



Case Study for Inclusion

United Kingdom

Johnny's Story - Teacher Version

Karen Hudson

## Johnny's Story

### Background:

When Sharon was pregnant with Johnny she wasn't aware that he had Down Syndrome, it was a Post Natal diagnosis. Johnny was born by emergency caesarean section so from the onset there were several professionals involved in his care; paediatricians, special care nurses the midwife. After his birth, they asked Johnny's parents what they knew about the chromosome abnormality that causes Down Syndrome. She asked many leading questions so they actually mentioned Down Syndrome before the paediatrician did! Dad said 'Are you talking about Down Syndrome here?' She said 'Yes' and then went on to tell us why she thought Johnny had Down Syndrome - pointing out the physical features that Johnny had which are associated with Down Syndrome. They took blood samples to get a firm diagnosis.

However, when Johnny was about three days old they found a heart murmur and he was diagnosed with atrioventricular septal defect (AVSD). After Johnny's congenital heart defects were diagnosed (complete AVSD and PDA) his parents were told he would need surgery between 6 months old and 2 years old.

However, at 3 months old Johnny's reflux became worse. This was a result of Johnny's heart swelling (early stages of heart failure) due to his congenital heart defects. He was prescribed diuretics to reduce the swelling and to help the reflux. Two weeks later the feeding tube was put back in as his reflux worsened. Eventually he couldn't tolerate even 50ml feeds every 2 hours so he was put on a continual tube feed and admitted into the children's heart unit to await surgery. At 4 1/2 months old Johnny had his open heart surgery and a week later they were home, he really bounced back!

Mum was contacted by another Mum about ECCDS and she thought it sounded ideal. Portage was ok but it was for any child with special educational needs, it wasn't focussed specifically on the needs of children with Downs Syndrome. She wanted something that was more than just a cup of tea and some moral support, so she took Johnny along to Education Centre for Children with Down Syndrome at Hexham.

### Resources:

A short film called 'Our best friend' which was made by Johnny's Mum as part of the celebrations for World Down Syndrome Day

<https://www.magisto.com/int/album/video/KDk4VwJaFwUhOiQHDmEwCXp5?l=vsm&o=i&c=e>

The booklet "Johnny's Story"

Makaton sign language resources

**Context:****What is Down Syndrome?**

Down Syndrome is caused by the presence of an extra chromosome in a baby's cells. In the majority of cases, Down Syndrome is not an inherited condition. Down Syndrome usually occurs because of a chance happening at the time of conception

**What are the characteristics of Down Syndrome?**

The most common features associated with Down syndrome include:

- Low muscle tone (babies appear "floppy")
- Flat facial features, with a small nose
- Upward slant to the eyes
- Small skin folds on the inner corner of the eyes
- Small, abnormally shaped ears
- Single deep crease across the centre of the palm
- Hyper-flexibility (excessive ability to extend joints)
- Fifth finger has only one flexion furrow instead of two
- Extra space between the big toe and the second toe
- Enlarged tongue that tends to stick out, although current thinking is that the tongue is actually normally sized but the mouth cavity is smaller than usual

**Down Syndrome in the UK**

- Two babies with Down Syndrome are born every day in the UK. Around one in every 1,000 babies born will have Down Syndrome
- There are 60,000 people in the UK with the condition
- Although the individual chance of a baby having Down Syndrome is higher for older mothers, more babies with Down Syndrome are born to younger women, reflecting the higher birth rate in this group
- Down Syndrome is not a disease. People with Down Syndrome are not ill and do not "suffer" from the condition
- All people with the Syndrome will have a varying degree of learning difficulty. However, the majority of people with Down Syndrome will walk and talk and many will read and write, go to ordinary schools and lead fulfilling, semi-independent lives
- Today, with the right support, people with Down Syndrome can enjoy a life of sixty years plus.

## **Description of Good Practices**

### **Ethos**

At the ECCDS the ethos is one of positivity and celebration. The centre is committed to helping children and their parents acquire essential skills that will equip them to meet the future with confidence. Their mission statement is 'Education.....every child's birth right' and the group is very clear that it is offering more than support for parents it offers very structured programmes of educational activities which are age appropriate for the children and adapted for their specific needs.

Johnny's Mum said that "ECCDS has been really empowering for us as parents, it has given us such a positive view of people with Down Syndrome and such hope for Johnny. It has opened a whole new world for us and for him. The ECCDS group has really helped us to challenge the perceptions that people have of Down Syndrome, we know now that Down Syndrome doesn't have to define Johnny, it is just a barrier that we need to bring down. ECCDS has empowered us as parents. We have lots of hope for Johnny and we are really pleased that he has been born now."

### **Collaboration**

'The Education Centre for Children with Down Syndrome' (ECCDS) work on collaboration in two distinct ways: collaboration with parents at their groups and collaboration with nurseries, schools and employers.

#### At the group:

At the group in Hexham the Johnny takes part in a range of activities and his Mum or Dad sit with him. While they engage Johnny in the activities the ECCDS staff model, for his parents, the kind of approach to take with each activity and how to support him to complete the tasks and what signs to use.

The activities Johnny takes part in follow the same pattern every week:

- Welcome time
- Fine and gross motor activities
- Speech and language activities
- Snack time
- Mathematical activities
- Singing (just the children and staff)

Each activity has a slightly different focus but the structure remains the same providing predictability for the children.

Many of the resources used by the children have been made by the staff with a specific purpose in mind and each week Johnny gets something to take home to enable him to continue his learning and development at home. This is really important, Johnny needs lots of opportunities to see things modelled for him and to practice his skills. Johnny's Mum said "He's very good at playing and exploring on his own but every day we try to do something we have learnt at Hexham, it might be flash cards or Jolly Phonics or counting on our fingers. The resources that we get from the ECCDS group are really great and support us to help Johnny"

#### In Johnny's Nursery:

Staff from the 'The Education Centre for Children with Down Syndrome' (ECCDS) currently offer a variety of courses, conferences and workshops for all the courses, the learning objectives are:

- To explore Down syndrome and the impact it has on children's learning and achievements
- To evaluate present practise and reflect on a range of practical strategies for classroom and whole school or Nursery implementation

One of the practical ways that 'The Education Centre for Children with Down Syndrome' has supported the Nursery that Johnny attends is by training the staff who work with him to use Makaton Sign Language

Sharon (Johnny's Mum)

*Helen from ECCDS has been into the nursery and worked with the staff there she has given them some Makaton training so that they can use Makaton with him. His Key Worker is really great and is using all of the signs, they are trying to introduce a sign a week with everyone at the nursery. Helen's speech and language activity is Johnny's favourite when we're at Hexham and it is great that Helen has done the outreach at the Nursery, it makes them feel confident – they are all benefitting – not just Johnny.*

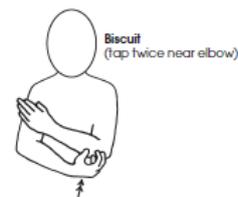
This is a really important aspect of the collaboration that will support Johnny to confidently use Makaton Signing to support his communication while his spoken language is developing. Because the Nursery are teaching Makaton signing to all of the children and doing things like signing common songs and stories as well as parts of the daily routine it means that Johnny's peers will be able to understand his communication and they will be able to sign back. This will enable Johnny to develop positive relationships with his peers.

## Communication

Communicating with spoken language is one of the challenges for children with Down Syndrome. Helen from ECCDS says the aim of the speech and language programmes is

- To help children develop understanding and production of words and sentences [signed, spoken or written] related to chosen people, things and events in the children's lives.
- To develop important skills that will support the children's learning.
- To support parents in developing expertise and skills to help their children.

Helen from ECCDS says it is not easy for children with Down syndrome to get started on saying words. We know they can sign these more easily so that is where we start, with Makaton. As we sign we also say the word and the more the child feels the signing movements and hears the sound of the word, the better he or she will be able to store this word in his/her memory and therefore start using it. So we use words children will hear at home and that they will find interesting and useful, like favourite foods



## Developing sentences

Our brains are very clever at knowing how to put words into the correct order to make sentences. They seem to know instinctively 'who' is doing 'what' and 'where'. We use this instinctive knowledge and build on it for our children using a programme called Narrative Therapy. The children are taught to answer the questions 'who?', 'what doing?' etc with the correct response "My mummy", "carrying the bag" and so on with the help of colour coded written words and pictures.

## Developing speech

Speech is very difficult for most children with Down syndrome. Saying the speech sounds and putting them together into words is a big hurdle. We help children step by step to overcome this hurdle by seeing where speech sounds are made in the mouth and learning how they feel when they say each sound. We also help them to listen to how these sounds appear in words and to say the words clearly enough so other children can understand them.

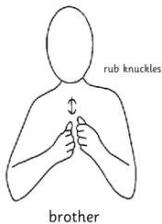
It is really important that everyone who has contact with the child uses the signs so that the child is able to have the common signs reinforced and that when they are trying to communicate using signs those around them are able to understand them.

In the video we saw Johnny using the signing twice. The first time was when he was practicing walking, his Mum was saying 'Good Boy' and Johnny was making the sign for good as he walked.



This is the sign for good. It is an easy sign to make and because of its link with praise it is one that most children learn quickly.

Later on we saw Johnny making the sign for 'Big Brother'.



To sign 'brother' form both hands into fists and rub the knuckles together. When the child is getting started, many signs are approximations rather than perfect, just like with speech. We could see that this was the case with Johnny, although he did use two hands and they were both like fists, then didn't really rub together, rather they were placed one on top of the other. This doesn't matter, the important thing is that Johnny can make himself understood and they signs will become more refined over time.

Johnny's Mum and Dad use as much signing as they can with him.

### Outline session plan

	<u>Learning</u>	<u>Activity</u>	<u>Resources</u>
Introduction 15 minutes	To establish a shared understanding of the 'keys' of inclusion	Look at the keys one at a time, begin with asking the students what they understand by the terms, then elaborate to establish a clear basic understanding.	<b>Red – students</b> <b>Blue – Teachers</b>  Keys on individual laminated sheets
Introduction 30 minutes	To establish a shared understanding of Down Syndrome and to introduce Johnny	Begin the session by playing the short movie. Ask the students to make short notes while the watch. Use these to begin a discussion about children with Down Syndrome.  Share the booklet and give sufficient time for the students to read the text. Support students to understand unfamiliar vocabulary.	Video  Booklet: Johnny's Story

20 minutes	To begin to consider the 'keys' within Johnny's story	<p>In small groups, ask them to identify as many bits of evidence to support the keys as they can.</p> <p>Students can choose how to do this – they may highlight the booklet, make notes on their student sheet or create a spider diagram or thought shower.</p>	<p>Keys on individual laminated sheets</p> <p>Paper, pens, highlighters</p>
10 minutes	Share the findings of each group and identify the strongest keys	<p>Allocate each group a 'key' and ask students to feedback to the group, ask other groups to make additions if appropriate.</p> <p>Use the Identifying Good Practices Grid (below) to ensure no important points are missed.</p> <p>Encourage other groups to contribute.</p>	Identifying Good Practices grid
5 - 10 minutes	Consider the themes of communication and collaboration	<p>Re-focus on the aspects of collaboration and communication.</p> <p>Compare the evidence of good practice in Johnny's story with other case studies you have engaged with so far.</p>	
10 minutes	Learn some Makaton signs	<p>Use the resources provided to learn some signs that Johnny would be interested in.</p> <p>You might want to focus on being a big brother, singing and dancing or something else!</p>	Makaton Sheets
20 minutes	Independent work planning a story or a song using Makaton	Work in pairs or small groups.	Planning sheet
20 minutes	Share and evaluate	Each group to share their work and teach it to the others if time allows.	

Identifying the good practices in the materials

Key	Questions you can ask students to help focus their observations.
<b>Collaboration</b>	<p>Which partners are involved in the supporting Johnny and his family?</p> <p>What are the benefits of the collaboration for each of those involved?</p>
<b>Reflection</b>	<p>Does reflection take place in this case study?</p> <p>What are the indications of reflection presented in the case?</p> <p>Do all the participants of the educational process make reflections?</p>
<b>Holistic</b>	<p>What are the indications of the holistic child this case?</p> <p>What do you think about the well-being of a child?</p> <p>What domains of children development mentioned in the case show the holistic approach?</p> <p>Can you evaluate these?</p>
<b>Ethos</b>	<p>Can you describe the ethos in this case?</p> <p>How is the ethos shared by all those involved?</p> <p>Can you draw any similarities between this and other cases?</p>
<b>Adaptation</b>	<p>Where and how have there been adaptations made for Johnny?</p> <p>Does Johnny receive special pedagogical assistance?</p> <p>What kind of assistance?</p> <p>Is it sufficient enough?</p>
<b>Communication</b>	<p>How would you describe the effectiveness of Makaton as a communication system?</p> <p>What are the benefits for Johnny, staff at the center and the nursery and Johnny's parents and family?</p> <p>Are there any potential disadvantages?</p> <p>Give your arguments.</p>
<b>Add any other observations you wish to draw the participant's attention to</b>	