



## **Downright Special Update – May 2023**

Welcome to our latest half-termly update! In this issue you'll find updates and info on:

- Staff & Volunteer News
- Social Events including our Summer Fundraising Walk & Picnic!
- Training for Parents and for Schools
- Downright Special Friday Groups
- New Health Resources (eye conditions and paediatric reviews social story)
- Complex Needs
- Building a Bright Future Preparing for Adulthood
- Listening Services
- Fundraising

### **Staff & Volunteer News**

---

Welcome to our newest volunteer Lisa Bell! Lisa has recently joined us as a volunteer supporting the smooth running of our social events. She will be working alongside current volunteer Toni Bullock to help make sure our children, young people and families can enjoy our events as much as possible.

This term we also welcome sixth-form student Rhianna to our Friday morning sessions. Rhianna is on work experience with us from now until end of term as part of her Health & Social care studies.

### **Downright Special Social Events**

---

Since the last update we have enjoyed our Easter Egg Hunt, the East Riding Bikers Easter Egg Run, a visit to Circus Starr and trips to Hollywood Bowl. We also held another parent/carer 'coffee and chat' session, this time with guest speaker, Katie Catchpole from East Riding SENDIASS. We've continued to send out social stories before events 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**

##### **Sunday 2<sup>nd</sup> July – Teddy Bears Picnic Dance Party for Ages 0-11**

- 12.30pm-1.45pm, Swanland Village Hall
- Led by Joanna of The Little Yorkshire Dance Academy
- Biscuit decorating, crafts and a dance session
- Please book here: <https://www.ticketsource.co.uk/downrightspecial/t-xmyrvzg>
- Bookings close on 27<sup>th</sup> June. Sorry no siblings on this occasion.

### **Sunday 2<sup>nd</sup> July – Youth Club Dance Party for Ages 11-25**

- 2.00pm-3.15pm, Swanland Village Hall
- A dance session with Joanna of The Little Yorkshire Dance Company
- Biscuit decorating & crafts
- Bring a friend!
- Please book here: <https://www.ticketsource.co.uk/downrightspecial/t-ojvqlqj>
- Bookings close on 27<sup>th</sup> June.

### **Sunday 9<sup>th</sup> July – Family & Friends Summer Fundraising Walk & Picnic**

Come and join us for a summer get-together at East Park, Hull. We'd love to see lots of our families and friends there!

- arrive 9.45am for a 10am start
- 30 minute leisurely walk around the park following a planned route (buggies, wheelchairs and scooters welcome)
- All children and young people will receive a goody bag, medal and certificate at the finish line.
- We will be making a day of it with a picnic and play in the park afterwards
- Sign up today!! <https://www.ticketsource.co.uk/downrightspecial/t-avyoann>
- The first 30 people to sign up, will receive a FREE Downright Special T-Shirt to wear on the day. Additional T-Shirts can be purchased when signing up for £8.00 each. T-Shirt sizes are from children's 3-4 years - adult 3XL
- All ages welcome! Any questions email [louise@downrightspecial.co.uk](mailto:louise@downrightspecial.co.uk)

\*\*\*\*\*SAVE THE DATES\*\*\*\*\*

### **Sunday 17<sup>th</sup> September – Youth Club Pizza-Making Party for ages 11-25**

11am-1pm, Ask Italian, Hull

### **Saturday 23<sup>rd</sup> September –Soft play & Pizza Party for Ages 0-11**

10am-12pm, Monkey Bizness, Hull

### **Saturday 11<sup>th</sup> November – Christmas Crafts for all ages**

10am-12pm Darby & Joan Hall, Cottingham

### **Sunday 10<sup>th</sup> December – Christmas Party**

12pm-3pm, Lazaat's, Cottingham. Bookings open in October.

## **Downright Special Training**

---

Our Summer 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.

This term we also have three sessions aimed specifically at parents on Puberty, Toilet Training and The Mental Capacity Act, Lasting Power of Attorney & Deputyships.

All courses and information sessions can be booked here: [www.ticketsource.co.uk/downrightspecial](http://www.ticketsource.co.uk/downrightspecial)

<b>Downright Special Education Training</b>	
Wed 14 Jun 2023, 3:45PM - 4:45PM	Preparing for Successful Transition – Teams online course
Wed 28 Jun 2023, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome - Teams online course
Wed 12 Jul 2023, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome - Teams online course

<b>'Parent Power' Training and Information Sessions</b>	
Saturday 10 <sup>th</sup> June 2023 1pm-3.30pm (approx.) Bodmin Road Church	Supporting a safe and healthy puberty for teenagers with Down Syndrome – delivered by Nicola O’Riordan and Sam Findlay
Thu 15 Jun 2023, 9:30am - 12:30pm Bodmin Road Church	Toilet Training for Children with Down Syndrome (all ages), Bodmin Road Church, Hull – delivered by Laura Nichols and Gillian Bowlas
Wed 21 Jun 2023, 7pm-8.30pm Online via Teams	Planning for the Future: Mental Capacity Act, Lasting Power of Attorney & Deputyships - Teams online information session, led by Paul Mounce of Gosschalks Solicitors

## Downright Special Fridays

A reminder that any parents are welcome to pop in to see us on a Friday morning, even if your child has never attended or has outgrown our sessions or only comes to the afternoon groups. You can come just for a cuppa or to ask our staff for some help and advice.

If your child doesn't currently attend and you would like a place, then please do get in touch and we will see what we can do. We have already started the enormous task of planning the groups for September so please let us know if anything has changed for you.

Dates for next term

June 2nd – no group (half term)

June 9<sup>th</sup> – no morning groups (staff training)

June 16<sup>th</sup>, 23<sup>rd</sup>, 30<sup>th</sup>

July 7<sup>th</sup>, 14<sup>th</sup>

If your child attends fortnightly or attends an afternoon session, you will receive a separate email confirming dates.

*Our team put a lot of time and effort into preparing resources, so please email us on [office@downrightspecial.co.uk](mailto:office@downrightspecial.co.uk) as soon as you can, or contact your group leader 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** <https://www.hullccg.nhs.uk/downsyndrome/hull/>

A reminder that the revised edition of the Hull & East Riding Care Down Syndrome Care Pathway was published on World Down Syndrome Day and is now available to download. Do let us know if you have any comments. Has the pathway helped you? Are there any gaps? At appointments are the healthcare staff aware of the pathway? Is there anything missing or incorrect that you like to see changed in next year's update? Contact [sam@downrightspecial.co.uk](mailto:sam@downrightspecial.co.uk) with your feedback.

### **New Resource Alert!! Paediatric Review Social Story**

Our Health Lead Sam has developed a social story to help support children, young adults and their parents when attending their paediatric appointments at Hull Royal Infirmary. It can be used to help prepare for appointments or used during the visit to help navigate through the stages of an appointment. The resource will hopefully help make the appointment a positive experience and reduce levels of anxiety. Older ones can use it themselves as an easy-read so they can learn to become independent and confident attending appointments. The resource was emailed out to everyone at the end of April but if you think you missed it then email [office@downrightspecial.co.uk](mailto:office@downrightspecial.co.uk) and ask for the information to be sent again.

### **Another New Resource!!! Eye Conditions Alert**

Sam and student nurse John have created a useful one-page resource that can be saved on your phone and taken to eye test appointments. The image lists a few of the eye conditions that may be more prevalent in people with Down syndrome and that should be checked for regularly as well as signposting professionals to the Down Syndrome Medical Interest Group evidence-based information on vision. You should have received an email early in May but get in touch if you missed it.

## Down Syndrome and Complex Needs

---

### **Complex Needs Group**

Over the last 12-18 months, Health Lead Sam has been meeting and consulting with a small group of parents to better understand the issues facing families whose children have Down syndrome plus other needs such as autism. The input and discussions have now been written up as a report that has been shared with those involved and also with the Trustees. The next steps are for the trustees to look at the recommendations and for an action plan to be developed. We have already implemented a number of recommendations including adjustments to social events, the paediatric review social story and trying to share more information about DS and autism through our social media sites but there is more that we hope to be able to do. We also hope to be able to share the report more widely and make it available to anyone who would like a copy. Huge thanks to the parents involved for their valuable contributions to this project.

### **Complex Needs Resources**

The DSA have lots of new information and fact sheets about Down Syndrome and complex needs including autism, ADHD, mental health and physical health.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/>

They also have two webinars coming soon:

**Dual Diagnosis of Down's Syndrome and Autism Webinars:**

Part One Thursday 8 June 2023 | 10.30 – 11.45 am | £10

Part Two: Thursday 6 July 2023 | 10.30 – 12 noon | £10

You can book via the DSA website

<https://www.downs-syndrome.org.uk/our-work/services-projects/training/>

## Building a Brighter Future/Preparing for Adulthood

---

### Parents Working Group

Huge thanks to the parents who have participated in the second of our working groups, this time looking at the transition to adulthood. The aims of this group were to understand the challenges facing the child/young person at this age, the challenges facing them as parents/carers, to understand what is working well and what would help (magic wand question), to look at each area of PFA, understand what was important to families and what the issues were, to take each of the issues identified and make suggestions for what could be done to improve the identified problems.

Over the last year, five meetings were held looking at the four areas of Preparing for Adulthood: Good Health, Relationships, Employment, Independent Living.

The information gathered has now been written up into a report which has been shared with Trustees, along with a series of recommendations for how the charity could support young people and their families at this stage in their lives. We have already implemented some new pieces of work such as adding more information within the DS Care pathway on transition to adult services, training and information sessions organised on: Wills & Trusts; Mental Capacity; Deputyships & Lasting Power of Attorney, Puberty. The rest of the recommendations will be discussed with the trustees and an action plan put in place.

### Listening Services

---

The Down's Syndrome Association has launched a new 'listening service' for parents, parents-to-be or family carers of people who have Down syndrome, offering 40-minute appointments over zoom. [downs-syndrome.org.uk/listening-service](https://www.downs-syndrome.org.uk/listening-service)

Contact also has a 'listening ear' 1:1 telephone service for families in need of emotional support. <https://contact.org.uk/help-for-families/listening-ear/>

### 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](mailto: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](http://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, items for events such as our Easter Egg Hunt or Awareness Week Café. [https://www.amazon.co.uk/hz/wishlist/ls/1PGPTF1B551EW?ref=wl\\_share](https://www.amazon.co.uk/hz/wishlist/ls/1PGPTF1B551EW?ref=wl_share)

### Movement for Good Awards

**Please nominate Downright Special for The Movement for Good awards for a donation of £1000.** To nominate Downright Special please complete the short nomination form below:

[https://movementforgood.com/?utm\\_source=Email-giving&utm\\_campaign=Draw2-reminder&cmp=1&utm\\_medium=HTMLEmail#nominateACharity](https://movementforgood.com/?utm_source=Email-giving&utm_campaign=Draw2-reminder&cmp=1&utm_medium=HTMLEmail#nominateACharity)

Our Charity Number is: 1175863

Charity Type: Disability

Winners are drawn in June, September and December. You can only vote once this year.

### Co-op Local Community Fund

Downright Special is delighted to be chosen to benefit from the Co-op Local Community Fund for the next 12 months.

Every time a Co-op member buys selected own brand products or services, 1% of the money they spend goes to local causes in the community. Please choose Downright Special by clicking on the link below: <https://membership.coop.co.uk/causes/68198> or in the Co-op App homepage, click on community and then scroll down to find Downright Special.

### Tesco

**Finally, thank you** to everyone who voted for us with their blue tokens when they shopped at Tesco. We won the most votes and have been awarded £1500 towards our social events for the next twelve months!

## 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.