A booklet for parents and carers about supporting a child with Down's Syndrome when they start nursery



## Let's Talk about Your Child starting Nursery



For more information or to obtain any of our other publications please visit www.dsscotland.org.uk Hi, I'm Emma Rose .....

I was born in March 2021, and I had a hole in my heart, an unsafe swallow and respiratory complications and I have Down's Syndrome.

My dad got the impression from the medical staff that I may not thrive, and he was concerned about my development and future. My dad had to learn quickly about NG feeding



tubes and oxygen along with all the other baby stuff as any first dad has to learn. He felt overwhelmed when I was born and worried, but he was open minded and loved me unconditionally. The journey has had its challenges, but my dad and I are even closer because of them.

#### Emma's dad's perspective

I was apprehensive about Emma staring nursery and the team around me gave me reassurance, but I was still very unsure of how she would cope in such a busy noisy environment.

I felt better once I visited the nursery and met the staff who would be looking after her. They all needed peg training and they were getting it the day after my visit which was reassuring. The communication between nursery and myself is good and I went to see her in the nursery once she started..

She was loving it and I was struggling to get her out the door to come home. She has grown into a fun, bubbly cheeky little girl who lights up the room and I am happy to say I can see her thriving and believe nursery will help her development come on leaps and bounds and she will exceed all our expectations.

#### Introduction

Starting nursery 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, development or health and support needs as well as uncertainty about accessibility, if your child is not yet toilet trained, safety inside the nursery or your child running out of class.

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 nursery, as well as information and guidance to support nursery to have a better understanding of how to support and include your child effectively and positively.

#### What nursery education is my child entitled to?

Early learning and childcare for your child is funded by the Scottish Government.

The current entitlement is up to 1,140 hours of funded early learning and childcare a year (around 30 hours a week in term time) if your child is 3 or 4 years old\*. Some 2-year-old children are also eligible. You can check if you are eligible by clicking the link here.

Children under 3 who have a disability can be eligible for an early nursery placement to provide additional support for their learning and development, and an extended period to consolidate their learning alongside age appropriate peers which can positively support their development. However, this is based on an assessment of the individual's needs. Local authorities must assess a child under age 3 who may need additional support due to a disability. Your child's lead health professional can make a referral to your Local Authority for your child to receive an earlier nursery

placement, or you also have the right to self-refer. If support is deemed necessary you may get support from an education professional e.g., a home visiting teacher or other appropriate health professional, e.g., speech and language therapist. If your local authority decides that your child does not require additional support, they must detail their reasons for this to you in writing.

If you wish to make a self-referral for your child to be assessed for an earlier nursery placement, we can help you draft the letter and provide additional information to support your request, just get in touch.

#### Things to think about when choosing a nursery

- In many local authorities a child's Health Visitor is often the 'key' or named person (according to GIRFEC see more here) involved in planning for a child to start nursery so it is useful to ask your health visitor if they can advise and guide you through this process. During the planning period for starting nursery your child's Health Visitor will share relevant and proportionate information about your child with staff from your chosen nursery/early learning childcare (ELC) provider. It is also good practice for a health visitor to be involved in review or multi agency meetings for your child once they start nursery too. You may hear the term 'Transition' used when you first start talking about starting nursery or school. This is the term used that simply means a period of planning for change.
- If you have a nursery in mind, we recommend that you visit the nursery to meet the staff and head of the nursery and to see what the nursery is like inside to help you visualise your child there. Talk to staff about your child, your aspirations for them, what their needs are and share any worries you might be having. You should get a feel for the place, ask if they have any prior experience of including children with Down's syndrome. If they haven't, please let them know that Down's Syndrome Scotland can support them to learn how to positively include and support a child with Down's syndrome in their nursery and can provide information or training they may need. A positive attitude to including a child with additional needs in their nursery is the most important thing to ensure that your child can thrive in that environment. We are here to support you and the nursery through this journey. You can find information about training and support we can provide for nursery settings covering a range of topics such as 'Meeting the Support needs of a Child with Down Syndrome in your Nursery' and Communication Skills training, here.

### Once you decide on a nursery what are the things you need to think about?

- Some children with Down's Syndrome may have associated health conditions, which may require them to need additional health support such as and an Ng tube, or they may be on oxygen etc. It is important to make the nursery aware of this early on so that they can make any necessary adjustments and arrange for any specific training that staff may need to support your child's health needs.
- We recommend that you create a Communication Passport (sometimes called 'All About Me') for your child if you don't have one already. This is a useful booklet which gives nursery 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. Here are a few examples of these and how to create one for your child; All about Me, Personal Communication Passports (with board maker symbols), Pamis digital passport.
- Children with additional educational support needs are entitled to an Enhanced Transition. This means, they usually receive extra planning and familiarisation visits to their new nursery before they start so they can meet some of the staff and have longer to become familiar with the environment. It usually also involves opportunities for you to have meetings with staff at the nursery and any other professionals who may be involved with supporting your child: for e.g. your Health Visitor, Speech and Language therapist, Physiotherapist, someone from Down's Syndrome Scotland. It is useful during the enhanced transition visits to join your child on a visit to the nursery, perhaps with their key worker at nursery to begin with and ask any questions you may have or are unsure of. Ask the nursery to provide photos/videos of the new nursery 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 and create a feeling of familiarity before their first day.

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- Communication: Children with Down's syndrome are strong visual learners and often poor auditory learners. It is best to limit the amount of verbal instruction given and allow extra time for processing verbal information. Encourage the nursery 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 nursery can use visual forms of communication, Alternative Augmentative Communication (AAC) like Makaton or 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 and support their communication needs. Nursery may need to upskill staff to use AAC if they are not trained in these already. We recommend for nursery to use Makaton/Signalong to support your child's communication and for them to 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. You can find information here about how we can support nursery with Communication Skills training specifically for children with Down's syndrome here.
- Speech and Language Therapy: To support your child's speech and language development it is critical that your child and the nursery receive regular input from a Speech and Language Therapist (SLT) who can support with a programme of a 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 SLT will be required to assess your child's swallow and bite. A nursery 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 or if your child has a specifically prescribed eating and drinking plan. Nursery 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 nursery is aware of these. Ask them about getting an Occupational Therapy (OT) assessment for your child before they start nursery. OT can provide equipment and training to nursery 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 nursery with your child present will be useful as the OT can check the suitability of the environment such as desk height, suitability of chairs, toilet/washbasin heights etc. The Visual Impairment (VI) team can provide extra support and guidance for the nursery for any additional support required to support your child's vision.
- Hearing: Let nursery 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 and provide visual reinforcement for all verbal instruction. If your child uses hearing aids, make sure the nursery knows about them and will support your child to wear them at nursery. The Hearing Impairment (HI) team can provide extra support to the nursery for any additional support required to support your child's hearing.
- Young children starting nursery often have a short concentration span and can be easily distracted and this can be more difficult for children with Down's syndrome. Encourage nursery to support your child with this by providing a range of short, focused and clearly defined tasks with short breaks in between. The free flow structure of a nursery setting may be daunting for a child with Down's syndrome, especially if there are too many choices. It would be useful for nursery to limit the choice of activities to two activities at a time maximum -e.g., sand pit or water play. Having an activity box containing a range of things that your child enjoys such as books, card games and fine motor skill

games can be useful to use when they need a change of activity or time out, and also encourage 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 be useful for nursery to have a safe and quiet space your child can go to for a break which will support them to engage in the situation better.

- Toileting: Please don't worry if you have not yet started toilet training your child or if they are not yet fully toilet trained, need prompting to go to the toilet or need support with dressing/undressing, washing their hands or personal care. As long as you make the nursery aware of your child's toileting needs, they can work with you to provide consistent support for your child. Nurseries are very accustomed to children learning these skills when they start. There are useful resources and aids available to support development of this that you can share with the nursery if you feel it would be useful to support your child. Some useful resources can be found at the links below:
  - Help with toileting ERIC
  - Continence Foundation
  - <u>Do2Learn: Educational Resources for Special Needs</u>
  - Bowel and Bladder UK
- 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 nursery 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
  nursery day to keep them safe.
- Structure and routine: Children with Down's Syndrome will prefer and succeed best in a structured environment with familiar routines and clearly focused activities. The free flow structure of nursery settings is often more difficult and 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 nursery routine it is important to let nursery know. Likewise, nursery should also inform you about any changes in nursery routine/environment/changes to key staff, well in advance where possible, so that you can talk about this with your child to prepare them for the change.

- Differentiating some aspects of the Curriculum can better support your child in nursery. The ability to recognise and work with sounds in spoken language (Phonological awareness) can vary in in children with Down's syndrome and your child may respond better to the learning whole word or sight word approach which focuses on learning whole words rather than learning individual letters in isolation. Down's Syndrome Scotland are here to provide training and support and our Teaching Reading module is specifically designed to help nursery staff understand this. You can find the information here to share with nursery.
- Children with Down's Syndrome may experience challenges with social interactions in the nursery setting due to communication difficulties and social and emotional development delays, particularly as they move into the age 3-5 room; however, there are many ways these can be overcome with an effective and positive inclusion approach.

Adults can be great 'bridge-builders' for children who are at a stage of parallel play (i.e., playing next to or near to other children but not with them) to help them form friendships and understand social etiquettes. Nurseries usually have a free play approach where children can choose their own area of play i.e., waterplay, sand play, roleplay, book corner etc. If you feel your child could find this daunting or overwhelming it can be beneficial for nursery to support them with choosing between two of the activities instead. It is also useful for nursery to provide some structured activities at play time to support positive social opportunities to mix with peers and positively support social development. Nursery could also consider creating a 'Circle of Friends' for your child, which is a positive inclusion approach, you can find more information about this to pass onto the nursery here.

Nursery can also support your child's social development through using social stories to teach about social behaviours and communication such as how to ask someone to play with them or asking to join in with others at play, you can see an example <a href="here">here</a>.

- Nursery can feel like a noisy and busy environment when children first start. It is helpful to let your child's nursery know if there are any sensory issues your child has that you are aware of, such as being either overly (hyper) sensitive or under (hypo) sensitive to their environment such as noise, textures, lighting etc so they can seek specialist guidance and create a plan to support your child with this. An Occupational Therapist (OT) can provide specialist guidance for the nursery to positively support your child's sensory needs.
- Identify how the nursery 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
  nursery and have a mechanism to keep nursery informed about your
  child's wellbeing and any factors that may affect their time at nursery,
  such as, if your child has not had a good night's sleep, has been unwell,
  or is upset about something.
- If your child currently accesses our <u>ABC programme (Achieving Better Communication)</u> their nursery may be able to facilitate for them to attend their sessions from nursery, 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 your child's nursery.

Our Family Support Team are here to support you with choosing a nursery and throughout your child's time there to ensure the nursery have all the support they need about your child's specific learning profile so that your child has the most effective and positive experience. We can also attend nursery 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 nursery.



Shona Robertson
Family Support Lead
North West



Debbie Campbell
North East



Karen Philip Central



Laura Traynor



Lauren Lockhart

South





#### **Training, Support and Consultation Service**

We offer a range of training and support to nurseries 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 nursery or 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.

Nurseries can also access training at our Professional study days.

We can also offer a Consultation Service to nurseries which involve one of our Family Support Team visiting nursery to observe your child in different settings and then provide nursery with strategies to positively support and include your child.

More information about study days, our consultation service and the training and support we can provide for educational professionals can be found at our website <a href="here">here</a> or by contacting Varshali Swadi our Professional Engagement and Training Coordinator at <a href="here">varshali@dsscotland.org.uk</a>.



#### **Achieving Better Communication (ABC)**

Many nurseries access our Achieving Better Communication (ABC) programme to support communication development. If your child doesn't attend ABC currently you can find out more <a href="here">here</a>.

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

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

- Have your child wear shoes with velcro fasteners if they can't yet tie laces/buckles as they will find them easier to put on & 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.
- Its always good to make sure they have tissues in their bag and encourage them to use them to wipe their nose and mouth. As well as pop the tissue in the bin and wash their hands when done.
- 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 to encourage their independence.
- It will be useful before starting nursery 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)
  - $\circ$  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. You can access these resources on <u>Hub 21</u> or email <u>familysupportservice@dsscotland.org.uk</u> to request a copy.
  - Makaton for the School Day
  - Developing Early Skills

#### **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 - view these <u>here</u>
  - Do2Learn also have helpful visuals and cards you can use in the classroom - you can view these <u>here</u>
- Fostering Friendships
  - Twinkl have resources on activities and practical tips for helping support friendships you can view these <u>here</u>
  - Teach starter have created a social story for teaching skills for playtime - you can view this <u>here</u>
- Enquire factsheets:
  - Nursery Support
  - Rights for early years
  - Enquire Parent Platform
- Getting it right for every child (GIRFEC) is a commitment by the Scottish Government to provide all children, young people, and their families with the right support at the right time. You can find additional information on this <a href="here">here</a>.

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

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 please call us on 0300 030 2121 or email us at familysupportservice@dsscotland.org.uk.

For further information visit: www.dsscotland.org.uk



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