



Supporting children  
with Down's Syndrome

## **Sparkles: Supporting Children with Down's Syndrome**

Charity number: 1168036

The trustees are pleased to present their annual report together with the financial statements of the charity for the period ending March 2021.

### **Chairs Report**

This year Sparkles has supported over 26 children with Down's syndrome in and around Buckinghamshire. 25 children are accessing weekly specialist speech and language therapy, 19 are accessing termly physiotherapy and 24 are accessing termly occupational therapy.

It would not be possible to write this report without acknowledging the huge impact of the Covid-19 pandemic. Within our charity, the impact of the initial lock down in March 2020 meant an abrupt and unforeseen end to all face-to-face therapy sessions. Some of our children are extremely clinically vulnerable and there was a huge amount of concern for all our members at the time.

We found ways to support our families and our therapists worked hard to send resources, activity sheets and Makaton signs via email to help keep up the vital therapy we provide and to provide some familiar routines during the first lockdown.

In June, our committee arranged a month of fundraising. The "21 Sparkles Challenge" saw our families taking on challenges including: learning 21 signs; singing 21 songs; learning to count to 21; learning 21 tricks; and walking 2.1km per day. Our families certainly stepped up to the challenge and raised over £4000.

In August, we were grateful to receive a grant which funded a day event with Animal Antiks. The families who attended had a fantastic day and it was really positive to bring families together again face to face. A welcome break from the virtual world and lock down.

Following the summer break, we resumed our therapy sessions in September and had to make the transition to virtual sessions. I cannot thank our therapists enough for the incredible job they did in creating virtual sessions that not only helped our children progress, but were fun, engaging and innovative. Our speech and language therapy sessions were incredibly creative, at one point our therapist was sending items down a long tube toward the camera on her laptop to create the sense of the object zooming towards the child watching – and the children loved this and were really excited to name the object as quickly as they could. Our families sent videos of their child's progress in physiotherapy, and these were used to plan the next session and future targets.

I would like to thank our committee for their supportive creativity in arranging a virtual Christmas party for our families. Gift packs were posted out to all the children and included cookies, colouring

packs, Santa hats and more. The online event involved games, activities, a raffle and even a visit from Santa himself. The raffle raised over £1000.

It has not been possible to carry out our traditional fundraising events this year. There has been no sponsored walk or evening fundraiser and our members have not been able to arrange their sponsored events involving groups of people. Despite this, we have continued to receive donations and thanks to the creativity, dedication and hard work of our committee and our families, we have continued to raise valuable funds even in these exceptional circumstances.

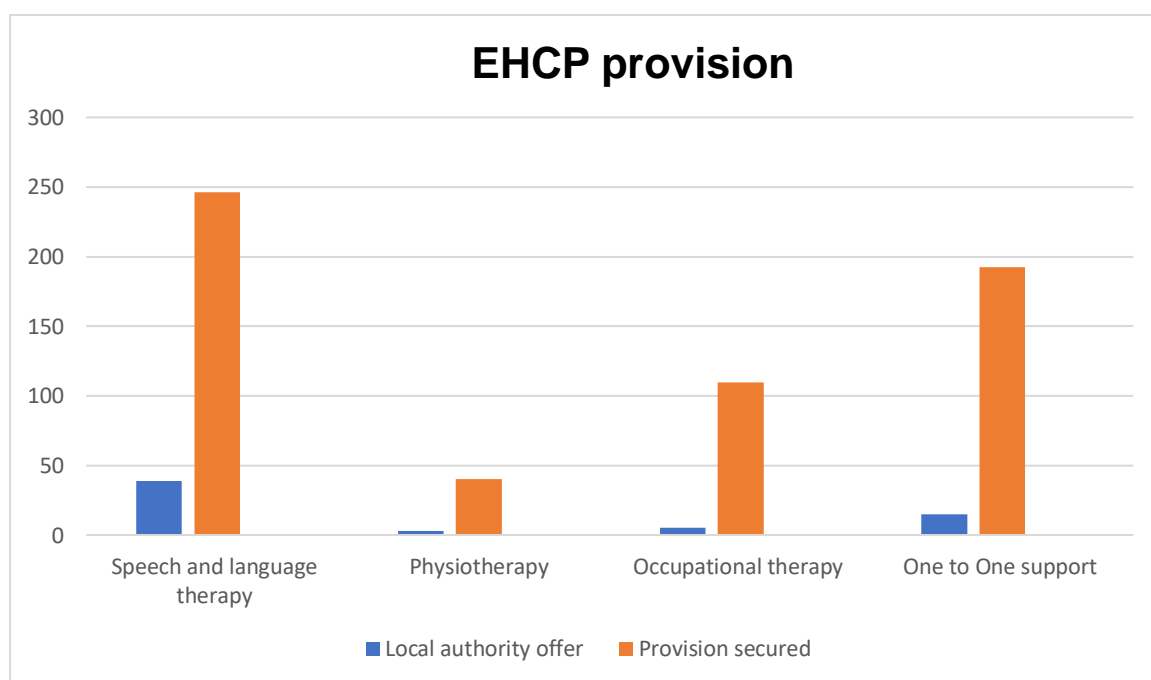
Following a review of the package of support for Education and Health Care Plans (EHCP) we were able to offer the package again this year, to the four children starting school in September.

### **Summary of the Review of Education and Health Care Plan (EHCP) Sparkles package of support Sep 2019 - August 2020**

#### Aims of the programme

To support families through the EHCP process, by providing expertise and a representative to liaise with the local authority in the process and by reducing the cost to families by funding private assessments and consultancy fees.

#### Outcomes



#### Additional outcomes

The desired outcome is not merely to increase hours, it is to meet the needs of the individual children. Some children will need more OT hours than others, some more physio than others. Some may need specialist support from vision impairment, hearing impairment or health-based needs. The review of the EHCP considers all of these areas and requests for statutory assessments have been made when required for the individual child.

LA offers had wording such as “when appropriate” and “to be used flexibly” these are not quantified and specific hours and therefore the LA cannot be held accountable if sufficient provision is not in place.

The plans secured also have very clear wording around the level of specialism required. For example “therapist must be specialist in Down’s syndrome”.

Where parents could self-fund a report from Inclusively Downs, they were able to secure specialist teaching hours. Buckinghamshire is the only county to have a Down’s syndrome specialist teaching service. Other counties have generic specialist teaching services.

An important difference between the LA’s offer and the secured plan, is the clarity and accountability of the hours. It is stated in the plan how many contact/direct hours therapy and then in addition hours for report writing, attending annual reviews and liaising with staff and parents.

The physio secured includes additional hours for staff training, much of this is to be delivered by Debbie.

Additional clarity within the plans - therapist to feedback to parents after each session; level of training staff required to have; trained in specific techniques for children with Down’s syndrome; provision of specialist seating at home and school; OT trained in sensory integration

#### Feedback from parents

5 out of the 9 parents have given feedback. Feedback was obtained by a telephone call between me and the parent. Semi-structured questions were used to guide relevant information in the areas highlighted below. Feedback has been anonymised.

Understanding of EHCP process before starting the programme

Generally, parents had very little understanding of the process and were not clear on what should be included in the plan. One had completed courses from other charities so had some understanding.

Emma’s workshop was found to be really useful, gave a heads up on the legality of the process, but was a lot of information in a short space of time.

#### Professionals

Many parents had to self-fund appeals and this stretched their finances and added pressure to the situation. They were all pleased with the final outcome, one saying the results were amazing.

Parents were very happy with the quality of the therapists reports although delays in getting the reports were common.

#### Would you recommend to others?

All parents said they would recommend the programme to others, saying it was really valuable and the outcomes for their children were amazing.

#### Summary

The support offered by Sparkles has clearly contributed to some amazing outcomes and we now have at least 6 children with Down’s syndrome who will start their school life with high quality, specialist therapy at the recommended amount. The plans these children have are legally binding documents and reflect the appropriate provision of therapy as agreed by the local authority when

challenged. Without challenge, the local authorities will offer a reflection of the limited services they have, and this falls very short of meeting the needs of our complex, amazing children.

The results are so much more than numbers of hours. The plans are clear on the level of specialism required; the need for training within schools; the particular health needs of individuals and how these are to be met; and they do what the EHCP was always meant to do - describe the needs of children and how these needs will be met.

We have learnt lessons from this first year. The need for funding to support appeals is clear. We must ensure that no family is left without an adequate EHCP as a result of financial differences. We need to better support our therapists in the process - the proposed changes to include terms and conditions for parents and the prioritising of cases aims to reduce the pressure felt last year.

### Conclusion

Sparkles has made a great start in reducing inequality among the provision of support for children starting school. With the agreement to fund the appeal process for the next cohort and clearer expectations for parents and therapists I am confident this year will continue to produce amazing outcomes that will support our mission to provide children with Down's syndrome with responsive, high quality therapeutic support that enriches their lives and supports their families.

In closing, I would like to thank our team of therapists for their continued hard work and support, our generous donors, the trustees and committee members, all our families and our amazing children, who are at the heart of what we do.

To find out more about Sparkles please visit our website: [www.sparkles.org.uk](http://www.sparkles.org.uk) or email us: [info@sparkles.org.uk](mailto:info@sparkles.org.uk)

### **Objectives and Activities**

#### The purposes of the charity are:

Sparkles is a small, parent-led charity that funds the provision of speech and language, physiotherapy and occupational therapy sessions to pre-school children with Down's syndrome living in and around Buckinghamshire. We also organise appropriate leisure and recreational activities for our members and their children, which provides a valuable support network to parents and siblings.

Today, the therapeutic support that we offer through Sparkles is a valuable addition to NHS services, which are not compromised by joining.

Our vision is that all children with Down syndrome in Buckinghamshire; from birth to infant school age; have the opportunity to reach their full potential through early speech and language therapy, physiotherapy and occupational therapy.

#### Activities

Shaping our activities is our mission to provide children with Down syndrome with responsive, high quality therapeutic support that enriches their lives and supports their families. This is delivered in

four main areas: Speech and language therapy, physiotherapy, occupational therapy and support for families.

### *Speech and Language Therapy*

Sparkles speech and language therapy sessions take place at Children's Centres in High Wycombe and Aylesbury. Each session is 45 minutes long, weekly (term time only) and held in groups of no more than 3 children and their parent / carer.

Children with Down's syndrome will usually experience challenges with communication to varying degrees, including receptive (understanding) language and expressive (speaking and composing sentences) language skills.

Carried out by specialist speech and language therapists, the sessions are based on Makaton: a system designed to support spoken language where signs and symbols are used alongside speech, in spoken word order.

Our speech and language therapy focuses on helping our children to talk, but also covers the essential skills needed to communicate effectively. The sessions are designed to engage our members from a young age and include:

- Music, songs and games;
- Listening and comprehension;
- Turn taking;
- Picture and word matching;
- Lip seal and tongue control exercises;
- Phonics; and
- Combining words and sequencing sentences

The sessions are provided at no cost to the families. Parent's report that there is either a lack of speech and language therapy available on the NHS or an inconsistent level of provision and that Sparkles is a lifeline, easing frustration by enabling communication and helping parents to feel supported.

### *Physiotherapy*

At Sparkles, we offer 3 to 6 physiotherapy sessions each year with a specialist practitioner, depending on the age and need of the child. The sessions are 45 minutes long, one-to-one with the child and parent/carer, and based in a children's physiotherapy clinic in High Wycombe.

Children with Down's syndrome can have low muscle tone and hyper-flexibility, which can make mastering gross motor skills harder. Delays in physical development are not uncommon. Targeted physiotherapy helps our children achieve major milestones such as sitting, crawling and walking.

The sessions are individually tailored, fun and child-centred enabling children to reach their full potential and grow with confidence. Parents are provided with a programme of exercises and activities to follow at home to support their child.

The sessions are provided at no cost to the families, except where late cancellation fees may apply.

### *Occupational Therapy*

At Sparkles, we offer 3 to 6 occupational therapy sessions each year, depending on the age and need of the child. The sessions are 45 minutes long, one-to-one with the child and parent/carer, and based in a highly equipped clinic in Aylesbury.

We are working with a team of experienced occupational therapists who are highly skilled in the assessment and treatment of children with learning, behavioural and developmental difficulties.

Some children with Down's syndrome may experience sensitivity to certain food textures, sounds, bright lights and unfamiliar situations, resulting in distress and behavioural issues.

Sparkles occupational therapy focuses on these and other sensory processing issues, based on a theory known as Sensory Integration: how our brain receives and processes sensory information so that we can do the things we need to do in our everyday life. This therapy is currently not offered by the NHS.

The sessions give parents a greater understanding of sensory processing issues experienced by their child and strategies to limit their impact on their development and day-to-day life.

The sessions are provided at no cost to the families, except where late cancellation fees may apply.

### **Public Benefit**

In planning our activities for the year and our objectives for the future, the trustees have considered the Charity Commission's guidance on public benefit, including the guidance on public benefit and fee charging. Sparkles relies on fundraising by its members, grants and donations in order to cover the cost of the therapies provided. In accordance with the purposes of the charity, all therapies are provided at no cost to the families attending. This is due to consideration of accessibility for those on low incomes.

### **Objectives**

- 1 To identify the number of families of children with Down's syndrome, in our target area, not currently receiving our services and make them aware of Sparkles by working closely with other organisations and professionals.
2. To evaluate our therapeutic services to ensure we are providing appropriate, high quality services, that make the best use of our resources.
3. To establish external funding streams to create a financially sustainable service with funding from external sources composing 50% of our income by the end of 2020.
4. To improve internal communications with parents and families to engage more parents to be more actively involved in Sparkles and enable annual succession planning as children leave Sparkles.
5. To improve our marketing and communication to support our objectives, with a new website, and new marketing materials targeted at parents and at professionals.

### **Achievements and Performance**

This year's achievements include:

The continued provision of speech and language therapy, physiotherapy and Occupational therapy. This is a huge achievement given the global pandemic and the lock down restrictions we have all faced.

The continued support for children in their transition to primary school. Children are provided with an intensive block of speech therapy over the summer holidays prior to starting school. The therapist liaises with schools to create a bespoke package of therapy in order to ease the transition. This includes familiarisation with vocabulary relevant to the school environment, teachers and the first topic to be covered at school. This is followed up by two visits into school during the first year. Teachers and teaching assistants have reported this to be a valuable resource that helps them to support the child better and have a greater understanding of their needs and abilities.

Physiotherapy and Occupational therapy sessions also continue to be provided in the first year of school in order to ease the transition and help children settle into their new environment.

The introduction of a new programme to support families through the EHCP process, by providing expertise and a representative to liaise with the local authority in the process and by reducing the cost to families by funding private assessments and consultancy fees.

## **Financial Review**

### **Review of the charity's financial position at the end of the period**

Cash reserves are needed to bridge the gap between the spending and receiving of resources and to ensure continuity of the provision of core therapies. The trustees consider that the ideal level of reserves as at 31st March 2021 would be at least £40,000 to cover the provision of one year's speech and language therapy to all current members, based on £50 per session per child and c36 sessions per annum.

The actual level of cash reserves held at 31 March 2021 were £115,285, slightly higher than our position on 31 March 2020 of £111,289.

A reduction in speech and language therapy provision, physiotherapy and occupational therapy has resulted in a net cash inflow of £3,995. We are hopeful the lottery will continue to grow in numbers and have plans in place to establish more external sources of income.

Based on the existing reserves and cash resources, together with fundraising plans for the future, we are confident that Sparkles remains a going concern and can satisfy its liabilities as they fall due.

## **Structure, Governance and Management**

### *Governing Document*

Sparkles governing document is an association model constitution and the charity is a Charitable Incorporated Organisation (CIO) with voting members other than its charity trustees.

### *Appointment of charity trustees*

(1) At every annual general meeting of the members of the CIO, 1/3<sup>rd</sup> of the charity trustees shall retire from office. If the number of charity trustees is not 3 or a multiple of 3, then the number nearest to 1/3<sup>rd</sup> shall retire from office, but if there is only 1 charity trustee, he or she shall retire;

(2) The charity trustees to retire by rotation shall be those who have been longest in office since their last appointment or reappointment. If any trustees were last appointed or reappointed on the same day those to retire shall (unless they otherwise agree among themselves) be determined by lot;

(3) The vacancies so arising may be filled by the decision of the members at the annual general meeting; any vacancies not filled at the annual general meeting may be filled as provided in sub clause (5) of this clause;

4) The members or the charity trustees may at any time decide to appoint a new charity trustee, whether in place of a charity trustee who has retired or been removed in accordance with clause [15] (Retirement and removal of charity trustees), or as an additional charity trustee, provided that the limit specified in clause [12(3)] on the number of charity trustees would not as a result be exceeded;

(5) A person so appointed by the members of the CIO shall retire in accordance with the provisions of sub-clauses (2) and (3) of this clause. A person so appointed by the charity trustees shall retire at the conclusion of the next annual general meeting after the date of his or her appointment, and shall not be counted for the purpose of determining which of the charity trustees is to retire by rotation at that meeting.



### **Reference and Administrative Details**

Charity name: Sparkles: Supporting Children with Down's syndrome

Registered Charity number: 1168036

Charity's principal address: 3, Daly Way, Aylesbury, HP20 1JY

#### **Trustees:**

C. Scurlock Chair

T. Hall Secretary

D. Jones Treasurer

T. Hynes

C. Kaye

M. Selby-Boothroyd

G. Smith



CHARITY COMMISSION  
FOR ENGLAND AND WALES

## Receipts and payments accounts

CC16a

For the period  
from

01/04/2020

To

Period end date  
31/03/2021

Unrestricted

Restricted

Endowment

Total funds

Last year

### A1 Receipts

Donations	21,859	-	-	21,859	45,797
Fund raising- The Ball	-	-	-	-	-
Fund raising- Lottery	3,715	-	-	3,715	3,660
Fund raising- GYBO	-	-	-	-	7,917
Fund raising- Other	-	-	-	-	-
Interest	197	-	-	197	307
<b>Sub total (Gross income for AR)</b>	<b>25,771</b>	<b>-</b>	<b>-</b>	<b>25,771</b>	<b>57,681</b>

A2 Asset and investment sales,  
(see table).

Sub total	-	-	-	-	-
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### Total receipts

25,771	-	-	25,771	57,681
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### A3 Payments

Speech & Language Therapy	13,992	-	-	13,992	36,800
Physiotherapy	3,970	-	-	3,970	13,960
Leap OT	-	-	-	-	5,313
Expenses- The Ball	-	-	-	-	-
Expenses- Lottery Prizes	1,969	-	-	1,969	1,850
Expenses- Emma Hopkins	1,334	-	-	1,334	2,465
Expenses- Other	510	-	-	510	4,599
<b>Sub total</b>	<b>21,775</b>	<b>-</b>	<b>-</b>	<b>21,775</b>	<b>64,985</b>

A4 Asset and investment  
purchases. (see table)

Sub total	-	-	-	-	-
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### Total payments

21,775	-	-	21,775	64,985
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Net of receipts/(payments)

3,996	-	-	3,996	-	7,304
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A5 Transfers between funds

-	-	-	-	-	-
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A6 Cash funds last year end

111,289	-	-	111,289	118,592
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Cash funds this year end

115,285	-	-	115,285	111,289
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# Section B Statement of assets and liabilities at the end of the period

B1 Cash funds		B2 Other monetary assets		B3 Investment assets		B4 Assets retained for the charity's own use		B5 Liabilities	
Categories		Details		Details		Details		Details	





CHARITY COMMISSION  
FOR ENGLAND AND WALES

# Independent examiner's report on the accounts

## Section A Independent Examiner's Report

Report to the trustees/  
members of

On accounts for the year  
ended

Set out on pages

Charity Name Sparkles-Supporting Children with Down's Syndrome

Charity no (if any)	31 March 2021
------------------------	---------------

1168036

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended

Responsibilities and  
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent  
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below \*) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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

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

Signed:

*Raj Kumar Gupta*

Date:

18/01/2022

Name:

RAJ KUMAR GUPTA

Relevant professional  
qualification(s) or body

CIFPA INTERN

