

A booklet for parents and carers about supporting a child with Down's Syndrome starting school

Let's Talk about Your Child starting Primary School



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This is my son Matthew who is 7 years old.

When a child starts school it can be an anxious time for all parents, but when your child has additional needs there are extra worries for us.

I was worried that the teachers wouldn't understand him and wouldn't know how to teach him. I was terrified of sending him away for a full day with strangers, how would I know he was ok? Would they make sure he had a drink because he can't tell them he's thirsty? Who will make sure he doesn't just wander out the class and get lost or hide?

And my biggest fear, will he have any friends?

Two years on and my fears have melted away. Matthew is thriving in school! He has a lovely group of friends who just see him as their friend and he has built great relationships with the staff throughout the school.

We have had challenges along the way with communication and understanding his behaviour at times but working together with the school staff and with training and support from Down's Syndrome Scotland and Signalong training the staff in the school now have the knowledge needed to support Matthew.

I will always have worries about how he is doing in school and as he moves through primary, I'm sure we will come across more challenges! He has learned so much over the last two years in school. He is more confident, independent, and most importantly he is happy!!



Introduction

Starting school is a big step in your child's life (and yours!) and it can be a very exciting time, however we know for all parents it can create feelings of mixed emotions, from worrying if their child will cope on their own, settle in or make new friends. As a parent of a child with Down's syndrome we know you may have additional concerns related to your child's communication or developmental delays or health and additional support needs as well as uncertainty about accessibility, if they're not yet toilet trained or safety within the school.

We're here to support you through this time and we hope this booklet helps by giving you useful information to think about in preparing your child to start school as well as information and guidance to support school to have a better understanding of how to support and include your child effectively and positively.

Suggested Checklist

Review Educational Psychologist report

If there is an Educational Psychologist involved with supporting your child's transition to school, they usually provide a collaborative report to the school your child will be going to which outlines the level of support they recommend for your child in their new setting. You can ask to see a copy of this report so you can ensure that the level of support recommended in school is appropriate to your child's needs.

If there is no Educational Psychologist involved, your child's nursery/early years development centre (EYDC), should be able to provide a report to the school on the level of support your child may require based on their experience of them within the nursery setting.

Create a Communication Passport

We recommend that you create a Communication Passport (sometimes called 'All About Me') for your child if you don't have one already which gives school important information about your child, their communication needs, likes and dislikes and includes details of any health or developmental issues, sensory needs and family details, pets etc. You can find examples of these and how to create one for your child at the back of this booklet.



Look into an Enhanced Transition

Children with additional educational support needs are entitled to an Enhanced Transition. This means, they usually receive extra visits to their new school before they start so they can meet some of the staff and become familiar with the environment. It usually also involves opportunities for you to have joint meetings with staff from your child's nursery, their new school, and any other professionals who work with them so that you can discuss and agree the support your child will need.

It is useful during the enhanced transition visits to join your child on a visit to the school, perhaps with their key worker at nursery to begin with and ask any questions you may have or are unsure of. Ask the school to provide photos/videos of the new school environment and people who will be working with your child, so that you can use these to create a simple story board for your child to talk through with them over the summer holiday to help him/her remember what the new setting will look like and create a feeling of familiarity before their first day. Summer can feel like a very long time for a child to remember what school looked like and when they last visited.



Communication

Children with Down's syndrome are strong visual learners, but often poor auditory learners. Encourage the school to support your child's short-term auditory memory by limiting the number of verbal instructions they give and allow your child extra time for processing verbal information or instructions. The school can use visual forms of communication, Alternative Augmentative Communication (AAC) like Makaton/Signalong, PECS (Picture Exchange Communication System), symbols i.e., Board maker symbols, communication apps which can really help a child with Down's syndrome to learn. The school may need to upskill staff to use these Alternative Augmentative forms of communication if they are not trained in these already. We recommend that your school use Makaton/Signalong to support your child's communication and consider introducing a Sign/Board maker symbol of the week so that all children in the class can learn together and everyone learns about different ways to communicate. Using a visual board with Now and Next to keep your child on task and motivated are also useful.



Speech and Language Therapy

To support your child's speech and language development it is critical that your child and the school receive regular input from a Speech and Language Therapist who can support with a programme of carefully planned individualised activities, designed to develop your child's language, understanding and communication as well as speech articulation.

Furthermore, if your child has any issues with swallowing, chewing or acid reflux due to low muscle tone, input from a specialist Speech and Language Therapist (SLT) will be required to assess your child's swallow and bite. A school risk assessment should include if there are any risks related to your child's eating and drinking such as a hazard of choking or reflux and if supervision is required at mealtimes. School should be able to make these referrals with your consent if you don't already have input from a named Speech and Language Therapist.



Occupational Therapist Input

If your child has issues with their motor skills or vision, ensure that school are aware of these. Ask them about getting an Occupational Therapy (OT) assessment for your child before they start school. OT can provide equipment and training to school to support your child's mobility, safety and development such as coloured treads on stairs, low handrails, slant boards for task work or when reading, support and strategies for fine motor development and writing skills and can arrange for a specialist chair for seating to support posture and stability if required. A full OT assessment of the school environment with your child present will be useful as the OT can check things like height of lunch hall stools, height of toilets or wash basins etc. School can also get input from the Visual Impairment (VI) team if extra support is required.

Hearing

Let school know if your child has any hearing issues and encourage them to proactively support hearing difficulties by making sure that your child is within their own hearing distance, always speak directly to them, gain eye contact when speaking with them, reinforcing speech with facial expression, sign and gesture, provide visual reinforcement for all verbal instructions and when other children give an answer in class repeat this aloud to ensure that it has been heard. If your child uses hearing aids, make sure school knows about them and will support your child to wear them at school. School can get extra support from the Hearing Impairment (HI) team if required.

Accommodations your child might need in the classroom

Young children starting school often have a short concentration span and can be easily distracted and this can be more difficult for children with Down's syndrome. Encourage school to support this by giving them a range of short, focused and clearly defined tasks with short breaks in between. When sitting on the floor as a class it would be best to ask that your child sit at (not on!) the class teacher's knee and a carpet square or similar can help to encourage them to sit in one place. Suggest to school that an activity box containing a range of things that your child enjoys such as books, card games and fine motor skill games can be used when they need a change of activity or time out which also encourages choice making within a structured situation. Allowing one other child to join in, is a good way of encouraging friendships and cooperation. If you feel your child gets overwhelmed at times, it can also be useful for school to have a safe and quiet space your child can go to if they need to take a break if they are feeling overwhelmed and to support them to engage in the situation better.

Potential dangers in the school environment and any additional support they may need to keep them safe

Executive function happens in the frontal lobes of our brain and is the part of the brain that helps us to plan, organise and control impulses. Executive function in children with Down's syndrome can be delayed and in addition to difficulties with staying on task and maintaining focus, your child may also have difficulty with controlling impulses. Your child may have no concept of danger and a risk assessment for their safety should be completed by school before they start. This may include recommendations

such as ensuring the playground is fenced off and that doors, gates and other areas of potential danger are always closed and your child has adequate support during the school day to keep them safe.

Toileting

If your child is not yet toilet trained or needs prompting to go to the toilet, needs support with dressing/undressing, washing their hands or personal care, make school aware of your child's toileting needs to ensure they have adequate staffing to provide this support and can seek relevant guidance or resources and aids to support your child with this. Some useful resources can be found [here](#).

Summer holidays can be a good time to start with toilet training. Do2Learn have lots of free picture cards that you can print out and use with your child, you can access these [here](#). You can share them with the school, so they are using the same for consistency. Visuals will help your child understand the sequence of learning to use the toilet. Remember we are here to support you with this should you need us.

Structure and routine

Children with Down's syndrome will prefer and succeed best in a structured environment with familiar routines and clearly focused activities. Informal times of the day are more difficult as children with Down's syndrome can be upset by sudden changes in their routine. Simple visual timetables using photographs or signs as prompt cards will help prepare your child for each new activity in advance. Should there be any changes at home or with school morning routine it is important to let school know. Likewise, school should also inform you about any changes in school routine/environment well in advance where possible, so that you can talk about this with your child to prepare them for the change.

Changes to the curriculum

The curriculum may need to be differentiated for your child, in subjects such as literacy and numeracy and possibly PE and other subjects depending on their level of comprehension and vocabulary. Local Education Authorities have a duty to ensure that the needs of all individual pupils are met through providing 'adequate and efficient' education and appropriate additional support when required to enable each child to 'fully benefit' from their education.

We are here to provide training and support for schools and our Teaching Reading and Numeracy modules are specifically designed to help schools differentiate the curriculum in these subjects. You can find out more about our training courses and share these with your school [here](#).

Friendships

One of the biggest areas parents tell us they worry about is the Social Gap widening as their child progresses through school. It is useful to encourage school to provide structured activities at play time to support your child to have positive opportunities to mix with their peers which will support their social development. Schools can consider creating a Circle of Friends for your child and using social stories to teach about things like asking someone to play with them or asking to join in, you can find resources on this that you can pass on to your school at the back of this booklet. Some schools also have a buddy system which can positively support your child during social breaks at school. To positively support your child's development of social skills, confidence and independence it is best that they are encouraged and supported to interact with their peers at break times and not be on their own with an adult as this can not only alienate them from their class but it can have a negative impact on peer relationships and social development. .

Identify how the school will communicate with you to inform you about your child's day.

We recommend that a two-way communication diary is used so that you can be kept up to date with your child's day at school and have a mechanism to keep school informed about your child's wellbeing and any factors that may affect their time at school, such as, if your child has not had a good night's sleep, has been unwell, or is upset about something.

Accessing ABC at School

If your child currently accesses our [ABC programme \(Achieving Better Communication\)](#) their school may be able to facilitate for them to attend their sessions from school, so mention this to them so that your child can continue receiving consistent support for their communication development.

Meet our Team

Remember you are not on your own, we are here to support you and school.

Our Family Support Team can attend school meetings with you, online or in person where feasible to help with the transition process through education as well as annual reviews, IEP (Individual Education Plan) or CSP (Coordinated Support Plan) reviews which you may be asked to attend at school.



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Training, Support and Consultation Service

We offer a range of training and support to schools and education professionals.

We are here to help teachers and educational support staff in supporting and positively including children and young people with Down's syndrome in their school.

We offer bespoke training and support on specific topics as well as dedicated consultation sessions and a series of four on-line interactive training modules with one of our Support Team.

Schools can also access training at our [Professional study days](#).

We also offer a [Consultation Service](#) to schools which involves one of our Family Support Team visiting school to observe your child in different settings and then provide school with strategies to positively support and include your child.

More information about the training and support we can provide for educational professionals can be found at our website [here](#) or by contacting Varshali Swadi our Professional Engagement and Training Coordinator at varshali@dsscotland.org.uk.



Achieving Better Communication (ABC)

Many schools access our Achieving Better Communication (ABC) programme to support communication development. If your child doesn't attend ABC currently you can find out more [here](#).

We can also provide Makaton workshops and Communication Skills training in schools. Our ABC Lead, Katy Lironi, is a qualified Makaton Tutor and is available to support you and school with Makaton training, workshops, resources, and enquiries.

You can email Katy at: katy@dsscotland.org.uk



Some practical tips suggested by our parent members to support your child's independence at school

- Have your child wear shoes with velcro fasteners if they can't yet tie laces/buckles as they can be easier to put on and take off independently.
- Having them wear fully/part-elastic waisted trousers/skirts and velcro shirts/polos can be so much easier for positively developing their independence if they can't yet manage zips/buttons.
- Looping a keyring or pull tag onto coat/bag zippers can help better support your child's grip when pulling to open & close.
- Putting a bigger loop inside their coat helps make it easier for them to hang their coat independently.
- Writing their name larger on bags, coats, snack/lunch boxes etc will help your child to identify them easier and supports them to recognise and read their name too.
- It's always good to make sure they have tissues in their bag and encourage them to use them to wipe their nose and mouth and then pop it in the bin afterwards (And wash their hands when they are finished).
- Drinks containers – non-spill if needed and one they can open independently.
- Give your child lunch/snack tubs that they can open on their own and help to encourage their independence.
- It will be useful before starting school to teach your child:
 - how to ask for help (verbally, using a sign or symbol)
 - what to do if upset/frustrated/ annoyed (e.g. deep pressure on palm, chew tubes)
 - to say no politely
 - turn taking/queuing up/waiting in line/spatial distance.



Our Resources

- We have a number of resources which can help you support your child;
 - [Makaton for the School Day](#)
 - [Developing Early Skills](#)

You can access these resources on [Hub 21](#) or email familysupportservice@dsscotland.org.uk to request a copy.

Other Resources

- Examples of Communication Passports
 - [All about me - Include Me Too](#)
 - [Personal Communication Passport - Call Scotland](#)
 - [PAMIS Digital Passport](#)
- Help with Toileting
 - Eric (The Children's Bowel & Bladder Charity) have lots of resources including a social script, flashcards and videos - you can view these [here](#)
 - Do2Learn also have helpful visuals and cards you can use in the classroom - you can view these [here](#)
- Fostering Friendships
 - Twinkl have resources on activities and practical tips for helping support friendships you can view these [here](#)
 - Teach starter have created a social story for teaching skills for playtime - you can view this [here](#)
- Book Bug
 - Book Bug have a resources available to help with the transition from nursery to Primary 1 you can view this [here](#)

This booklet is designed to help you prepare for your child with Down's syndrome starting school.

Down's Syndrome Scotland provides information and support to families, carers and professionals who care for and work with people with Down's syndrome.

If you would like to access further support or information please call us on 0300 030 2121 or email familysupportservices@dsscotland.org.uk.

For further information visit:

www.dsscotland.org.uk



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