery Fund | | – | – | – |
| Conference, Training & Assessments | 43,691 | 3,385 | 47,076 | 34,060 |
| Sub-total for Information, Training & Assessments | 43,691 | 72,616 | 116,307 | 132,728 |
| Charitable Trusts & Foundations | | 72,700 | 72,700 | 66,300 |
| Companies | | 100,355 | 100,355 | 51,540 |
| Department of Digital, Culture, Media & Sport | | 106,414 | 106,414 | 35,000 |
| Big Lottery Fund | | 179,732 | 179,732 | 167,987 |
| Welsh Assembly | | – | – | 6,250 |
| DHSSPS | | 26,285 | 26,285 | 26,285 |
| EU Active Inclusion | | 38,412 | 38,412 | 32,024 |
| Contributions to Youth & Project Activities | | 24,216 | 24,216 | 20,513 |
| Sub-total for Beneficiary Projects & Services | – | 548,114 | 548,114 | 405,899 |
| Charitable Trusts & Foundations | | – | – | 13,316 |
| Companies | | 7,959 | 7,959 | 15,425 |
| Heritage Lottery Fund | | – | – | – |
| Sub-total for Campaigning & Research | – | 7,959 | 7,959 | 28,741 |
| Total income from charitable activities | 43,691 | 628,688 | 672,379 | 567,368 |

3b Income from charitable activities (prior year)

| | Unrestricted | Restricted | 2019 Total | 2018 Total |
|---|--------------|------------|---------------|---------------|
| | £ | £ | £ | £ |
| Charitable Trusts & Foundations | – | 80,723 | 80,723 | 44,980 |
| Companies | – | 17,945 | 17,945 | 250 |
| Big Lottery Fund | – | – | – | 10,000 |
| Conference, Training & Assessments | 31,620 | 2,440 | 34,060 | 54,090 |
| Sub-total for Information, Training & Assessments | 31,620 | 101,108 | 132,728 | 109,320 |
| Charitable Trusts & Foundations | – | 66,300 | 66,300 | 39,000 |
| Companies | – | 51,540 | 51,540 | 126,961 |
| Sport England | – | – | – | 96,687 |
| Department of Digital, Culture, Media & Sport | – | 35,000 | 35,000 | – |
| Big Lottery Fund | – | 167,987 | 167,987 | 168,185 |
| Welsh Assembly | – | 6,250 | 6,250 | 18,750 |
| DHSSPS | – | 26,285 | 26,285 | 26,285 |
| EU Active Inclusion | – | 32,024 | 32,024 | 32,024 |
| Contributions to Youth & Project Activities | – | 20,513 | 20,513 | 29,339 |
| Sub-total for Beneficiary Projects & Services | – | 405,899 | 405,899 | 505,207 |
| Charitable Trusts & Foundations | – | 13,316 | 13,316 | 400 |
| Companies | – | 15,425 | 15,425 | 14,880 |
| Heritage Lottery Fund | – | – | – | 8,510 |
| Sub-total for Campaigning & Research | – | 28,741 | 28,741 | 23,790 |
| Total income from charitable activities | 31,620 | 535,748 | 567,368 | 638,317 |

4a Income from other trading activities (current year)

| | Unrestricted £ | Restricted £ | 2020 Total £ | 2019 Total £ |
|---|-------------------|-----------------|--------------------|--------------------|
| Lettings | 101,778 | 1,160 | 102,938 | 116,555 |
| Fundraising events | 25,455 | | 25,455 | 16,524 |
| Subsidiary trading | 21,499 | | 21,499 | 24,611 |
| Total income from other trading activities | 148,732 | 1,160 | 149,892 | 157,690 |

4b Income from other trading activities (prior year)

| | Unrestricted £ | Restricted £ | 2019 Total £ | 2018 Total £ |
|---|-------------------|-----------------|--------------------|--------------------|
| Lettings | 116,432 | 123 | 116,555 | 98,652 |
| Fundraising events | 16,524 | – | 16,524 | 19,382 |
| Subsidiary trading | 24,611 | – | 24,611 | 22,726 |
| Total income from other trading activities | 157,567 | 123 | 157,690 | 140,760 |

5a Analysis of expenditure (current year)

| | Cost of raising funds £ | Charitable activities | | | | Governance costs £ | Support costs £ | 2020 Total £ | 2019 Total £ |
|--------------------------------------|----------------------------------|--|--|--------------------------------|----------|--------------------------|-----------------------|--------------------|--------------------|
| | | Information, Training & Assessments £ | Beneficiary Projects & Services £ | Campaigning & Research £ | | | | | |
| Staff costs (Note 8) | 178,137 | 342,871 | 482,924 | 169,490 | 27,945 | 170,326 | 1,371,693 | 1,249,686 | |
| Staff training & recruitment | 330 | 80 | 2,486 | – | 364 | 9,923 | 13,183 | 16,090 | |
| Postage, telephone, fax and email | 7,722 | 7,020 | 6,868 | 1,678 | 1,233 | 16,810 | 41,331 | 42,210 | |
| Research & museum costs | – | – | 25,596 | 64,728 | – | – | 90,324 | 25,377 | |
| Information resources | 404 | 6,590 | 11,870 | 44,862 | – | – | 63,726 | 61,066 | |
| Conferences and training costs | 530 | 5,911 | 8,303 | – | 2,450 | – | 17,194 | 19,521 | |
| Projects and activities | – | 32,298 | 61,315 | 65,245 | – | 33,608 | 192,466 | 193,922 | |
| Fundraising events | 74,975 | – | 150 | – | – | – | 75,125 | 102,412 | |
| Fundraising costs | 45,834 | – | – | – | – | – | 45,834 | 29,102 | |
| Appeals, advertising and media | 13,948 | – | – | – | – | – | 13,948 | 4,140 | |
| Travel & meetings | 1,799 | 26,523 | 60,509 | 3,942 | 8,277 | 1,997 | 103,047 | 107,295 | |
| Consultants, Advisors and profession | 4,271 | 59,119 | – | – | 16,632 | 6,195 | 86,217 | 71,445 | |
| Office running and equipment costs | 2,985 | 3,346 | 6,634 | 1,851 | 1,764 | 125,430 | 142,010 | 155,425 | |
| Rent, Insurance & Maintenance | – | 271 | 23,108 | 90 | – | 77,266 | 100,735 | 97,093 | |
| Depreciation | – | – | 1,200 | – | – | 56,317 | 57,517 | 41,417 | |
| | 330,935 | 484,029 | 690,963 | 351,886 | 58,665 | 497,872 | 2,414,350 | 2,216,201 | |
| Support costs | 75,582 | 145,477 | 204,900 | 71,913 | – | (497,872) | – | – | |
| Governance costs | 8,905 | 17,142 | 24,144 | 8,474 | (58,665) | – | – | – | |
| Total expenditure 2020 | 415,422 | 646,648 | 920,007 | 432,273 | | – | 2,414,350 | | |
| Total expenditure 2019 | 363,723 | 553,293 | 878,676 | 375,409 | – | – | | 2,171,101 | |

5b Analysis of expenditure (prior year)

| | | Charitable activities | | | | | | | |
|------------------------------------|----------------------------------|--|--|--------------------------------|--------------------------|-----------------------|--------------------|--------------------|--|
| | Cost of raising funds £ | Information, Training & Assessments £ | Beneficiary Projects & Services £ | Campaigning & Research £ | Governance costs £ | Support costs £ | 2019 Total £ | 2018 Total £ | |
| Staff costs (Note 8) | 153,330 | 315,974 | 439,695 | 140,467 | 27,222 | 172,998 | 1,249,686 | 1,260,444 | |
| Staff training & recruitment | 7,346 | 269 | 6,030 | 312 | 1,764 | 369 | 16,090 | 7,838 | |
| Postage, telephone, fax and email | 9,279 | 18,767 | 9,037 | 3,767 | 1,161 | 199 | 42,210 | 40,451 | |
| Research & museum costs | 525 | 5,674 | 18,701 | 477 | – | – | 25,377 | 16,197 | |
| Information resources | 1,334 | 15,836 | 4,617 | 39,279 | – | – | 61,066 | 49,623 | |
| Conferences and training costs | 576 | 9,721 | 8,000 | – | 1,224 | – | 19,521 | 14,208 | |
| Projects and activities | – | 42,513 | 52,206 | 99,203 | – | – | 193,922 | 180,341 | |
| Fundraising events | 102,412 | – | – | – | – | – | 102,412 | 61,600 | |
| Fundraising costs | 29,102 | – | – | – | – | – | 29,102 | 37,027 | |
| Appeals, advertising and media | 960 | – | – | 3,180 | – | – | 4,140 | 30,024 | |
| Travel & meetings | 2,698 | 25,454 | 61,310 | 3,454 | 10,504 | 3,875 | 107,295 | 99,352 | |
| Consultants and professional fees | 5,629 | 360 | 300 | – | 14,448 | 50,708 | 71,445 | 84,309 | |
| Office running and equipment costs | 3,972 | 5,308 | 9,882 | 2,332 | 2,437 | 131,494 | 155,425 | 130,740 | |
| Rent, Insurance & Maintenance | – | – | 29,641 | 13,121 | – | 54,331 | 97,093 | 105,321 | |
| Depreciation | – | – | 1,200 | – | – | 40,217 | 41,417 | 53,626 | |
| | 317,163 | 439,876 | 640,619 | 305,592 | 58,760 | 454,191 | 2,216,201 | 2,171,101 | |
| Support costs | 66,359 | 136,748 | 190,293 | 60,792 | – | (454,191) | – | – | |
| Governance costs | 8,585 | 17,692 | 24,619 | 7,865 | (58,760) | – | – | – | |
| Total expenditure 2020 | 392,107 | 594,316 | 855,530 | 374,249 | – | – | 2,216,201 | | |
| Total expenditure 2019 | 363,723 | 553,293 | 878,676 | 375,409 | – | – | | 2,171,101 | |

6 Grant making

| | 2020 £ | 2019 £ |
|---|---------------|---------------|
| Cost | | |
| Down Syndrome International: International Liaisons | 51,000 | 20,000 |
| Down Syndrome International– International Health Consensus Project | – | 45,000 |
| University of Cambridge– Mental Regression Research | 45,000 | – |
| | <u>96,000</u> | <u>65,000</u> |
| At the end of the year | | |

Down Syndrome International: The grant supporting the International Liaisons project will enable the fellowship of Down Syndrome organisations around the world to be facilitated.

Down Syndrome International: The grant supporting the International Health Project will enable Health Guidelines to be established concerning the medical care of people with Down's syndrome. These guidelines will be adopted by the World Health Organisation.

University of Cambridge: The grant supports the research into mental regression in adults with Down's syndrome.

7 Net income / (expenditure) for the year

This is stated after charging:

| | 2020 £ | 2019 £ |
|---|-----------|-----------|
| Depreciation | 57,517 | 41,417 |
| Operating lease rentals: | | |
| Property | 27,965 | 26,794 |
| Other | 6,416 | 4,346 |
| Auditor's remuneration (excluding VAT): | | |
| Audit | 11,200 | 11,000 |

8 Analysis of staff costs, trustee remuneration and expenses, and the cost of key management personnel

Staff costs were as follows:

| | 2020 £ | 2019 £ |
|---|------------------|------------------|
| Salaries and wages | 1,202,265 | 1,111,346 |
| Social security costs | 114,039 | 104,169 |
| Employer's contribution to defined contribution pension schemes | 55,389 | 34,171 |
| | <u>1,371,693</u> | <u>1,249,686</u> |

No employee earned more than £60,000 during the year (2019: none).

The total employee benefits including pension contributions and employer's national insurance of the key management personnel were £192,807 (2019: £185,448).

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

Trustees' expenses represent the payment or reimbursement of travel and subsistence costs totalling £788 (2019: £576) incurred by 8 (2019: 8) members relating to attendance at meetings of the trustees.

9 Staff numbers

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

| | 2020 No. | 2019 No. |
|---------------------------------------|-------------|-------------|
| Raising funds | 9.2 | 8.8 |
| Information, Training and Assessments | 9.3 | 7.6 |
| Beneficiary Projects and Services | 15.3 | 17.1 |
| Campaigning and Research | 5.0 | 4.3 |
| Support | 5.0 | 5.0 |
| Governance | 1.0 | 1.0 |
| | <u>44.7</u> | <u>43.7</u> |

10 Related party transactions

There are no donations from related parties which are outside the normal course of business and no restricted donations from related parties.

Down Syndrome International uses office space at the Down's Syndrome Association headquarters. Grants are given by Down's Syndrome Association to support the work of Down Syndrome International. The Chief Executive of Down's Syndrome Association, Carol Boys, is also a trustee of Down Syndrome International.

DSA is the payroll agency for DSI. At the year end there was a debtor of £41,534 relating to DSI.

The Down's Syndrome Association made the following payments to Down Syndrome International during the year:

| | 2020 £ | 2019 £ |
|-------------------------------|---------------|---------------|
| Grant Payments | 51,000 | 50,000 |
| Membership Fee | 240 | 240 |
| Projects, Meetings and Events | 8,902 | 3,005 |
| Merchandise | 13,565 | 18,165 |
| Total | 73,708 | 71,410 |

In addition Down's Syndrome Trading is a subsidiary of Down's Syndrome Association. There was no balance owing to Down's Syndrome Association at the end of the financial year.

11 Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes. The charity's trading subsidiary Down's Syndrome Trading Limited gift aids available profits to the parent charity so no tax is payable.

12 Tangible fixed assets**The charity and the group**

| | Freehold Property £ | Long Leasehold Premises £ | Improvements to Property £ | Fixtures and fittings £ | Puller Exhibition Assets £ | Computer Equipment £ | Total £ |
|--------------------------|---------------------------|------------------------------------|-------------------------------------|-------------------------------|-------------------------------------|----------------------------|------------|
| Cost | | | | | | | |
| At the start of the year | 1,286,250 | 60,000 | 78,712 | 74,775 | 42,128 | 113,992 | 1,655,857 |
| Additions in year | – | – | – | 9,074 | – | 42,512 | 51,586 |
| Disposals in year | – | – | – | – | – | – | – |
| At the end of the year | 1,286,250 | 60,000 | 78,712 | 83,849 | 42,128 | 156,504 | 1,707,443 |
| Depreciation | | | | | | | |
| At the start of the year | 264,600 | 34,800 | 48,217 | 73,570 | 29,491 | 108,765 | 559,443 |
| Charge for the year | 29,400 | 1,200 | 3,049 | 2,871 | 4,213 | 16,784 | 57,517 |
| Eliminated on disposal | – | – | – | – | – | – | – |
| At the end of the year | 294,000 | 36,000 | 51,266 | 76,441 | 33,704 | 125,549 | 616,960 |
| Net book value | | | | | | | |
| At the end of the year | 992,250 | 24,000 | 27,446 | 7,408 | 8,424 | 30,955 | 1,090,483 |
| At the start of the year | 1,021,650 | 25,200 | 30,495 | 1,205 | 12,637 | 5,227 | 1,096,414 |

All of the above assets are used for charitable purposes.

13 Listed investments

| | The group 2020 £ | 2019 £ | The charity 2020 £ | 2019 £ |
|--|------------------------|-----------|--------------------------|-----------|
| Fair value at the start of the year | 277 | 345 | 279 | 347 |
| Net gain / (loss) on change in fair value | (185) | (68) | (185) | (68) |
| Fair value at the end of the year | 92 | 277 | 94 | 279 |
| Historic cost at the end of the year | 15 | 15 | 15 | 15 |
| Investments comprise: | | | | |
| | The group 2020 £ | 2019 £ | The charity 2020 £ | 2019 £ |
| Shares listed on the London Stock Exchange | 93 | 278 | 93 | 278 |
| Unlisted shares in UK registered companies | – | – | 2 | 2 |
| | 93 | 278 | 95 | 280 |

14 Subsidiary undertaking

The charitable company owns the whole of the issued ordinary share capital of Down's Syndrome Trading Limited (DST), a company registered in England. The subsidiary is used for non-primary purpose trading activities. The Chief Executive of DSA is also a Director of DST. All activities have been consolidated on a line by line basis in the statement of financial activities. Available profits are gift aided to the charitable company. A summary of the results of the subsidiary is shown below:

| | 2020 £ | 2019 £ |
|---|-----------|-----------|
| Turnover | 22,684 | 25,672 |
| Cost of sales | (12,088) | (15,805) |
| Gross profit | 10,596 | 9,867 |
| Administrative expenses | (6,088) | (4,793) |
| Management Charge | (1,000) | (1,000) |
| Profit / (loss) on ordinary activities | 3,508 | 4,074 |
| Gift aid to parent undertaking | – | – |
| Profit / (loss) for the financial year | 3,508 | 4,074 |
| The aggregate of the assets, liabilities and funds was: | | |
| Assets | 28,555 | 25,045 |
| Liabilities | (1,500) | (1,500) |
| Funds | 27,055 | 23,545 |

15 Parent charity

The parent charity's gross income and the results for the year are disclosed as follows:

| | 2020 £ | 2019 £ |
|---------------------|-----------|-----------|
| Gross income | 2,329,307 | 2,217,984 |
| Result for the year | (67,052) | 22,311 |

16 Stocks

| | The group 2020 £ | 2019 £ | The charity 2020 £ | 2019 £ |
|----------------|------------------------|---------------|--------------------------|--------------|
| Finished goods | 12,546 | 12,295 | 8,536 | 7,520 |
| | 12,546 | 12,295 | 8,536 | 7,520 |

17 Debtors

| | The group 2020 £ | 2019 £ | The charity 2020 £ | 2019 £ |
|------------------------------------|------------------------|---------------|--------------------------|---------------|
| Trade debtors | 15,038 | 52,477 | 15,038 | 52,477 |
| Other debtors | 46,547 | 8,540 | 44,962 | 8,537 |
| Prepayments | 20,019 | 27,835 | 20,019 | 27,835 |
| Accrued income | – | 1,215 | – | 1,215 |
| Amounts owed by subsidiary company | – | – | – | – |
| | 81,604 | 90,067 | 80,019 | 90,064 |

18 Creditors: amounts falling due within one year

| | The group 2020 £ | 2019 £ | The charity 2020 £ | 2019 £ |
|------------------------------------|------------------------|----------------|--------------------------|----------------|
| Trade creditors | 15,636 | 46,478 | 15,636 | 46,478 |
| VAT payable | – | – | – | – |
| Taxation and social security | 33,195 | 32,286 | 33,195 | 32,286 |
| Pension | – | 5,703 | – | 5,703 |
| Accruals | 57,724 | 52,190 | 56,224 | 50,690 |
| Deferred income | 13,765 | 61,917 | 13,765 | 61,917 |
| Amounts owed to subsidiary company | – | – | 18,123 | 6,089 |
| | 120,320 | 198,574 | 136,943 | 203,163 |

19 Deferred income

Deferred income comprises restricted donations, membership fees and sales.

| | The group 2020 £ | 2019 £ | The charity 2020 £ | 2019 £ |
|---------------------------------------|------------------------|---------------|--------------------------|---------------|
| Balance at the beginning of the year | 61,917 | 125,378 | 61,917 | 24,286 |
| Amount released to income in the year | (61,917) | (125,378) | (61,917) | (24,286) |
| Amount deferred in the year | 13,765 | 61,917 | 13,765 | 61,917 |
| | 13,765 | 61,917 | 13,765 | 61,917 |

20a Analysis of group net assets between funds (current year)

| | General Unrestricted £ | Designated funds £ | Restricted funds £ | Total funds £ |
|-----------------------------------|------------------------------|--------------------------|--------------------------|------------------|
| Tangible fixed assets | – | 38,363 | 1,052,120 | 1,090,483 |
| Investments | 92 | – | – | 92 |
| Net current assets | 1,296,136 | 190,000 | 78,284 | 1,564,420 |
| Net assets at the end of the year | 1,296,228 | 228,363 | 1,130,404 | 2,654,995 |

20b Analysis of group net assets between funds (prior year)

| | General Unrestricted £ | Designated funds £ | Restricted funds £ | Total funds £ |
|-----------------------------------|------------------------------|--------------------------|--------------------------|------------------|
| Tangible fixed assets | – | 6,432 | 1,089,982 | 1,096,414 |
| Investments | 277 | – | – | 277 |
| Net current assets | 1,375,151 | 145,000 | 105,771 | 1,625,922 |
| Net assets at the end of the year | 1,375,428 | 151,432 | 1,195,753 | 2,722,613 |

21a Movements in funds (current year)

| | At the start of the year £ | Incoming resources & gains £ | Outgoing resources & losses £ | Transfers £ | At the end of the year £ |
|---|----------------------------------|---------------------------------------|--|-----------------|--------------------------------|
| Restricted funds: | | | | | |
| Training – Amyloid Disposition and Alzheimer's Disease Wales | 5,400 | 700 | (6,100) | – | – |
| Office | – | – | – | – | – |
| Northern Ireland | | | | | |
| DHSSPS | – | 26,285 | (26,285) | – | – |
| Youth Activities | – | 5,110 | (5,110) | – | – |
| Northern Ireland Fixed Asset Reserve | 25,200 | – | (1,200) | – | 24,000 |
| Other Northern Ireland funds | – | 54,623 | (88,538) | 33,915 | – |
| DSActive | 8,523 | 236,802 | (197,226) | – | 48,099 |
| Training and Conferences | 15,000 | 5,000 | (15,000) | – | 5,000 |
| Speech and Language Information | 12,050 | 5,000 | (17,050) | – | – |
| Having a Voice | – | 96,543 | (96,543) | – | – |
| Campaigning and Research | – | 4,453 | (4,453) | – | – |
| WorkFit – Employment Project | – | 10,459 | (10,459) | – | – |
| WorkFit North – Big Lottery Fund | 15,737 | 88,809 | (154,400) | 49,854 | – |
| Midwives Training | 25,842 | 170,239 | (162,988) | – | 33,093 |
| 50th Year Memories and Stories | 7,006 | 966 | (7,972) | – | – |
| Theatre Fund | 4,213 | – | (24,245) | – | (20,032) |
| LDC Fixed Asset Reserve | 12,000 | 7,778 | (7,654) | – | 12,124 |
| Pullen Exhibition Assets (Heritage Lottery funded) | 1,052,145 | – | (32,449) | – | 1,019,696 |
| | 12,637 | – | (4,213) | – | 8,424 |
| Total restricted funds | 1,195,753 | 712,767 | (861,885) | 83,769 | 1,130,404 |
| Unrestricted funds: | | | | | |
| Designated funds: | | | | | |
| Systems Upgrade | 10,000 | – | – | 90,000 | 100,000 |
| Building Fund | 50,000 | – | – | – | 50,000 |
| Employment Project | 40,000 | – | – | – | 40,000 |
| Mental Regression Reserarch | 45,000 | – | (45,000) | – | – |
| Fixed Asset Reserve | 6,432 | 51,586 | (19,655) | – | 38,363 |
| Total designated funds | 151,432 | 51,586 | (64,655) | 90,000 | 228,363 |
| General funds | 1,351,884 | 1,559,880 | (1,468,799) | (173,769) | 1,269,196 |
| Non-charitable trading funds | 23,544 | 22,684 | (19,196) | – | 27,032 |
| Total unrestricted funds | 1,526,860 | 1,634,150 | (1,552,650) | (83,769) | 1,524,591 |
| Total funds | 2,722,613 | 2,346,917 | (2,414,535) | – | 2,654,995 |

21b Movements in funds (prior year)

| | At the start of the year £ | Incoming resources & gains £ | Outgoing resources & losses £ | Transfers £ | At the end of the year £ |
|--|----------------------------------|---------------------------------------|--|-----------------|--------------------------------|
| Restricted funds: | | | | | |
| Training – Amyloid Disposition and Alzheimer's Disease | 5,000 | 21,380 | (20,980) | – | 5,400 |
| Wales | | | | | |
| Office | 8,208 | 6,073 | (14,281) | – | – |
| Northern Ireland | | | | | |
| DHSSPS | – | 26,285 | (26,285) | – | – |
| Youth Activities | 1,655 | 1,540 | (3,195) | – | – |
| Northern Ireland Fixed Asset Reserve | 26,400 | – | (1,200) | – | 25,200 |
| Other Northern Ireland funds | – | 42,747 | (108,200) | 65,453 | – |
| DSActive | 31,545 | 80,987 | (104,009) | – | 8,523 |
| Training and Conferences | 12,087 | 15,531 | (12,618) | – | 15,000 |
| Speech and Language | – | 17,600 | (5,550) | – | 12,050 |
| Information | – | 53,731 | (53,731) | – | – |
| Having a Voice | – | 7,805 | (7,805) | – | – |
| Campaigning and Research | – | 25,525 | (25,525) | – | – |
| WorkFit – Employment Project | 38,379 | 112,410 | (135,052) | – | 15,737 |
| WorkFit North – Big Lottery Fund | 60,042 | 168,287 | (202,487) | – | 25,842 |
| Midwives Training | 10,057 | 11,019 | (14,070) | – | 7,006 |
| Heritage Lottery Fund | 4,213 | – | (4,213) | – | – |
| Theatre Fund | 16,412 | 16,092 | (20,504) | – | 12,000 |
| LDC Fixed Asset Reserve | 1,084,933 | – | (32,788) | – | 1,052,145 |
| Pullen Exhibition Assets (Heritage Lottery funded) | 16,850 | – | – | – | 16,850 |
| Total restricted funds | 1,315,781 | 607,012 | (792,493) | 65,453 | 1,195,753 |
| Unrestricted funds: | | | | | |
| Designated funds: | | | | | |
| IT Upgrade | 10,000 | – | – | – | 10,000 |
| Building Fund | 50,000 | – | – | – | 50,000 |
| Employment Project | 40,000 | – | – | – | 40,000 |
| Mental Regression Research | – | – | – | 45,000 | 45,000 |
| Fixed Asset Reserve | 1,806 | – | (3,216) | 7,842 | 6,432 |
| Total designated funds | 101,806 | – | (3,216) | 52,842 | 151,432 |
| General funds | 1,259,149 | 1,609,972 | (1,398,942) | (118,295) | 1,351,884 |
| Non-charitable trading funds | 19,490 | 25,672 | (21,618) | – | 23,544 |
| Total unrestricted funds | 1,380,445 | 1,635,644 | (1,423,776) | (65,453) | 1,526,860 |
| Total funds | 2,696,226 | 2,242,656 | (2,216,269) | (12,611) | 2,722,613 |

Purposes of restricted funds**Training – Alzheimer's Disease**

This fund supports training of health and care professionals who work with people with Down's syndrome and Alzheimer's disease.

Wales

The main funder for work in Wales is the Welsh Assembly Government as part of its scheme for organisations operating in the social care sector for people with learning disabilities. The grant is used to support the work of our projects in Wales. Additional funding sources have been secured to promote development work in North Wales and our WorkFit programme in Wales.

Northern Ireland

The main funder of our core work in Northern Ireland is the DHSSPS. Also we have been grateful to receive funding from the Big Lottery Fund to support the Harvest Project working with older people.

Any funds raised as a result of the fundraising activities carried out in Wales and Northern Ireland are also restricted to our work in those regions. The staff team in Northern Ireland organise training and support their affiliated groups and individual families with advice and support. They also organise numerous activities for people with Down's syndrome and run weekend breaks and holidays. We also own a chalet in Northern Ireland and the Northern Ireland Fixed Asset Reserve represents the net book value of the chalet.

DSActive

Funding raised to provide participation in sport opportunities for young people with Down's syndrome. This enables the young people with Down's syndrome to develop their physical, social and emotional health through the joy of sport.

Training and Conferences

These funds are raised to support our comprehensive training and conference programme.

Education

These funds are used to continue the Down's Syndrome Association's important work in all areas of education for people with Down's syndrome. This includes providing help and advice on the Statementing process, design and production of Curriculum Support packs, organisation of training and conferences for education professionals, as well as responding to a variety of calls and requests for information

Information

These funds are used to provide information and advice. We provide a help line 5 days a week and distribute leaflets and publications. The information department also publishes the *Journal* twice a year which is distributed to the members of the Association. Our publications and leaflets are continually being developed and updated. Our information department also has specialists who offer advice and support to families about welfare benefits, in particular the Disability Living Allowance.

Having a Voice

Specific donations have been given to grow the Having a Voice project which empowers young adults with Down's syndrome to be active citizens in their communities.

Campaigning and Research

This income relates to support received to fund the My Perspectives photographic competition and also to undertake donor research.

WorkFit- Employment Project

These funds are used to support the work the Association does to support adults with Down's syndrome. This includes our unique WorkFit project which helps adults with Down's syndrome into employment.

Our WorkFit project in the North of England is currently funded by the Big lottery Fund.

Midwives Training

This funding is used to provide essential training to midwives as part of our "Tell it Right, Start it Right" campaign.

50th Year Memories and Stories

A project funded by the Heritage Lottery Fund to capture the memories and stories of people with Down's syndrome over the last 50 years. The fund is currently in deficit as grant claims are made in arrears.

Theatre Fund

This fund is used to maintain the glorious Victorian theatre at the Langdon Down Centre which was originally built and used by Dr John Langdon Down.

LDC Fixed Asset Reserve

This represents the value of the assets including buildings and fixtures and fittings which were acquired from the Langdon Down Centre Trust on merger.

Pullen Exhibition Assets

This represents the value of the glass display cases, which were purchased for the Pullen Exhibition, with Heritage Lottery Funds.

Purposes of designated funds

Systems Upgrade

The trustees have designated these funds to ensure that resources are available should any systems infrastructure need to be upgraded and other sources of funding cannot be secured.

Building Fund

The trustees have designated these funds to provide a sinking fund which will be used as necessary for building maintenance.

Employment Project

The trustees have designated these funds to initiate the employment project which will support adults with Down's syndrome into work.

Mental Regression Research

The trustees have designated these funds to commence a research project with the University of Cambridge into the issue of mental regression in adults with Down's syndrome.

Fixed Asset Reserve

This represents the value of general funds invested in buildings, fixtures and fittings and computer equipment and is therefore not readily available for other purposes.

22 Reconciliation of net income / (expenditure) to net cash flow from operating activities

| | 2020 £ | 2019 £ |
|---|-----------------|------------------|
| Net income / (expenditure) for the reporting period (as per the statement of financial activities) | (67,618) | (157,660) |
| Depreciation charges | 57,517 | 53,626 |
| (Gains)/losses on investments | 185 | 182 |
| Dividends and interest from investments | (9,947) | (6,916) |
| (Increase)/decrease in stocks | (251) | (1,022) |
| (Increase)/decrease in debtors | 8,463 | (18,337) |
| Increase in creditors | (78,254) | (23,517) |
| Net cash (used in) / provided by operating activities | (89,906) | (153,644) |

23 Operating lease commitments

The group's total future minimum lease payments under non-cancellable operating leases is as follows for each of the following periods:

| | Property 2020 £ | 2019 £ | Equipment 2020 £ | 2019 £ |
|--|-----------------------|---------------|------------------------|--------------|
| Within one year | 30,300 | 11,302 | 6,025 | 1,030 |
| In the second to fifth years inclusive | 19,925 | 15,492 | 12,299 | 3,316 |
| | 50,225 | 26,794 | 18,324 | 4,346 |

24 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 £1.

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

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WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of DSA members and supporters.



www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



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