



Down's Syndrome Community Group

TRUSTEES ANNUAL REPORT **From 1 APRIL 2024 to 31 MARCH 2025**

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Charity Details

Charity Name: Downright Perfect

Registered charity number: 1200893

Registered office: 38 Russel Road, Bournemouth, Dorset, BH10 7HD

Bankers: Co-operative Business Bank

Structure, Governance and Management

Downright Perfect was registered as an unincorporated association in 2014 registered under number 1159214. An application was made to convert the Charity to a CIO Foundation and on 2 November 2022 a new charity number 1200893 was registered, it is governed by a Constitution. On 5 April 2023 the assets of charity 1159214 were transferred to new CIO number 1200893.

The accounting period for the old charity, 1159214, ran from 28 July to 27 July. The accounting period for the new charity, 1200893, runs from 1 April to 31 March.

The current trustees are:

Emma Louise Cross

Gillian Mary Clark

Patience Margaret Saunders

Claire Oakley

The board meets as and when required during the year but communicates regularly electronically to discuss matters between meetings.

All of the trustees give their time voluntarily and none received any benefit other than that which any other beneficiary would receive. Alongside the trustees the Charity has day to day support from a volunteer, Katherine Clark Sevilha, who acts as the Charities Clerk to Trustees assisting with all matters including administration. The Charity has also built up a team of volunteers who assist at events and a volunteer who makes baby blankets for our New Parent Hospital Packs.

The trustees are continuously seeking input from its beneficiaries to help in their decision making and have done this through seeking feedback and ideas in different formats such as social media, evaluation forms and general discussion at events such as the regular Pre-Schoolers groups. The trustees remain flexible in their planning and have adjusted the focus of their efforts throughout the period as the needs of the Charity's beneficiaries have become apparent. An example of this is the development of parent/carer only events as the need for parents to build relationships with each other in an environment where they were not also caring for their children became apparent.

Charitable objectives

The object of the CIO is to relieve the charitable needs of children and young people with Down's Syndrome and their families and carers in Dorset and the surrounding areas by the provision of, but not limited to, advice and support, recreational and social events and facilitating access to therapies and resources.

Public Benefit Statement

In considering its strategy, aims and objectives, Downright Perfect's trustees have paid due regard to the Charity Commission's general guidance on Public Benefit. The trustees are satisfied that through its primary activities the charity provides identifiable benefits consistent with its charitable objects. The trustees do not consider that these activities produce any identifiable detriment or harm. The trustees are satisfied that any private benefit is incidental to its public benefit activity.

Aims

Downright Perfect's aim is to support children and young people with Down's Syndrome and their families in Dorset and surrounding areas.

As our understanding of the needs of our members has grown, the trustees have developed a structure to maintain focus on the areas of support the Charity has identified and agreed to support. This structure has also helped us to identify where our focus for strengthening our support should be. A copy of our structure can be found at Annex A.

Achievements and Future Plans

Parent Support: Hospital Packs

Hospital packs continue to be distributed by the maternity units at Bournemouth/Poole, Dorchester and Southampton and we have had a number of new members join the charity as a result of having received these packs which demonstrates to us that they are an effective means to reach out to parents when they have their baby.

This year we have been working very hard to build our partnership with University Hospitals Dorset and one of the results of this has been an increased awareness among staff of the Hospital Packs which ensures that they are being properly distributed.

Over the next year, we will be exploring how we can strengthen our relationships with the maternity units in Southampton and Dorchester which will in turn ensure that packs are being given out by staff.

Parent Support: Information sessions & Peer Support Workshops

Introduced this year, we have held a second online session on early intervention and support with a focus on speech and language development presented by Downs Syndrome Education International attended by 34 parents/professionals.

In October 2024 we ran our second parent only peer support evening which took place in a ceramic painting café. It was attended by 12 parents/carers and provided an opportunity for attendees to talk, connect and seek advice in a calm environment when they were not also caring for their children. This particular event worked well with many attending asking when the next one will be and those who could not attend expressing interest.

After the success of our parent only peer support workshop and the interest expressed by members in this type of event, this year we are exploring other parent only events including a parents wellness day.

Parent Support: Counselling Grants

Over the last couple of years, the need for formal counselling support for parents has become increasingly apparent. The waitlists for services through the NHS are extensive and the cost of private therapy is prohibitive for most. Accordingly, we have launched a programme of grants to assist with the costs of accessing counselling. A grant from Co-op Community Grants has been received for this purpose and is treated as restricted funds.

Events: Pre-Schoolers

Our Pre-Schoolers groups are a fundamental part of the services Downright Perfect provides creating opportunities for parent peer support, community building and for children to benefit from playing with each other in a safe and judgement free environment. Attendance at our groups varies between 6 to 20 children including siblings and most attend regularly. We have run 19 Pre-Schoolers sessions in this period. These sessions allow an hour of free play where children can play together and parents can provide each other with peer support. We then have half an hour of more structured time when we do a group story with visual aids and song time where each child gets to choose a song for the group to sing using a props representing nursery rhymes.

Events: Day trips

This year we held our summer trip at Highmead Community Farm attended by 40 people and Saturday Club sessions. These sessions normally take place during school holidays and/or at weekends so that more people can attend including Dads who we are finding attend significantly less than Mums.

These days out are intended to create opportunities which are members may not otherwise have or struggle with.

Next year we will continue to explore different types of events as we learn what works best for our members. We will also repeat the events that we have done previously that have worked well as we know that familiar venues and set ups are beneficial to our members.

Events: Friends & Family

We believe that it is important to involve wider family and friends in our events where possible. We are aware of situations where the child's diagnosis has not been widely accepted within the wider family and where issues around language and understanding of Down's Syndrome has caused problems within families or friendships. It is our intention that by inviting wider family members and friends to attend some of our events it will help promote inclusion and understanding across all of the adults and other children in their lives.

In this period we have held our annual Christmas party and a World Down's Syndrome Day party in partnership with Shine21.

Trustees have decided not to run a large World Down's Syndrome Day party in 2026 to enable the trustees to explore opportunities for engagement with schools and medical settings around the day.

Community Engagement & promoting inclusion: Education & Wider Community

Before the start of the Autumn school term in 2023 we launched a 'School Book Pack' project which involved our members nominating their child's school to receive a pack of fiction books which feature characters with Down's Syndrome. The aim of this project was to ensure that there are books available in all of our members classrooms with characters like them and to provide teachers with a basis on which to discuss Down's Syndrome with other pupils. With the pack we also provided leaflets on the importance of using the correct language around Down's Syndrome and a poster for their staff room on the same. We also included a letter with an offer for us to deliver a talk to staff on key issues surrounding Down's Syndrome.

In March 2025 we were delighted to be asked to go into a local secondary school, who had chosen us as one of their charities of the year, to give a talk in an assembly to students about Down's Syndrome and the charity. The brief talk was well received and the opportunity to raise awareness of what life today with Down's Syndrome is like to pupils with no knowledge of the facts around the condition felt like a wonderful engagement opportunity. We plan to explore ways that we can do more in this area.

Community Engagement & promoting inclusion: Medical

At the end of our last period we obtained a commitment from the Head of Midwifery at University Hospitals Dorset for them to engage with us and for us to provide training to staff on an annual basis. Over the last year we have completed a number of 'walk rounds' of the UHD maternity unit as an opportunity to meet staff and raise awareness of the charity so that they know they can signpost new parents to us. We are extremely proud to have delivered 2 very well attended training sessions to midwives at UHD which are going to become an annual session for new wives. These sessions discuss language, outdated views on life with down's syndrome and a parents perspective of receiving a diagnosis. On 21st March (World Down's Syndrome Day) we featured on BBC South Today for our partnership working with UHD.

This year we have also done a walk around of the paediatric unit at Poole hospital and a talk to Southampton Hospital Cardiac unit.

Supporting Development: Financial Grants

Another key element of our support services is the offer of financial grants to members to assist with the costs of accessing specialist resources and therapies.

In this period the trustees agreed to a sum of £300 per grant and 8 grants have been given in this period.

This year we intend to continue offering these grants which help parents to support their child's development and are increasing the sum per grant to £350. Trustees will review the level of grant and consider if the level can be maintained or increased.

Supporting Development: Early Development Groups

We continue to explore options as to how we can better support our members development, especially around speech and language. Our trustees do not have the necessary experience/ qualifications to lead these groups themselves and we continue to seek a professional partner to work with to increase the support we offer around early development.

Feedback

We continue to invite our members to give up feedback on the service we provide and invite input on ways we can increase the support we offer.

Some examples of the feedback received this year can be found at 'Annex: Feedback'.

Financial Review

The accounts filed are for the period 1 April 2024 to 31 March 2025.

When deciding upon the financial strategy for the year, the trustees reviewed the feedback received from members, the types of support that we want to ensure that we can continue to provide and the ways in which we want to increase or improve our services.

Having regard to the above considerations, the trustees set a budget set a budget anticipating a c.£7k loss; however, our actual loss has been £1k. The trustees have been delighted that income of £11k which has been a result of a number of successful grant applications and the generosity and support in fundraising efforts from the charities beneficiaries.

Policy on reserves

During this year the Charity has maintained a Reserves Policy explaining that reserves of £18,400 are kept being the basic costs of providing our core services for 12 months.

The Charity is currently holding £28,292 being £9,892 more than our current Reserves Policy. In view of our plans to improve our development support, which will involve set up costs and costs of regularly paying professional therapists, the trustees have taken a conservative approach to spending in anticipation of these increased costs. Once the trustees know what these costs will be, the Reserves Policy will be reviewed to reflect these increased operating costs and the reserves position reviewed generally.

Declaration

The trustees declare that they have approved the trustees report above on 7th July 2025.

Signed on behalf of the charity's trustees:

Signature:



Full name: Emma Louise Cross

Position: Chair of Trustees

Date:

7th July 2025

Signature:



Full name: Patience Saunders

Position: Trustee

Date:

7th July 2025

ANNEX: FEEDBACK

What do you believe the charity is doing well and what could the charity do differently to better support your child?

Excellent at raising the profile of the charity and educating medical staff. Also great at organising special events and providing a wide range of activities. Particularly good at supporting younger children with DS. Perhaps could provide a few more activities for older children

The regular preschooler groups are a great chance to meet with other parents, get support and develop friendships. The big events, like the Christmas party and WDS party are incredible - you put so much effort in to make sure they are smooth, accessible and affordable.

DP are supporting local families, especially with having the preschoolers group to welcome families when baby first arrives and also advocating for change with health care professionals. A lot is happening and I don't know how you all do it!

I like that the charity supports maternity services with the delivery of a diagnosis. And would love it if they could branch out to offer support to Paediatrics.

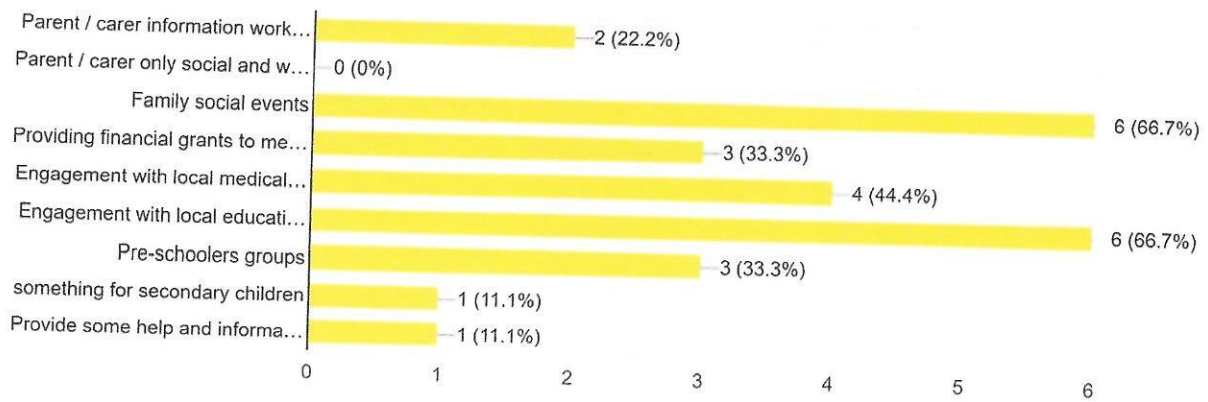
Lots of support and help for new parents of babies born with Downs Syndrome. Lots of events for more able children with Downs

charity is very creative and forward thinking - it would be nice to try and get older children together for events

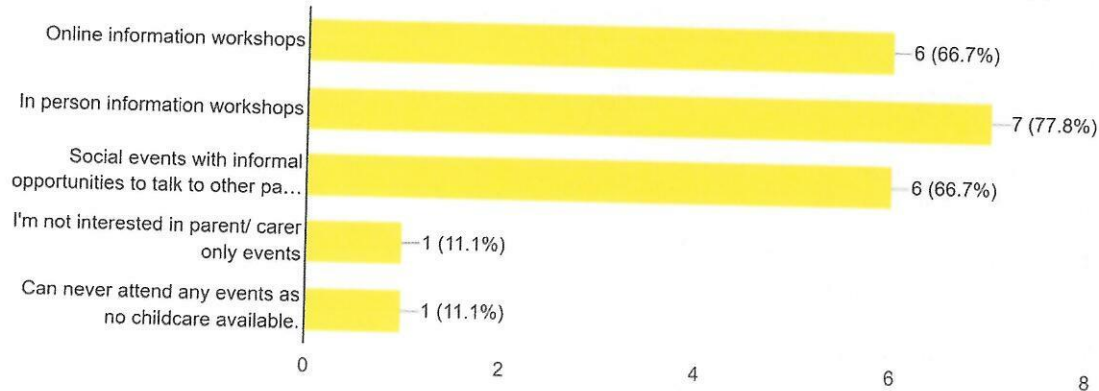
Working with midwives and social events for all ages and everything else

Working with midwives and social events for all ages and everything else

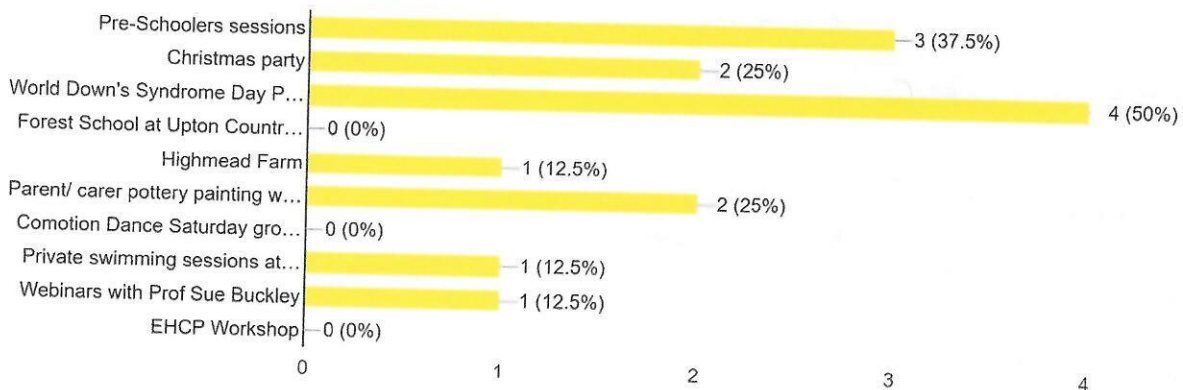
What would you like the charity to focus its time and funds on? (select max of 3 answers)



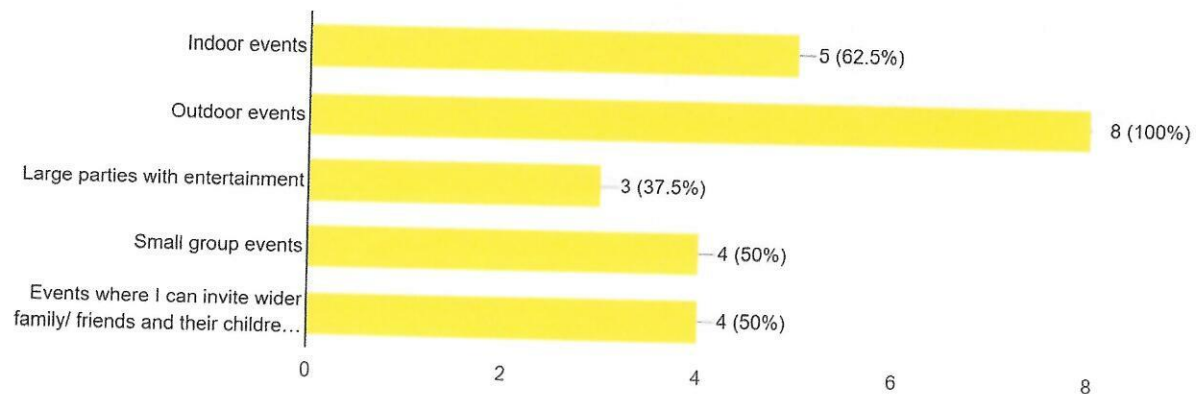
What type of parent/ carer only events do you prefer? (select all that apply)



What has been your favourite event the charity has run? (select max 2 asnwrs)



What type of events do you prefer? (select all that apply)



What do you think of the ticket prices for DRP events?



How has the charity helped you?

Offered support when I was in hospital

Support

By enabling us to meet up with other families and providing support to parent/carers.

Linked to Q1 - the comms with Emma and welcome pack we received in Ronald was fab and meant I knew when we eventually went home we'd have support/our new gang. Huge help around making changes for families with educating and empowering healthcare staff / supporting chief complainer over here! I've made friends who "get it" in a safe space and Oliver will grow up with buddies with extra chromosomes as well as buddies without - that's important.

not directly , but it gives me peace of mind that younger people with DS are well supported

The charity has helped me meet and develop friendships with other parents. This makes us feel part of a community. We can get support on the hard days and joke about things when we can. It's good to meet people who understand what you're going through and care about you and your family. Emma, Katherine, Claire and all the other volunteers are always so helpful and welcoming.

It's really helpful to be in touch with other local parents to anticipate things for the future like access to education.

Have previously very kindly been given gift vouchers to buy sensory toys for Ben and also been sent Christmas vouchers

100% supportive

What does having a local group mean to you?

It's important to feel not alone and have support.

Was much better when my son was younger

It means a lot as it means we're able to get to know other families in a similar situation and be able to share information and give and receive advice.

PADS are great but the local element of DP is much more personal (again, linked to other answers!) and a part of our daily (perhaps weekly?!) life

its good to know a group is advocating in the local area

It means we have a community- we have support and understanding from people who have similar experiences.

When Ben was small really enjoyed the monthly meet-ups local to us, as Ben has got older his additional diagnoses make meeting up really difficult.

To meet other families with us children

It's really important, links for parents, grandparents and children

What are the challenges you have faced or are currently dealing with?

None at the moment, but have had problems with Paediatrics taking me seriously when discussing Jasper

Safety

Challenging behaviour from child with DS but also from sibling due to having a sibling with DS.

Poor handling of diagnosis. Feeling like I'm going into battle whenever I need to advocate for O. The services seem to be there but it's just hard work eg booking the Covid jab - that's a local admin thing, all they needed to do was email round all surgeries /hospital etc so everyone knew where/how to book but instead I spent weeks (multiple times) going round in circles. Portage is great locally but the red tape is frustrating because other LA's have it from day 1 until school unlike the eight weeks here. Nothing new that I'm saying but better to support all the way rather than need to play catch up when there's a delay...! Biggest one I think, linked to advocating, is trying to word things so that I'm exploring what O needs whilst not telling people how to do their jobs - I don't expect them to know everything, they can't, but listen to me or look it up eg early doors I asked GP about the blood test for increased chance of leukaemia - he said there is no test to predict if you'll have it. He didn't know so that was that - nevermind the guidance oh and don't get me started on the guidance around low thresholds for antibiotics and infection "that's not a thing". Yes it is! Ok sorry, ragey ragey.

struggling to make friendships in (sen) school and in the down syndrome community, due to being an only child, and having communication challenges

Health problems - planned operations and acute admissions.
Not being sure for education decisions for the future.

Moving into adult services and losing all the people we know in terms of doctors, CAMHS support, social workers all at the same time is really difficult. Also sorting out financial benefits etc is so complicated with little to no help

Applying for school and EHCP

How to support our grandchild in the way to benefit him

Do you have any ideas for what the charity could do or have any other comments?

Perhaps by providing more advice re financial help and benefits available and providing a platform for sharing information about practical support eg. holiday clubs or other support available.

Thank you so much for all you do. You do a fantastic job !! Events are always so well-organised in a professional way. Thank you!

Just a huge thank you for all you do, we appreciate you all so much and you're genuinely making the world a better place for people with DS and their families. I've ticked include wider family/friends for events above as we have a few friends desperate to support by coming along but I'm mindful sometimes we need it as just the gang.

try to organise get togethers - maybe at the Treehouse - just for children with DS (to invite a range of ages).

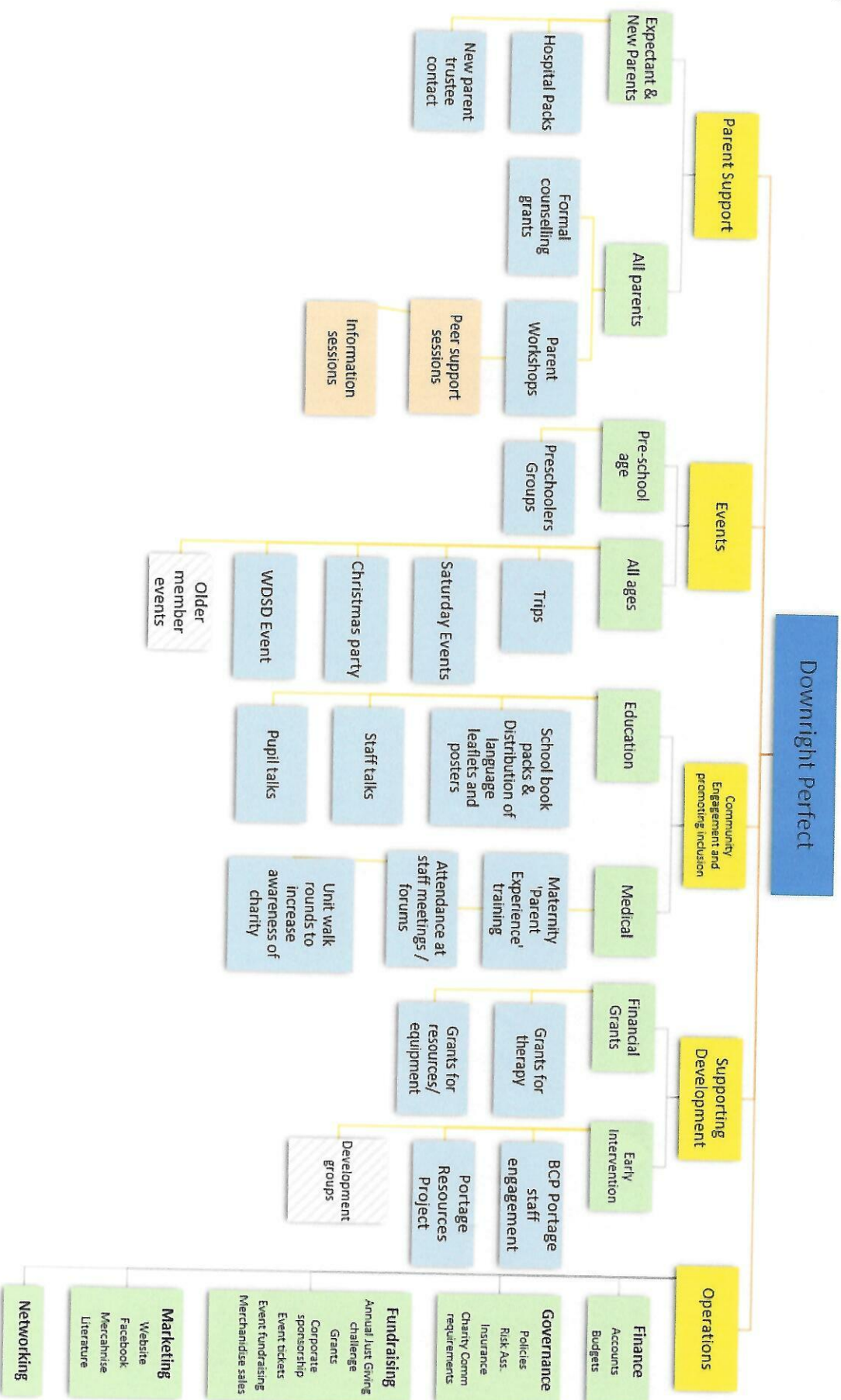
It would be helpful to know if any local solicitors or financial planners have experience with wills and trusts for dependents.

It would also be helpful at preschoolers to learn some more sign language if that's possible.

Music experience, maybe Bournemouth Symphony Orchestra small ensemble put on a short performance (they do community work). Or other small groups.

ANNEX: STRUCTURE

2





CHARITY COMMISSION
FOR ENGLAND AND WALES

DOWNRIGHT PERFECT

Receipts and payments accounts

For the period
from

01.04.2024

31.03.2025

**Charity
No.
1200893**

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
Receipts				
Transfer from charity 1159214	-	-	-	33473
Fundraising	4370	0	4370	5118
Donations	3651	0	3651	2102
Grants	2300	375	2675	5387
Event sales (tickets and awareness merchandise)	644		644	1392
Sub total (Gross income for AR)	10965	375	11340	47473

Total receipts	10965	0	375	11340	47473
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Payments


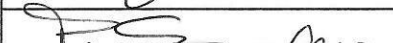
Bank charges	0	0	0	51
Governance	148	0	148	0
Xero software fees	168	0	168	0
Website / email	107	0	107	721
Volunteer expenses inc travel	204	0	204	170
Stationery / postage	205	0	205	92
Training	60	0	60	175
Awareness stock	395	0	395	934
Marketing / literature	761	0	761	1202
Fundraising expenses	523	0	523	169
New parent hospital bags	559	0	559	21
Parent support (inc events)	675	0	675	547
Pre-Schooler / Sat Club	0	1175	1175	1980
Resources / equipment	1368	20	1389	1620
Other initiatives (inc. sensory bags)	121	0	121	220
Engagement initiatives	432	0	432	0
School book packs	0	0	0	806
Other events (inc hospitality)	220	0	220	618
Annual Grand Day Out	405	0	405	812
Xmas (last years figure is for 2 parties)	1002	0	1002	1904
WDSD 2024	287	0	287	0
WDSD 2025 (last years figure is for 2 parties)	1751	0	1751	2378
Financial Grants	1462	0	1462	2977
Counselling Grants	0	0	0	180
Sundry	308	0	308	604
Sub total	11161	1196	12356	18181

Total payments	11161	0	1196	12356	18181
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Net of receipts/(payments)	-196	-821	-1016	29,291.71
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Transfers between funds	0	0	0	0
Cash funds last year end	25015	4277	29292	0
Cash funds this year end	24819	3457	28276	29.291.71

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
B1 Cash funds	Bank account	24819	3457
	Petty cash	0	0
		0	0
	Total cash funds	24819	3457
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
	N/A	-	-
B3 Investment assets	Details	Cost (optional)	Current value (optional)
	N/A	-	-
B4 Assets retained for the charity's own use	Details	Cost (optional)	Current value (optional)
	Soft play blocks, ball pit, foldaway playhouse and foam mats	-	-
	Various resources/toys used for pre-schoolers groups and other events	-	-
	Sound system	-	-
	Various awareness merchandise		
	See & Learn packs	-	-
B5 Liabilities	Details	Amount due (optional)	When due (optional)
	N/A	-	
Signed by one or two trustees on behalf of all the trustees	Signature		Date of approval
		Emma Louise Cross	28/04/2025
		Patience Saunders	28/04/2025

Notes

1. Accounting Policies

The financial statements of the Charity have been prepared in accordance with the guidance of the Charity Commission using the Receipts and Payments basis.

The Charity was previously an unincorporated association registered under number 1159214. An application was made to convert the Charity to a CIO and on 2 November 2022 a new charity number 1200893 was registered and on 5 April 2023 the assets of charity 1159214 were transferred to new CIO number 1200893.

The accounting period for charity 1159214 ran from 28 July to 27 July. The accounting period for charity 1200893 runs from 1 April to 31 March.

In accordance with Charity Commission guidance, following the conversion to a CIO, the first set of accounts covered the period 2 November 2022 to 31 March 2023. These accounts are now in line with our financial period but the figures for the last financial year are for the longer period referred to above and are not therefore a reliable comparison.

2. Restricted funds

The CIO has received the following grants which have been awarded for a particular purpose and are therefore treated as restricted funds.

Tesco Groundworks Grant of £1625 (£1250 received last financial year at £375 this year) for the running costs of Pre-Schoolers Groups and the purchase of some group resources. £429.50 of this grant was spent last year and the balance of the grant, £1195.50, has been this year.

Co-op Community Grant of £3761.60 for supporting the mental health of parents through the provision of counselling was received in 2023/24. £180 of this grant has been used leaving a balance of £3581.60.

3. Loans

During the year the CIO did not have a loan in place and;

- no one agreed to pay a loan if the CIO could not ('under guarantee')
- no loan was secured against the CIO's assets