



Downright Special Update – December 2023

Welcome to our last update for 2023! In this issue you'll find updates and info on:

- Downright Special Social Events
- Coffee & Chat Sessions
- Dance Survey
- Training
- Downright Special Friday Groups
- Health
- Down Syndrome with Complex Needs
- Preparing for Adulthood – Decision making post-16
- Fundraising

Christmas Break

Although Friday sessions are finished until January 12th and our staff will be having a well-deserved break from Friday 22nd December, we will continue to monitor the office emails, phone messages and social media. If you need any information or support, then please do get in touch. There might be a short delay in getting back to you, but we will do our best to help!

Email office@downrightspecial.co.uk, phone 01482 420160 or ask questions in the closed Facebook group for parents/carers: <https://www.facebook.com/groups/DownRightSpecialNetwork>.

We will be back in the office week commencing 8th January.

Downright Special Social Events

Since our last newsletter we have enjoyed our Halloween Dance Parties at Swanland Village Hall with Joanna from The Little Yorkshire Dance Academy, a lovely Christmas Crafts event and of course the event of the year – our Christmas party! We hope that you have all had the chance to enjoy at least one event in 2023 and if not, we hope to see you at one in 2024.

We've continued to send out social stories before events and we've been using the events checklist created from the work of our parents' complex needs group but please do give us a call if you'd like to chat about other adjustments that might be helpful for your child or young person.

Events Round-Up

Saturday 20th January– Ten Pin Bowling (ages 4-25).

11am-1pm, Hollywood Bowl, Hull

Book here: <https://www.ticketsource.co.uk/downrightspecial/t-vvkegex>

Saturday 3rd February – Sensory Makaton Story Time (ages 4 and under)

10.30am -12 noon at Bodmin Road Church, Hull

Led by Emma Thompson, Makaton Tutor from Handmade Voices.

Available to book soon!!!

We are currently finalising the event calendar for the full year so watch this space for news of further socials!

Coffee & Chat

Our coffee and chat sessions are a relaxed morning where parents and carers can get the chance to chat over coffee. Some of our staff members are usually on hand too to help with any issues or questions families may have.

Dates for next year:

Thursday 22nd Feb 2024 and 23rd May 2024

9.30am-11.30, Bodmin Road Church

No need to book but it would be helpful if you can let us know if you are coming so we have an idea of numbers.

Babies and under 5s not at school or nursery are also welcome to come along. Just let us know in advance so we can set up a play area with some toys!

Dance Group Surveys

Thank you to everyone who completed one of our surveys to gauge interest in setting up a regular dance session for our young people aged 11-25.

We had 18 parents complete the parents/carers survey and 8 young people who completed the Easy Read Survey. It was so lovely to hear what the young people themselves thought. We also got feedback that they loved being asked to fill in their own survey.

The responses showed that:

- There is definite interest in a regular session with 17 out of the 18 respondents interested
- There were some suggestions about the timings of sessions that we need to think about
- In both surveys it seemed most were not bothered either way about inviting a friend
- Around half of the respondents preferred parents to stay on site.

Next steps:

- Working up costings for regular sessions and a funding plan
- Decide on venue/timings
- Talk to Down Syndrome dance groups in other areas to get tips for running sessions

Hopefully we can give you more news early in the New Year!

Downright Special Training

Our Spring term training programme is now available to book. Although many of these courses are aimed at school staff, parents are very welcome to attend these too.

All courses and information sessions can be booked here: www.ticketsource.co.uk/downrightspecial

Downright Special Education Training	
Thu 25 Jan 2024, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome (all Key Stages)- Teams online course
Thu 8 Feb 2024, 3:45PM - 5:45PM	Teaching Maths to pupils with Down syndrome: Numicon Firm Foundations and the Maths Mum
Wed 28 Feb 2024, 3:45PM - 5:45PM	Teaching Maths to pupils with Down Syndrome: Numicon Breaking Barriers and the Maths Mum

Don't forget we also offer INSET training to nurseries and schools. Check out our website for more information. <https://www.downrightspecial.co.uk/inset>

Downright Special Fridays

You may have noticed that we have had quite a few visitors to Friday morning recently. We have been really pleased that, through our work with Dr Highet (Consultant Paediatrician) and Kate Woodrow (Advanced Nurse Practitioner) from the Community Paediatric Neurodisability Team, we have now had some trainee paediatricians come to see what we do and learn more about the charity.

We have also been pleased to have visits from trainee health visitors and new portage workers. Continuing is visits from new Speech and Language Therapists as part of their induction to Humber NHS Foundation Trust.

Thank you to our Friday families for accommodating all our visitors.

Dates for next term (morning groups):

January 12th, 19th, 26th

February 2nd, 9th

February 16th NO GROUPS (Half-term)

February 23rd

March 1st, 8th, 15th, 22nd

Our team put a lot of time and effort into preparing resources, so please email us on office@downrightspecial.co.uk as soon as you can, or give one of us a call/text if you are unable to attend a session. We do ask that you do try your best to attend every session please. Many of the

activities within lessons are repeated and built on from one session to the next, so the children will make more progress and probably enjoy the sessions more if they regularly attend.

Health

Down Syndrome Care Pathway

Sam is well underway with this year's updates to the Care Pathway with the Health Visiting information now complete. She is now working with SaPTs and iPASS to update their sections. (These are the local authority outreach sensory teaching services for physical, hearing and vision). The revised pathway will be published on World Down Syndrome Day, 21st March. You will find the care pathway here: <https://www.hullccg.nhs.uk/downsyndromehull/>.

If anyone would like to share their experiences of any of these services, please get in touch by emailing sam@downrightspecial.co.uk or chatting to her on a Friday in person or phone.

In November there was a Joint CQC/OFSTED inspection of SEND services in Hull and we were invited, along with Dr Lorna Hight and Kate Woodrow from the Community Paediatric Neurodisability Team, to talk to one of the inspectors about the Care Pathway. It was good to be able to showcase the excellent work that has been done so far but also to be able to highlight where there is more that could be done to improve access to health services and reduce health inequalities for people with Down syndrome in our area.

Down Syndrome and Complex Needs

We have been steadily working our way through the complex needs action plan that came from the working group of parents. We have divided the work into four topic areas: Social events, Fridays, Training, and Information & Advocacy. Here's a summary of the actions already done or underway. Other longer-term actions are on the action plan.

Social Events

- Complex Needs checklist for venues was developed and has been used very successfully for the last few events. We also invited a parent to help assess the venue for the Christmas which was very helpful.
- Plan repeating events within and across years in safe/familiar places with same routine. This what we have done for 2023 and have planned to do in 2024.
- Social stories have been written in advance of each event.
- Venues with multiple rooms for social events to cater for different needs. We did this for dance sessions and the Christmas party, both of which had quiet rooms available.

Fridays

- "All about me" forms completed/filed and kept up to date (annually or if something changes).
- Reasonable adjustments made for teaching sessions and info shared/flagged with social event organisers where relevant if adjustments would help there too. For each Friday the teachers jointly plan the themes and activities, making adjustments for each child's individual needs.

Training

- An audit of all our training courses is underway to check content is inclusive of complex needs. Our Intro to DS training has already been revised over the last few years to make more mention of DS and autism or complex needs.

Information and Advocacy

- Encourage families to share top tips/useful opportunities about things that are helpful for their child with complex needs. We have been regularly posting in the closed Facebook group for parents, this newsletter on resources and information available.
- Awareness week – choosing topics that celebrate all children with Down syndrome and ensuring we have a range of children represented in our posts.

Preparing for Adulthood – Decision making post-16

At the December meeting of the DSA Affiliated groups meeting, some useful information was shared on decision making once your young person turns 16.

- You Tube Video: Who Decides? Decision making from 16 years
<https://www.youtube.com/watch?v=gGdujmDVUKk&t=7s>
- Fact Sheet: Making everyday financial, health and welfare decisions post 16
<https://www.downs-syndrome.org.uk/wp-content/uploads/2021/04/Making-Decisions-post16.pdf>
- Fact Sheet: Decision making and Lasting Power of Attorney https://www.downs-syndrome.org.uk/wp-content/uploads/2022/05/LPA-Factsheet_.pdf

They also recommended that the 'go-to' document for guidance on the Mental Capacity Act is the MCA Code of Practice and in particular Chapter 12 on MCA and Young People.

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

[Paradigm UK](https://www.paradigm-uk.org/wp-content/uploads/2023/01/Print-copy-2023-MASTER-Supported-Decisions-Making-booklet-27-September-A5_Wiro_Bound_SEB.pdf.pdf) have also published this excellent booklet for parents, carers, or anyone else on how to support someone with a learning disability to make their own decisions. https://paradigm-uk.org/wp-content/uploads/2023/01/Print-copy-2023-MASTER-Supported-Decisions-Making-booklet-27-September-A5_Wiro_Bound_SEB.pdf.pdf

DSUK Facebook Groups

Down Syndrome UK <https://downsyndromeuk.co.uk/> led by Nicola Enoch, is the organisation for a number of initiatives you may already have heard of such as:

Positive About Down Syndrome for new and expectant parents

ST&R - support, training and resources for parents and professionals of primary age

Pants4School – toilet training

The DSUK Network – local support groups network (which we are part of as Downright Special).

The also host a huge number of **online support groups on Facebook** for parents or professionals on a range of topics including for Dads, toilet training, Muslim Mums, Maternity/Midwives, NG Tube Feeding, Bilingual Families etc. You can find the full list on offer here:

<https://downsyndromeuk.co.uk/about-dsuk/support-groups/>

Lending Library

We have a huge range of books and resources that you can borrow from us.

Our entire catalogue can be viewed online. You can browse for books and resources and then request/reserve the ones you'd like to borrow. Books can be borrowed for up to four weeks.

Email louise@downrightspecial.co.uk to request library login details or to request a pdf version of the catalogue.

Easy ways to support Downright Special

Sign up to Easy Fundraising

Easy Fundraising is an online shopping directory which features major online stores, including eBay and Amazon. Visit www.easyfundraising.org.uk whenever you shop online and we'll receive a free donation of up to 15% from every purchase you make and it won't cost you a thing! We've had a few new people sign up to this recently and we are so grateful for the support!

Amazon Wish list

You could purchase items from our **Amazon Wishlist**. This list is regularly updated with items we need such as stationary, specialist books, resources for Fridays or items for events. https://www.amazon.co.uk/hz/wishlist/ls/1PGPTF1B55IEW?ref=wl_share

Suggestions and Ideas

If you wish to chat about anything in this update, have suggestions or ideas for events, training or support you would like, or you'd like to pass on any tips, please do get in touch.

Have a very Merry Christmas and a Happy New Year.

We will see you in January!