Ups and Downs southwest

Year in Review

Down Syndrome Support
Children • Parents • Professionals

About Down Syndrome

Down Syndrome is a naturally occurring genetic difference, created by an extra chromosome. People with Down Syndrome do share some common physical characteristics, but each is a unique individual with their own strengths and weaknesses, individual character and personality, each influenced by their families, friends and communities – just like everyone else. No matter which type of Down Syndrome a person has (Trisomy 21, Translocation or Mosaicism), the effects of the extra chromosome will be unique to them. Everyone with Down syndrome has a learning disability; it takes longer to learn new information and master skills. But with greater understanding and inclusion, our young people can each fulfil their potential.

An Overview of our Services

Ups and Downs Southwest is a Down Syndrome support charity working with children and young people, their parents/carers and all professionals who offer education, health or social care support to children and young people who have Down Syndrome. Our service is delivered by a dedicated team of family support workers, school liaison workers, youth workers and a post-16 worker. We cover six counties, which include Devon, Dorset, Somerset, North Somerset, Bristol and Wiltshire.

A NOTE FROM OUR CHAIR OF TRUSTEES

It has been an honour and pleasure to serve as the Chair of the Board of Trustees for Ups and Downs Southwest for the last 15 months. The work of this charity is vital, now more than ever.

The Board of Trustees meets regularly to ensure the charity is well-run in line with its charitable objectives. We also review the finances and policies to ensure we comply with Charity Commission rules. Each member is a volunteer and brings knowledge and experience from backgrounds in banking, medical administration, educational psychology, social work and corporate management.

To be effective, we must have a thorough understanding of the actions and outcomes of the team's work. We receive a set of reports for each meeting. This includes information on the work undertaken in education, health, behavioural support, or social care; and assistance with completing education, health and care plans, or Disability Living Allowance applications. We also review case studies.

Being Chair has allowed me to witness first-hand the professionalism of the team and the impact they make on so many children and young people with Down Syndrome and their families. I have seen many examples where their work has produced truly life-changing outcomes. Joanna Thorn, our Director, is a consummate professional, leading the team with passion and dedication. Every member of the team, including full and part-time employees in Somerset and Bristol, and our Volunteer Befrienders, plays a valuable role and brings enthusiasm, empathy and expertise to their work. Their experience and knowledge is evident in the outcomes they deliver. I am constantly impressed by their work.

The past year has seen the expansion, delayed by Covid, of Ups and Downs' service into the Bristol area. It's now flourishing and accounts for just under half the work undertaken by the charity as a whole – an amazing feat in such a short time! Our Bristol team has added to the strong, established team we have in Somerset.

We have also put in place our Post-16 service, helping families navigate the options available and working with educational professionals and establishments to support our young people. I've seen testimonials from families supported by this service, which demonstrate how our team empowers and supports them.

Ups and Downs Southwest is my first experience of working in the charity sector, and I have been ever-conscious of the responsibility I and the Board members have. This is a difficult time as fund-raising becomes more challenging. With this responsibility has come the opportunity to work with the wider team of dedicated people that form Ups and Downs. I would like to thank them all for their support, commitment, and enthusiasm over my time as Chairperson.

I'm glad to welcome Louise Bliss as our new Chair of Trustees. Louise is the perfect candidate to take Ups and Downs Southwest into 2023 with her track record of successful leadership and charity sector experience, She also runs her own strategy consultancy and has personal experience of Ups and Downs' services, as she has a young child with Down syndrome. I know Louise will bring fresh enthusiasm to Ups and Downs Southwest. Onwards and Upwards!

Jade Hunt 2022 chairperson

Distance Support

We offer distance support to any parent/carer who needs it across all six counties in which we work. Many of our families do not require ongoing, regular support, but from time to time may wish to seek advice or guidance on a particular topic or issue.

Knowing that they can contact us at any time, be it by telephone, email of social media, to fire off that quick question, can really make a difference. Sometimes they just need to know we're there.

"I know that whenever I ring, or email, a member of the Ups and Downs Southwest team will always come back to me and quickly too. It gives me great confidence and comfort to know this as it seems life with our young man is a bit of a roller coaster – just when we think we have cracked one challenge, we are off again on another adventure".

The most common trends and themes listed under our Distance Support offer are in relation to education, behaviour, sleep, diet, and communication. Our dedicated family support and school liaison team carry a wealth of knowledge and experience between them and can offer reassurance, practical advice, and plenty of encouragement. Our goal is for parents/carers to feel empowered and confident in their role as care-givers and to have the utmost faith in their own abilities.

"Thank you (A) for the time you spent with me the other day; being able to discuss (J's) sleeping issues with someone who really gets it has been such a relief! We will be trying out a few of the techniques and will let you know how we get on."

During 2022 we delivered 852 counts of distance support to families across Devon, Dorset, Somerset, North Somerset, Wiltshire and Bristol. 273 counts were just for the Bristol area, offered by our dedicated Bristol team.

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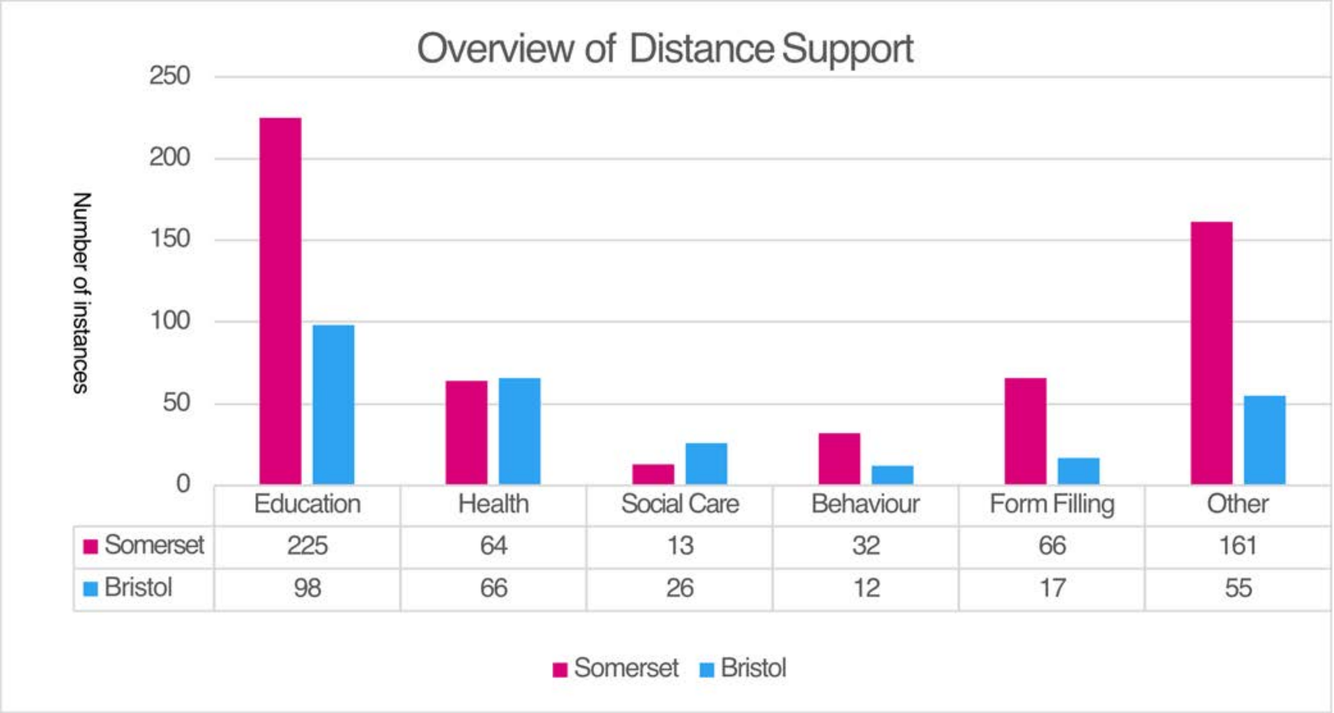
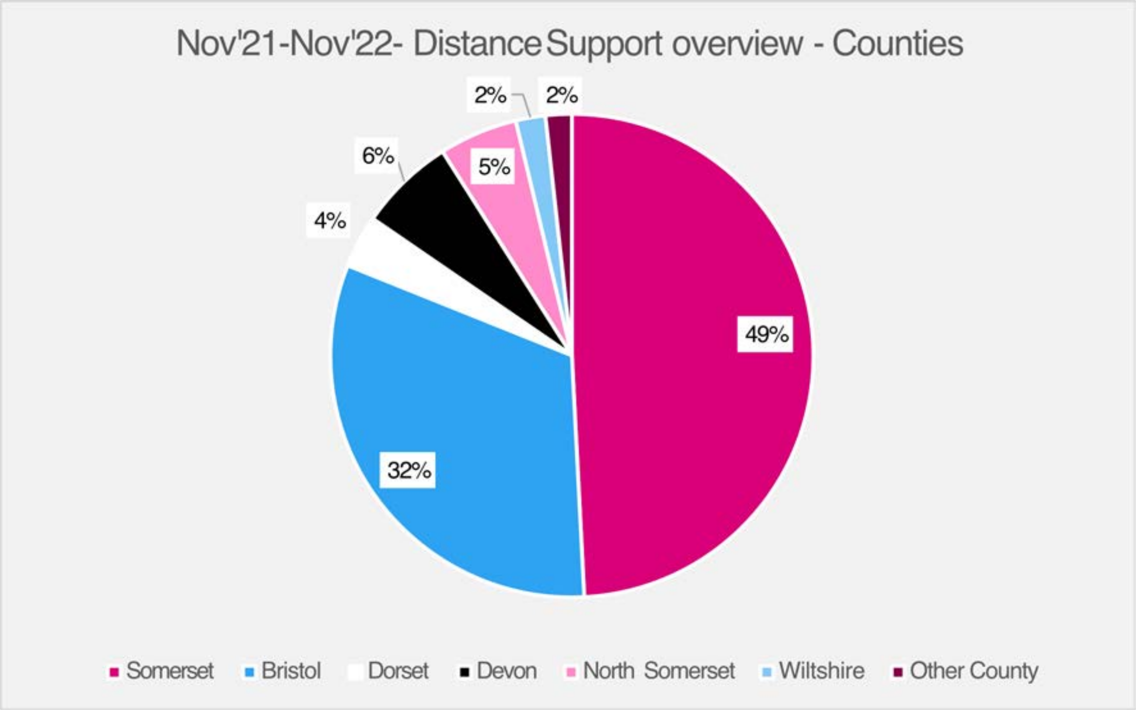


	Education	Health	Social Care	Behaviour	Form Filling	Other
■ Somerset	225	64	13	32	66	161
■ Bristol	98	66	26	12	17	55



Our major topic under distance support is in relation to education, with a total of 323 individual counts of request for support, information and advice.

The County of Somerset accounts for 49% of enquiries, with Bristol coming in with the second highest count at 32%.

New Babies

Statistically, one in every 1,000 babies will be born with Down Syndrome.

During 2022, 15 new babies registered with our service from across all six counties we cover. Seven of these babies are in Bristol alone.

Our aim is to engage with families right at the beginning of their journey and in many cases we have engaged with a family within the first 48 hours of them receiving a Down Syndrome diagnosis.

“Thank you for all the support and care you offer to us all; dealing with the challenges we face and knowing there is someone there who can offer support based on real-life experience is utterly invaluable; you understood the grief and tears, didn’t judge and offered an honest and balanced view of the future of our daughter”.

Receiving a Down Syndrome diagnosis can come as a shock for many parents and in the early stages, there are many questions to be answered and fears to overcome. Unfortunately, for some parents, the whole experience can be incredibly negative at the point of diagnosis.

> *“Thank you for all the support and care ……dealing with the challenges we face and knowing there is someone there who can offer support based on real-life experience is utterly invaluable….you offered an honest and balanced view of the future of our daughter”.*

Whilst the medical side of things is well explained, it is not always balanced with insight from the social model of disability. We aim to quickly offer a balanced view, ensuring that the medical side is fully understood, as well as looking at the social aspirations and potential achievements, along with possible challenges.

Because we carry over 25 years of experience, we are able to offer real assurance to parents and confidently answer their questions; setting them off on a positive pathway to ensure they are able to enjoy those early stages with their new baby.

New Referrals

On top of our new babies, we have welcomed a further 40 families to the Ups and Downs Southwest family during 2022.

This is an increase on 2021 due to a raised profile, families moving into our area, and an increase in the services we can offer and with which families wish to engage. We have been proud to be able to support several families who’ve relocated to the UK, including asylum seekers from Afghanistan.

Families in general will engage with us for a whole host of reasons. Some are looking for information and advice, many are looking to increase their social network and, for some families, they are facing multiple, complex needs and are seeking more in-depth support.

The support we offer includes:

- Emotional Support
- Information and advice
- Support with form-filling, such as Disability Living Allowance (DLA), Personal Independence Payment (PIP) and Blue Badge Applications
- Support with communication tools and development
- Support with Education
- Practical help through our Volunteer Befriender Programme
- Annual training programme covering topics such as behaviour, sleep, toileting, speech and language, sexual relationships and education in general
- Intensive, 12-week support plans

During 2022 we worked directly with 200 families across Devon, Dorset, Somerset, North Somerset, Bristol and Wiltshire.

12-Week Plans

12-week plans are offered where it is identified, through an assessment of need, that a family is dealing with multiple, complex issues. These issues may be directly linked to Down Syndrome, or to other factors such as parental mental and physical health, social and economic issues, severe isolation, complete lack of social support network, or severe health issues within the family. In short, issues which may push a family to breaking point.

In partnership with the parents/carers, a 12-week plan is drawn up and is then delivered by a Family Support Worker, a Volunteer Befriender, or both. The plans are designed to provide practical sessions which will arm parents with the tools, knowledge and insight to manage their situation, all backed up by emotional support through careful listening.

During 2022, we worked with 8 families through 12-week plans, several of which were extended for a second period.

12-week case study

Joshua is a young man whose family asked for assistance from Ups and Downs Southwest and his parents kindly agreed to be interviewed about the family's experience of the 12-week support programme:

Q Why did Ups and Downs get involved/what support were you seeking?

A Our son Joshua has some fairly extreme behaviours and, as a family, we were at the end of our abilities to work it out on our own and we weren't getting anywhere. We were effectively at breaking point and wanted to seek the help of people who had helped us before and to see if there was anything more that could be done, by people with professional experience of children with Down Syndrome.

Q What was the experience like when first making contact with Ups and Downs?

A As with each time we have contacted Ups & Downs in the past, the first contact was friendly yet professional and we were made to feel validated in our situation and that no matter what, it was okay to feel how we felt.

Sometimes it's not easy reaching out for help, but we were put at ease very quickly.

Q How did the journey with our service progress?

A Ups & Downs were able to offer us a Family Support Worker to visit initially, to try and understand our difficulties. After that initial visit, a 12-week support programme was offered to us; not just for Joshua, but for us as a whole family. The support worker understood that the situation we found ourselves in was not only affecting Joshua, but our whole family. We were given assistance with trying to understand what Joshua was feeling, why and what he was doing to try and help himself.

Our support worker offered us documentation and assistance with techniques on how to try and cope with some of Joshua's behaviours; on how to dissuade/distract him from them. For example, something as simple as letting him go and run it off, which may seem simple, but when you are entrenched in it and experiencing it, it's not always that easy.

We worked together to find things that we thought may help Joshua. A prime example of this was making a 'morning routine' sheet for our living room door. That gave Joshua visual representation of what was going to happen, the order in which it was going to happen, and also got him involved in removing each 'task' from the sheet as it was completed, allowing him to feel in control and involved in what was happening.

Other helpful items, such as going out for a short walk with us, creating an 'activity bucket' which engaged both children, making huge bubbles in the garden, for example. These were all things we would feel were too difficult, but given the 'outside the goldfish bowl' approach of the worker, she could see things that we simply could not. As for us, it was difficult to take a step back.

Having someone outside to talk to was huge for us, as while we have family to support us, it's been lovely to have someone else to speak to, to bounce ideas off and receive suggestions outside that fish bowl that we maybe couldn't see: Just knowing someone is there for us.

Our support worker was always open to offering to help us with school meetings, to be copied into emails to support us from a professional capacity, and to help us to gain access to answers and provide guidance on what we should be able to achieve as an outcome to certain situations. She was always offering advice, from a sometimes unique perspective.

The support worker continued to provide us with validation of our position, over and above the initial contact we made – this made us feel confident and comfortable in what we were being told/shown.

Q What specific difference did our support make?

A Understanding that we were doing everything that we could do and that we really did need some more help. We try to understand why Joshua's behaviours are as they are, or what has triggered that particular behaviour and accept that what he feels is real when we don't understand what is happening for him – whilst not always easy, knowing that we were trying really helps. Having the support when working with the Council/medical professionals – always knowing that there's someone there to back us up – makes a huge positive mental difference for us.

Q What would you say to any other family thinking of reaching out to us?

A Don't hesitate to ask for help or to ask a question. Know that it is alright to ask for help.

There is someone else out there to talk to – don't feel alone.

Education

Across the service, we have three members of the team who carry an educational specialism. Those team members work with parents in relation to their child's education, educational

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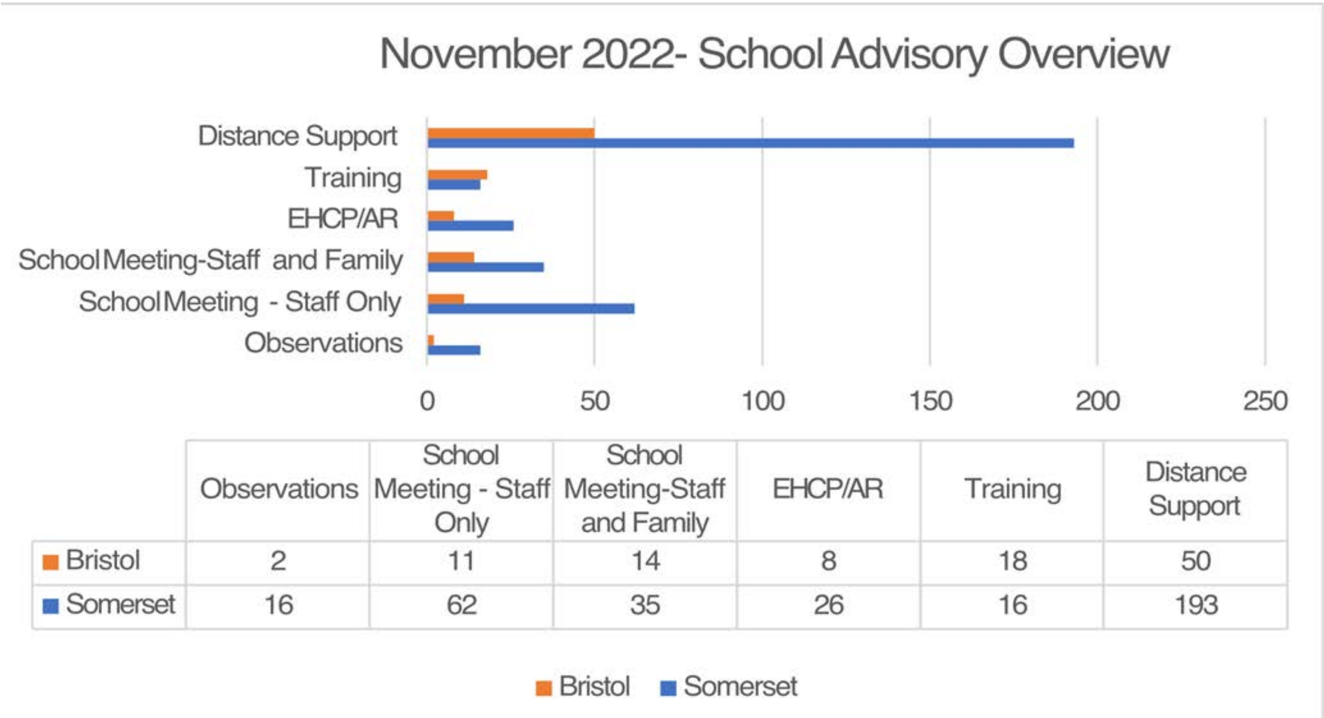
November 2022- School Advisory Overview

	Observations	School Meeting - Staff Only	School Meeting-Staff and Family	EHCP/AR	Training	Distance Support
🟧 Bristol	2	11	14	8	18	50
🟦 Somerset	16	62	35	26	16	193

settings – both mainstream and specialist – and will liaise between parents and educational settings to assist in achieving successful school placements for pupils with Down Syndrome.

This offer includes:

- Pupil Observations
- Attendance at key meetings
- Support with writing Education and Health Care Plans (EHCP)
- Training Packages

Pupil observation

> *"Thank you so much for your report on (S) - it is all really useful. Following your visit, we have changed his TA to having (SH) with him more often. His behaviour has already improved and so has staff morale!"*
>
> *CH Special Educational Needs & Disabilities Co-ordinator,*
> *Chew Stoke Church School*

Training feedback

Here are some comments from people who attended the training:

- The training was amazing.
- The strategies for approaches that can be used in English were very helpful.
- I like the idea of using the child in photos for their visual timetable. I will certainly be doing this.
- It was helpful to see and understand the information on reduced visual acuity.
- The training contained lots of useful and practical ideas.
- I will try using the Post-It notes to sequence sentences and the top and tail sentences to support sentence construction work.
- I now feel so much more confident in supporting the child in our school.
- I thought the training was excellent as there were so many practical ideas we can try out straight away.
- I loved the 'Blue Peter' example.

New Post-16 Service

During the latter part of 2022, we launched our new Post-16 service. Being currently trialled in Bristol only, the service has been designed to support young people who have Down Syndrome aged 16 to 25 with their post-16 educational choices and pathways.

We were hearing from parents that when it came to supporting their young person with their further educational choices, there was very little available by way of information and advice and even more worryingly, a really diminished pool of options available, compared to those young people without Special Educational Needs.

Our post-16 worker has been tasked with engaging with young people early to support them to consider their educational future, work with their parents to support the encouragement of their young person choices and work with educational settings to ensure a wider choice of options and support a smooth transitional pathway into the young person's chosen setting. The post-16 educational system is complex for Special Educational Needs (SEN) and we hope, through our service, to be able to ensure that the young person remains at the centre, has their voice heard and their vocational choices supported.

During the last quarter of 2022, we registered three young people onto this programme and all three of them have been intensively worked with in order to support their post-16 choices.

Post-16 family story

I engaged with the post-16 service at Ups and Downs Southwest because I was feeling overwhelmed and daunted about the future for my daughter.

All the parents at a Box Fit class which my daughter attends were telling me I had to have a five-year plan in place and so when I heard that Ups and Downs had a new Post-16 Service I said 'Yes please!'.

I really needed some help and guidance from someone who knew the options of what was out there. It has been so helpful to have someone on the journey with me who can help me to consider all the options, someone to talk things through with who knows the process. I have really valued the unbiased support.

It was really easy when I first made contact with the service. The support worker made me feel really at ease. I was hugely anxious before the meeting as I felt a massive pressure to make the right decision but afterwards I felt that there was light at the end of the tunnel and that I had shared a burden. I felt that I was not alone with this.

At the first meeting we talked about the journey ahead; the pros and cons of the various options; logistics such as transport; practical stuff. We discussed the options out there and we created a shortlist of possible post-16 settings. The worker has accompanied me on visiting these settings which has been really helpful as she knows the right questions to ask and we could discuss them afterwards in detail.

My aspiration for my daughter is that she can be the best that she can be. I have tried very hard to give her lots of insights into different fields of her life so she can make decisions about her life based on what she has done.

I hope she can live independently; a normal-ish life. She could still live at home but, for example, she could have her own keys and travel on her own to her sister's house. I would like her to contribute back to society, either by doing voluntary work, or in a paid job.

My daughter would like to learn to drive, so I'm looking for courses where she could learn off the road.

CONTACT

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