This has been another busy and successful year for Ups and Downs Southwest. So many families have engaged with us, some old, some new. We have celebrated events and achievements together and shared experiences and solutions. Our Three Year Development Plan is now established and guides the direction of our work and the finances we need to apply for. It also establishes a baseline so that we can assess our effectiveness.

Jo Thorn  
Director

Jackie Lawrence  
Finance and Administration

Michelle Sugg  
Fundraising and PR Officer

Sue Anderson  
Team Leader

Lindsay Bailey  
Family Support Worker

Jackie Andrews  
Family Support Worker

Our Expert Team

Jackie Sims  
Family Support School Liaison

Sharon Windsor  
Family Support Worker

Maddy Glover  
Youth Worker
2018 - Our year at a glance

Our Services

- 324 instances of distant support
- 18 Clinic sessions offering information, advice and support
- Delivery of 6 Training Sessions for Parents and Professionals
- Supported the completion of:
  - 28 DLA Forms
  - 15 EHC Plans
- 9 New Baby Home Visits
- 12 new families registered and 52 home visits across the South West
- 34 Youth Club Sessions
- 3 Whole Family Events

Our Achievements

- New Logo and Branding
- New Website
- New Team Members
- New Trustees
- 3 Year Development Plan
- 65 more instances of distant support than 2016/17
- Increase training sessions delivered
- 50% more youth club sessions

Our Funding

- Sainsbury’s
- SPARK
- Inspiring Communities
- The Henry Smith Charity
- Higos
- somerset COMMUNITY FOUNDATION
- BBC Children in Need
The team continues to offer support, information and help to our families, how and when they need it and at their own pace. This work is unique in the South West and we know it makes a difference to the children we support because our parents and our partner professionals tell us so:

“I really don't know what I would do without Ups and Downs. Sometimes I find myself in a horrible dark place and they are always there. Not just on the phone, but they come to see you to tell you it's alright and there's a way through. Then they help you find the way through. They'll come with you to meetings and everything.”

(Parent of a four year old child)

“(W’s) PIP was approved at the highest rate for both mobility and care. Your contribution was massive and you completely took the stress out of the process for us. I would have needed tranquilisers to have done that alone! It is especially important for (W) as hopefully one day he can lead a semi-independent life and that payment will help towards it. I know there will subsequent applications in the future but the award is for 6 years so that is a wonderful start.”

(Parent)

Highlights of 2018/19

On page 3 you will see our ‘Year at a Glance 2018’, but I would like to draw your attention to one or 2 elements especially. The service offers initial contact and distance support and this is often a way for parents to make a first contact with the team, or to seek help in a crisis or a challenging situation which seems unsolvable. This year has seen 324 such telephone calls, 65 more than last year. Some enquiries may be solved quickly with up to date information or signposting, but some will need much more support to untangle and resolve. We are so proud of this vital element of the service. This year has seen 9 new baby visits. Our workers are able to offer a depth of understanding to new parents that is unparalleled in the South West. Often, years later, a parent will remember the impact that visit had on the life of their family. Another star element of the work of the team.

“We felt completely lost and overwhelmed, like we had failed as parents straight away. We were bombarded with medical facts that we just could not take in. We just wanted to know if our little girl would walk, talk, go to school, get married. The worker from Ups and Downs came to our home and let us ask all those questions and so much more; a true anchor in the storm and who has remained with us ever since.”
It seems that each month of this year has brought significant event as well as all the day-to-day elements of the service. Here, in a nutshell are some of them:

February 2018

We made a pitch at the nerve wracking “Dragons Den” run by SPARK

We were successful in winning £10,000 for the charity

March 2018

“Sensory Processing” training in partnership with BIBIC for parents and professionals, offering an opportunity for parents to network with one another and share experiences.

April 2018

Annual Easter Party

Supported by the Bridgwater Harley Davidson Group with easter egg donations and arriving on their bikes!
A team of our intrepid young people completed the difficult Jubilee Challenge. This involved a 8.2 mile hike across the rugged terrain of Dartmoor, an over night camp and 6 training walks!

Bringing free expert advice and guidance to parents in accessing rights and entitlements as well as supporting individuals to navigate some very specific and challenging situations.
July 2018
Annual Summer Picnic
Bringing whole families together for fun in the sun and strengthening those all important social networks.

August 2018
8th Annual Golf Event
Enmore Golf Club
Always a huge hit with our children and young people.

Enmore Golf Club generously hosted their eight annual Golf Experience for Ups and Downs Southwest. This community event raises our profile but more importantly, provides a different and exciting experience for our children and young people with a chance for hidden talents to emerge. The sausage and chip supper always goes down a treat too!”

September 2018
Successful Inclusion in Secondary School Training
Delivered by Alison Powell.

This session explored some of the discrepancies in the understanding of the often complex guidelines schools operate under, versus the expectations of parents.
October 2018
Post 16 Conference
Attend by post 16 services in education, training, health and employment, to share information and advice to support our young people 16+

November 2018
Communication for All Training
A bespoke 5 week training course for parents supporting their children’s communication needs.

“My son is looking directly at me and has already learnt to sign “thirsty” instead of screaming in frustration and lying on the floor. It’s almost like magic!”

December 2018
Annual Christmas Party
Always popular with a visit from Father Christmas and lots of fun and games.

This training course has been developed by Ups and Downs Southwest especially to support children and young people who have Down Syndrome who have difficulties with their speech. It aims to give parents and carers the skills and techniques, including signing, to support their child’s communication needs. Once we have secured funding, we are able to deliver this training wherever there is a group of parents needing to access it. One course with 12 participants costs just £1,500. That’s £125 per child to start a positive communication journey!
January 2019

Sexuality and Relationships Education Training Session
Delivered by Victoria Ralf

January 2019

Significant Funding News
HPC award us £100,000 over two years to work with families and schools in Somerset.

January 2019

Sainsbury’s of Billet Street, Taunton announce they have chosen us as their charity of the year! Great fundraising and profile raising opportunity.
Ups and Downs Youth Groups

Throughout the year we have continued to develop and run our two Youth Groups, one in Weston-super-Mare and one in Sherborne.
Meet The Board

The Board of Trustees oversee the governance of Ups and Downs Southwest. They are a group of volunteers who freely give their time to the service. They bring a wide range of skills and experience including education, safeguarding, adult training, health, paediatrics, mental health, finance, business, IT and the voluntary sector.

The Trustees oversee the budget ensuring responsible stewardship of public and charitable monies. They also work alongside the staff team to develop and monitor the effectiveness of the service.

They are committed to the work of Ups and Downs Southwest
Securing funding to continue this work, constantly occupies much of the Board of Trustees time.

We appreciate the work of all our volunteers whose tireless efforts help our money to go further. All of you who are Family Support Volunteers, who help out at events and indeed the Board of Trustees, who are also volunteers are invaluable to Ups and Downs Southwest. Your energy and talents enrich the work of the service so much.

To those of you who raise funds for us, who hold collecting tins, run coffee mornings, hold cake sales and who wear odd socks, your efforts are much appreciated - Thank you.

As we move into the future, we are confident that our relationships with our families will ensure that the service is always responsive to needs. We continue to challenge exclusion and promote inclusion, to support and enable parents, to give a voice to our children and young people and whenever we can, make a difference to the lives and achievements of children and young people who have Down Syndrome across the South West.

Sue Dennis

Chair of Trustees