

# Down's syndrome resources for education

January 2024

## Who we are

The Down's Syndrome Association (DSA) is the leading charity supporting individuals who have Down's syndrome across England, Wales, and Northern Ireland.

We have been registered as a charity for more than 50 years and have a long-standing history of providing information, advocacy, training, and support to people who have Down's syndrome of all ages, their families and the professionals who work with them.

We have expertise to share in areas of health, education, employment, and social care and work extensively with professionals who provide direct services and researchers in the field of learning disability, both here in the UK and internationally.



The DSA regularly engages with The Department of Health and Social Care, Department for Education, NHS, NICE and other Government departments, and public bodies on responding to policy initiatives that should improve service provision for people who have a learning disability. We submit responses to public consultations and engage pro-actively on key policy issues which affect people who have Down's syndrome.

We include the voices of people who have Down's syndrome within all of our activities, aided by the Our Voice network. As well as guiding the work of the DSA, Our Voice members provide services for other organisations.

Our support frequently begins prenatally and extends to support through all life stages encompassing early development and education, transition into adult life and additional support on ageing and end of life, when needed.

If you have any questions, you can call our Helpline (tel: 0333 1212 300) or email using: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

## **Introduction to the issues**

We aim to ensure that educators feel more informed and confident about welcoming a learner who has Down's syndrome into their setting.

To this end we have put together this resource that details all of DSA's education-related resources along with downloads/links to relevant resources that have been produced in collaboration with/by other organisations.

Learning is a lifelong activity which means that education starts before the age of formal schooling and continues after formal education at schools and colleges.

Education offers learning opportunities for growth and development in every area, covering social development and academic skills including literacy and numeracy, with broad learning opportunities to enable learners to discover their interests, talents, and joys, and to support progression to careers of their choosing.

Children, young people, and adults everywhere have a right to an inclusive, equitable quality education and the promotion of lifelong learning in line with Article 24 (Education) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations, 2006) and Sustainable Development Goal 4 (SDG 4 – Education) of the United Nations 2030 Agenda for Sustainable Development (United Nations, 2015).

At the DSA, we believe in the rights of all learners who have Down's syndrome to inclusive and equitable quality education with the support that they and their families are entitled to in England, Wales, and Northern Ireland. The DSA is committed to children and young people having the option to attend local community schools and colleges however complex their needs may be.

The benefits to learners who have Down's syndrome of an inclusive education have been documented over the last 30 years. Inclusive primary education became well established for the majority of learners who have Down's syndrome during the 2000's (less so for those learners with more complex needs and dual diagnoses) although more variable (regionally) at secondary stage. Some learners' needs will be met in specialist settings.

The DSA has decades of experience of supporting educators in welcoming pupils who have Down's syndrome into their classrooms. We recognise the importance of evidence-based practice, and also strategies that work well in practice.

*'Thank you so much for all the time and preparation that went into the planning and delivery of Monday's session. I feel we have established a strong network of support around the child and her family. The staff all took so much away from the session and the notes will be excellent for constant reference and further training in the future. My key workers all set up for her journey ahead and staff are so keen and highly motivated to ensure she receives the best possible support. We are all so much more confident following your session.'*

*Thanks for the follow up notes. These will be circulated to all attendees and we will keep a copy on file for ref by any other practitioners who may be interested.*

*Hopefully we will also make full use of the array of excellent courses you advertise on the website. I hope we can maintain our professional links as well as enjoy your support for the growth and development of the infant and her family. Thank you again for caring and listening to our needs.*

*I really appreciate your swift and professional response to our call for support.'*

**Early Years Educator, 2023**

*'I just wanted to thank you for all your help these past few weeks with my daughter and her school..... I really wanted to just say thank you for your time, listening and sound advice.'*

**Parent, 2021**

## Good practice recommendations

Good practice recommendations include school/college leadership allocating time for teachers to plan, a shared vision of inclusion, working in partnership with families, teachers who understand that they are responsible for learning of all students in class and teachers who guide the work of teaching assistants. A high level of additional learning support assistance to meet individual needs is common.

Teacher training and further professional development should be available to teachers. Learners who have Down's syndrome can be taught the curriculum for the year group, adjusted to enable engagement with learning outcomes. All teachers should understand and know how to support behaviour (for all students with a learning disability). All schools/colleges should know about and be able to implement recommendations to promote learning for the varied needs of children and young people who have Down's syndrome as the strategies and modifications should be within their 'skills toolkit' for teaching any learner with similar additional needs.

Every individual is helped by teaching staff having high expectations. A parent, whose son's transition into his new school had gone really well shared this quote from one of his teachers:

*'It's our privilege to have him here. The students and the staff love him. He completes us, he's the cherry on the top. Even the grumpy maths teacher has been heard saying "when Morgan enters a room, the room lights up."*

## 'Specific learning profile', Adjustments and Support

Each of the points described below is referenced in [DSI International Guidelines for the Education of Learners with Down Syndrome](#)

While every learner who has Down's syndrome is an individual with a variety of strengths and challenges, there are some common features that are known to affect learning to a greater or lesser extent. These relate to vision, hearing, speech, language and communication, memory and cognition, fine and gross motor skills and health issues. Specific features represent probabilistic attributes and are not necessarily found in all learners who have Down's syndrome.

Where learning issues exist, additional learning support and adjustments must be provided to enable optimal learning. Many of these are not difficult to implement, for example, modification for vision may include materials written in black pen with increased letter size. The quality of support the child or young person receives can have a tremendous impact on his or her learning.

Reading is a relative strength for learners who have Down's syndrome, and sign and gesture support the learning of new vocabulary.

Learners may experience a range of issues that affect the clarity and fluency of their speech. Keyword sign is an effective approach that supports initial communication during the development of speech and where speech is difficult, learners should be supported to communicate in other ways, such as, for example, sign language, keyword sign, and electronic devices.

Support for communication development should continue throughout all stages of an individual's life. Some individuals who have Down's syndrome have more extensive social communication difficulties and approximately 10-18% meet criteria for dual diagnosis of autism spectrum disorder. Multiagency working must include speech and language therapy input into education.

Visual-spatial working memory is a relative strength, verbal working memory appears to be a significant weakness and long-term memory a relative strength. Adjustments should be made for limitations of verbal working memory and capacity for manipulating information in working memory. The ability to learn by imitation is a powerful strength in an inclusive classroom. There is some evidence for specific visual-spatial learning strength. Visual support for learning is an effective strategy for learners who have Down's syndrome.

The pattern of gross motor development is delayed. Encouraging active movement and participation in physical education, recreation, sports, and dance is important and will also promote good health.

Encouraging the use of computers for writing/recording will enhance the ability to communicate. Occupational therapists can support the development of fine motor skills and advise on devices and aids to compensate for limitations.

Ill-health has an impact on learning, so regular health checks are recommended, as for any child. Pain is experienced differently by people who have Down's syndrome; individuals are more sensitive to pain and may have a magnified pain response that lasts longer. Even articulate people who have Down's syndrome are known to have difficulty expressing the extent of their pain and locating it on their body. In an education context, if students exhibit challenging behaviour, it could be that they are in pain and unable to communicate.

See detailed age-related recommendations for pre-school, school, college and continuing education within the [DSI International Guidelines for the Education of Learners with Down Syndrome.](#)

Teaching and learning recommendations for learners who have Down's syndrome should apply to all types of school and college settings.



## **Wider Inclusion at School, College, in Extra Curricular Activities and Youth Services**

Service providers should plan for inclusion of children and adults across the curriculum and in extracurricular activities from the outset. This would include participation in school/college clubs, PE lessons and sports, residential trips and day outings, after school activities and youth services. This does not always happen and can result in children and young people missing out on opportunities to develop in ways that will promote their health and wellbeing, such as physical activity, friendship, and community participation.

## **Education, Health, and Care (EHC) Plans, Statements and Individual Development Plans (IDBs)**

Health and social care service providers should be involved at all stages of the Plan/Statement process. Health has an impact on education therefore the Plan should explain health issues, particularly vision and hearing, and be clear that education takes these into account as recommended, for example, for seating position, teaching and learning resources, and equipment such as glasses, magnifiers, hearing aids and soundfield systems. Social care should describe services to meet the child's needs.

## **Further and Higher Education**

There is a need for better access to inclusive college courses, vocational pathways, and post 16 opportunities for learners who have Down's syndrome. We would also like to see better access to opportunities to support people to prepare for adult life and their chosen vocations.

For example, some learners choose residential colleges with a view to this helping to prepare them for later life. The residential component enables people to experience living away from the family home and to develop independence skills. We strongly recommend that local colleges offer a part-time residential option to fulfil this need. Residential colleges may also offer specialist vocational courses that are not available at local colleges.



## Education – Our Role

We make direct representation to Government about education issues, and we respond to education related Government consultations. We ensure that the voices of people who have Down's syndrome are included in all of our education policy work. We are active members of rights-based organisations including the Special Education Consortium and the Council for Disabled Children's Special Educational Needs and Disabilities Information Organisations Group (SENDIOG), where we are able to make representations on behalf of learners who have Down's syndrome and where we work collaboratively with other key partners in the voluntary sector to improve the education system for all learners.

We provide support through our Helpline, resources via our website and online training opportunities (see below) for teachers/education support staff working in a range of education settings and also for parents and families.

## Our Training

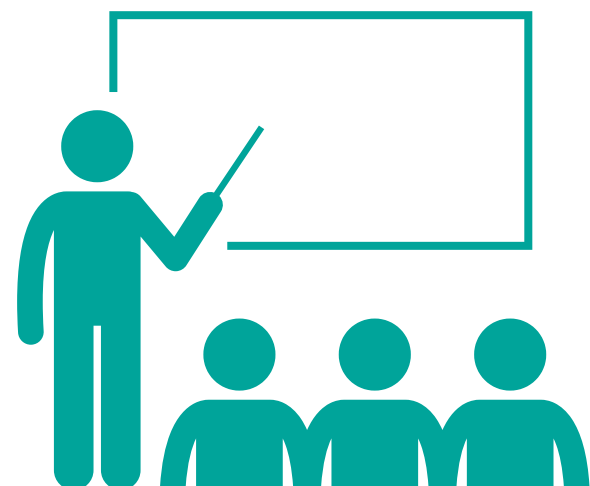
We offer a range of pre-recorded and live online training sessions for parents/carers, teachers, and support staff.

Subjects covered include:

- Early Communication
- Supporting Early Development from birth to 4 years
- Early Years and Primary Education (slides can be viewed [here.](https://www.downs-syndrome.org.uk)) ([downs-syndrome.org.uk](https://www.downs-syndrome.org.uk))
- Understanding and Supporting Behaviour in Children
- Puberty and Adolescence
- Relationships and Sex Education
- Secondary Education
- Dual Diagnosis of Down's syndrome and Autism (parts 1 & 2)
- Supporting the Well-being of Adolescents and Adults who have Down's syndrome
- Preparation for Adulthood (parts 1 & 2)
- Guest webinars on Education topics
- DSAActive training for leisure, recreational and sports activity providers to enable successful participation and inclusion
- Sensory Processing Awareness (children)

We also provide training sessions, commissioned by educators and organisations, that are tailored to individual requirements.

Further information about our training can be found here: [Training - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk).



# Table of Contents

[Ensuring Your Rights to an Inclusive Education](#)

™

[Inclusive Education](#)

[Whole School Inclusion – Every Activity, Everyone Included](#)

[School Leadership - How to be an Empowering Leader for Every Student](#)

[Empowering Future Inclusive Teachers](#)

[Person Centred Working](#)

[Inclusive Curriculum](#)

[Health Issues, Education, and Learning](#)

[Supporting People with More Complex Needs](#)

[Early Years Education](#)

[Back to School](#)

[Behaviour](#)

[Friendships](#)

[Inclusive Homework](#)

[Transitions for all ages and stages](#)

[Planning For Independence](#)





# Ensuring Your Rights to an Inclusive Education

Children and adults who have Down's syndrome must be able to enjoy full and equal rights alongside their peers. This includes the opportunity to participate fully in education and in their local communities as and when they wish.

Details of relevant legislation in England, Wales and Northern Ireland and the resources listed here from the DSA and other organisations can be found [here](#).



## Resources

- Education, Health, and Care (EHC) Needs Assessments
- Education, Health, and Care (EHC) Plans
- Education Rights Post 16
- School Transport
- Annual Reviews (Video)
- Rights Under the Equality Act 2010
- DSI International Guidelines for the Education of Learners with Down Syndrome
- 31st March Deadline for Post 16 Education, Health, and Care Plans
- Using Legislation and Guidance to make a Difference for Children and Young People (video)
- The Down Syndrome Act 2022
- How do I Choose What's Right for My Child?
- The Lived Experiences of Parent Carers of Children with Learning Disabilities Attending Mainstream Education (Emma Foley, Researcher)
- Securing Your Child's Right to an Inclusive Education (Video)
- Disabled Children: A Legal Handbook (Ch4 Education)
- The Noddy Guide to the Law 2023 (Matrix/Landmark Chambers)
- The Equality Act 2010 and Schools
- SEND Code of Practice 2015
- Quick Guide to Terminology (IPSEA)
- Best endeavours duty (IPSEA)
- Help in Exams (IPSEA)
- Challenging School Transport Decisions (Contact)
- SEND and Alternative Provision Improvement Plan

## Wales

- Equality Act 2010 Disabled School Pupils in Wales
- Additional Learning Needs (ALN) Code for Wales 2021
- Additional Learning Needs (ALN) Factsheet for Children, Young People, Parents and Carers
- A Guide for Parents About Rights Under the Additional Learning Needs (ALN) System

## Northern Ireland

- Statements
- Learning and Your Rights
- Disability Discrimination
- SEN Guide for Parents
- Code of Practice on the Identification and Assessment of Special Educational Needs

## Inclusive Education

As already stated, we believe in the rights of all learners who have Down's syndrome to inclusive and equitable quality education and lifelong learning opportunities.

Children who have Down's syndrome need skilled teachers who understand their current skills, abilities, strengths, and interests and who can teach them the next steps through engaging teaching and learning activities. They need to be welcome, socially included members within their classrooms and schools. The positive attitude of the whole school is fundamental: schools need a clear and sensitive policy on inclusion with committed and supportive staff, especially the senior management team.

Most children who have Down's syndrome need additional support for optimal learning in all types of schools. The quality of support the child or young person receives can have a tremendous impact on his or her learning. Class teachers and teaching assistants (TAs) should meet regularly to liaise, plan, feedback and monitor progress.

We realise that everyone has knowledge and experience in their context and think that sharing this is beneficial to everyone interested in providing, or receiving, a more inclusive education offer in the UK (and internationally).

As per the [DSI International Guidelines for the Education of Learners with Down Syndrome](#) - see page 4, we agree that:

**Inclusive education means 'that all students attend and are welcomed in their local educational setting and are supported to learn, contribute and participate in all aspects of that context'**

**Inclusive schooling means 'all are welcomed by their neighbourhood schools and taught in age-appropriate, regular classes engaging in all aspects of the student life of the school, and all receive support appropriate to their needs'.**

We recognise that by using these definitions, special schools and separate special classes are not considered 'inclusive', however we do understand that within the current education system in England, Wales and Northern Ireland, that they may be the only suitable option available for some learners.

From the discussions we have with families, we understand that unfortunately mainstream education settings do not always appear to be inclusive for learners who have Down's syndrome. We understand how difficult it is for families to be told that their child is not welcome.

Unfortunately, there are too many children and young people who have Down's syndrome who are being failed by education systems around the world. They are not given the support that they need to succeed in mainstream schools.

Therefore, we continue to provide support, resources and training opportunities to educators working across a range of settings, to help them develop a more inclusive approach to educating learners who have Down's syndrome.

Our Celebrating Success resources may be found [here](#). These resources contain examples of school inclusion, in the early years and at primary, secondary and further education, of pupils who have Down's syndrome.

You will find the following resources, blog posts and videos relating to developing an inclusive education practice [here](#).

## Resources

- Why Inclusion Matters in Education (Video)
- What Does the Term Inclusive Education Mean? (Video)
- Talking About the Education Campaign – Our Voice (Video)
- Steps for Developing Inclusive Practice for Pupils who have Down's Syndrome in Your Setting
- What is Inclusive Education?
- What are the Principles of Inclusion? (Video)
- Inclusive Education – A Discussion on the Concept and Practice in the Classroom (Video)
- How Can We Work Towards Including All Children?
- Supporting Children to Learn
- How Can Teachers Ensure That Learners Who Have Learning Disabilities Are Included with Their Peers? (Video)
- What Is Your Ethos When It Comes to Inclusion and Inclusive Education? (Video)
- Let's Talk – What Makes an Inclusive School (Video)
- How Can an Inclusive Atmosphere Be Best Created in the Mainstream Setting? (Video)
- Evaluation of Inclusive Practice for Students with Down's Syndrome in Devon Secondary Schools – Academic Year 2008-2009
- What Is the Role of Learning Support Assistants?
- What is the Role of the LSA in Ensuring All Learners Are Included with Their Peers?
- Leave No One Behind in Education – DSA Journal

# Whole School Inclusion – Every Activity, Everyone Included

At the DSA we believe that with the willingness, commitment and creativity of school staff and activity providers, it is possible to include pupils who have Down's syndrome in every aspect of school life including trips, extra-curricular activities and school events.

This topic is incredibly important for pupils who have Down's syndrome. After all, it is in informal social activities that we really get to know people and make friends. Without these opportunities to socialise with their peers, school can be an isolating experience.

Additionally, we know from the stories we hear from Our Voice members and families that it is through inclusion in school activities that many pupils – like all other pupils – find a new passion and some will even go on to achieve great things, for instance competing for their country.

## Tanzie's Residential Trip

Written by Sharon, Tanzie's mum

In Year 6, Tanzie's junior school went on a one week long residential trip each year. The trip was to a PGL activity centre, full of fun activities.

We started to discuss this with the school at the beginning of Year 5, because we knew that it would require additional planning for her. As a result of the planning that went into the trip, Tanzie had an absolutely amazing time and was included in all of the activities that took place.

Some of the factors that contributed to this included:

- Starting planning early – at least a year before the major activity. It is important that the school and parents work together for such a major activity.
- The school SENCO went on the residential trip the year before Tanzie was due to go, to see it through her eyes and to start thinking about any adaptations that might be needed. This allowed the school to start planning early.
- Tanzie had never slept away from home before, so we started to organise one-night sleepovers at her best friend's house, and then when her confidence grew, she stayed with her aunt for two nights on two separate occasions. This helped her be confident when staying away from home, as it was not her first time away.



- We packed each of her days' clothes in a plastic bag clearly marked with the day on it. At the end of each day, the dirty washing was put back in that same bag. This helped Tanzie with her organisation when she was on the trip, allowing her to be more independent.
- A couple of months before the trip, I went to visit the residential centre with the teacher leading the trip and the SENCO. I was able to look at the site, discuss the catering/her dietary preferences, and also discuss the activities. I noticed that the safety helmets all looked rather large so they made sure they would have smaller ones available. This meant I could provide my input to the planning, to ensure that any necessary adaptations could be made.
- Although the school normally did not communicate with parents during the residential trip, after the first night away they telephoned me to provide an update and reassure me that all was going fine. This allowed me to relax a little bit while she was away. This flexibility was appreciated.

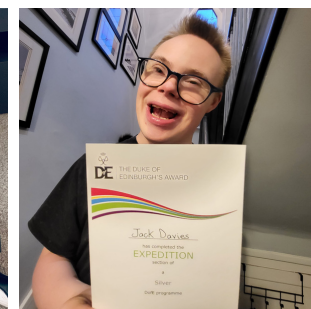


## The right to inclusion

Since its formation, the DSA has worked tirelessly to promote equality for people who have Down's syndrome. Children and adults who have Down's syndrome must be able to enjoy full and equal rights alongside their peers. This includes the opportunity to participate fully in their communities as and when they wish.

At [this link](#) you will find the following resources:

- Being Included and Discrimination – Your Rights Under the Equality Act
- The Equality Act 2010 and Schools (May 2014)
- Top Tips for an Inclusive Sports Day
- Top Tips for an Inclusive Residential Trip
- How Can Outdoor Learning Support Inclusion?
- DSActive
- A Discussion About How the DSA Supports Inclusion Within Sports and Leisure Activities (Video)



## Inclusion success stories

- Isla: Taking Part in School Productions
- Harry: Taking Part in YMCA Youth Club
- Morgan: Taking Part in Youth Club and Social Activities
- Beatrice: Taking Part in School Swimming Lessons
- Tanzie: Taking Part in a School Residential Trip
- Harshi: It's Ok to Talk to Me
- Dylan: A Great Sporty Experience at School
- Betsy: Inclusion in Her Local Dance Class
- Swansea FC and Down's Syndrome Football
- Meet Jack Hale – Special Olympics Skier (Video)
- David and His Taekwondo Teacher Talk Inclusion (Video)
- Introducing DSActive Tennis (Video)
- Perry and The Charlton Upbeats (Video)
- Sam: My Experience of Sport at School (Video)
- Joe: My Experience of Cheerleading at School (Video)



## School Leadership – How to be an Empowering Leader for Every Student



At the DSA we recognise the important role that education leaders play in developing inclusive settings. They are responsible for developing the culture of the setting and can be particularly influential on the attitudes and practices of staff. We want to be able to support education leaders to promote inclusive cultures and practices in their setting, developing a strong community commitment to a common purpose of inclusion of all pupils.

Changing a school culture is not easy. It is not something that will happen overnight, but we know that effective school leaders can stimulate whole school reform towards inclusive practice, for the benefit of a diverse cohort of learners – including learners who have Down's syndrome.

Below is a list of resources about school leadership; these may be found [here](#).

## Resources

- Recommendations for Leading for Inclusion
- How Can SENCOS and Leaders Support Teachers to Include Learners with Intellectual Disabilities? (Video)
- How Can Policy for Inclusion at the Strategic Level, be Best Implemented & Supported in Classrooms? (Video)
- What is Your Ethos When it Comes to Inclusion and Inclusive Education? (Video)
- What is the Role of the SENCO? (Video)
- Why Should the Policy of the Inclusion of all Learners be Adopted by All Schools? (Video)
- What do Leaders Need for Inclusion to be Taken Seriously?
- Leave No One Behind: Including All Children and Young People

## Empowering Future Inclusive Teachers



Inclusive education, which is the practice of welcoming, valuing, and supporting the learning of all learners in classroom together, requires teachers who can successfully manage the learning in these settings.

Newly qualified teachers must enter the profession with the knowledge, skills and approaches that will enable them to feel confident to teach all their students not just some.

Effective teachers will also engage in career-long professional learning. We know that effective inclusive education is skilled work for teachers and requires a reflective attitude to professional practice, based on a research orientation. It is also important to seek opportunities to gain experience and to experience success working in inclusive classrooms with a diverse student population.

Below is a list of DSA and other resources for newly qualified and experienced teachers alike who are seeking to develop inclusive practice; these may be found [here](#).

## Resources

- About Down's Syndrome (Including Terminology Guide)
- Supporting Children to Learn
- DSA Education Resources
- DSI International Guidelines for the Education of Learners with Down Syndrome - Professional Learning on Down's Syndrome (Extract)
- DSI International Guidelines for the Education of Learners with Down Syndrome - Planning for Inclusive Practice (Extract)
- DSI International Guidelines for the Education of Learners with Down Syndrome
- Amy's story: Volunteering at Her Local School
- Bethan's Presentation on What Helped her at School
- Support in My Mainstream School: Brogan's Story
- What Works in Practice (Sarah Geiger and the Barnet Down Syndrome Leading Edge Group)
- What Can an Inclusive Lesson Look Like? (DSI)
- How Can We Support Early Career Teachers Who Are Including a Learner(s) With an Intellectual Disability?
- How Can Student Teachers Have an Inclusive Mindset? (Video)
- How Are Student Teachers Equipped to Teach Learners Who Have Intellectual Disabilities? (Video)
- How Can Early Career Teachers Best Prepare for a Diverse Class? (Video)
- What Obstacles Are Faced by Newly Qualified Teachers Entering a Diverse Classroom? (Video)
- How Can a Mindset of Being Ready for Inclusive Education Improve a New Teacher's Practice? (Video)
- How Can Teachers Ensure That Learners with Intellectual Disabilities in Their Class Are Included? (Video)
- How Can Teachers be Supported to Develop as Inclusive Practitioners? (Video)
- How Can We Best Work with Peripatetic Staff? (DSI)
- What is the Role of the Speech and Language Therapist? (Video)
- What is the Role of the Occupational Therapist? (Video)
- How Can Teachers Build a Good Working Relationship with Parents? (Video)
- What is the role of the SENCO? (DSI)

## Person Centred Working

Good support is responsive to the needs and wishes of the individual.

The level of engagement a person can contribute to planning their support will be different depending on their individual needs.

At the DSA, we strongly believe that our work should be informed by people who have Down's syndrome.

People who have Down's syndrome are experts by experience and they are the people who know what life is like for them.

**a person needs person centred planning**



We listen to what they have to say, and we share their stories. We have set up and support 'Our Voice' which is a network of hundreds of people who have Down's syndrome who live in England, Wales, and Northern Ireland. Our Voice works on projects, helps to guide our work, and tells us what they think about the work we do. We work together to think of new ideas and make resources that people want.

Some members meet weekly and some work on projects in focus groups. Our Voice supports the DSA with making new resources, quality checking our information and co-producing training. Group members work on self-advocacy activities and campaigns.

At the DSA we recognise the importance of producing and publishing accessible information for people who have Down's syndrome. We often use 'Easy Read' communications in our work.

'Easy Read' refers to the presentation of text in an accessible, easy to understand format. It is often useful for learning disabled people.



We are grateful to the Our Voice members who help us develop Easy Read information on a wide range of topics.

If you would like to involve people who have Down's syndrome in your own work, a useful website is the Listen Include Respect website, which includes some helpful guidelines.

A short video is also available to tell you more about these guidelines and how they can be put to work.

Below is a list of DSA and other resources (including easy read) that can be found [here](#).

## Resources

- This is Our Voice (Video)
- DSA Easy Read Information
- Top Ten Tips for Supporting Self-Advocacy (Video)
- Support Planning: Putting The Person at the Centre
- Who Decides: Decision Making From 16 (Video)
- Making Decisions Post 16
- Making Choices and Developing Independence
- How Can Teachers Build Good Relationships with Parents? (Video)
- How Can Parents Build/Maintain a Positive Relationship with School? (Video)
- Listen To Me Videos
- Mental Capacity and Decision Making – Lasting Power of Attorney
- What is Person Centred Planning (Council for Disabled Children)
- Information About Easy Read (Foundation for People with Learning Disabilities)
- Easy Read Photo Library and Training (Photosymbols)
- Person Centred Planning Tools (Helen Sanderson)
- Person Centred Planning Prompt Sheet (Inclusive Solutions)
- One Page Profiles (Inclusive Solutions)
- Personal Planning Book (Foundation for People with Learning Disabilities)
- Preparation for Adulthood Planning Tools (NDTI)
- Thinking Ahead: Planning Guide for Families (Together Matters)

## Inclusive curriculum

Learners who have Down's syndrome have the right to a broad and balanced curriculum, on an equal basis with others. This should not be based on our predictions about what the learner might achieve or be limited to skills that they might need in adulthood. Academic achievement should be expected for all learners with Down's syndrome with provision of appropriate learning supports.

The learner who has Down's syndrome should be included in all phases of the lesson, including whole class instruction, and they should be supported in all activities through planned adjustments.

Learners who have Down syndrome should move up with their chronological age group to maintain peer relationships and friendship groups, and to progress through the national curriculum with adaptations as required. The classroom should be the primary learning environment, where they should spend the majority of their time in class with their peers.

Following the [DSI International Guidelines for the Education of Learners with Down Syndrome](#), we believe that there needs to be attention to provision of learning adjustments and curriculum differentiation that support the learning of everyone in the class, rather than just a focus on the pupil who has Down's syndrome.

It is therefore important that teachers have enough time to plan their curriculum, to ensure that it is inclusive of all learners in their classroom, including pupils who have Down's syndrome. Where specific interventions might be beneficial for a learner who has Down's syndrome (for instance Numicon to support learning numeracy), the interventions are also likely to benefit other learners in the classroom too.

Below is a list of DSA and other resources that can help you with curriculum planning; these may be found [here](#):

## Resources

- The Teacher's Role in Creating an Inclusive Curriculum (Video)
- Planning for an Inclusive and Accessible Curriculum
- How to Support Pupils to Learn About Disability
- DSI International Guidelines for the Education of Learners with Down Syndrome – Curriculum Modification
- Supporting Children to Learn
- Supporting Communication in the Classroom
- Relationship and Sex Education (RSE)
- Makaton and Down's Syndrome (The Makaton Charity)
- Using Numicon in Teaching Numeracy (Down Syndrome Ireland) (Video)

## Health Issues, Education, and Learning

Ill-health has an impact on learning, so regular health checks are recommended, as for any child and young person. There are a number of health issues that educators need to be aware of as these may have an impact on well-being, learning, behaviour, and safety (please note these are just some of the health conditions that may occur, it is not an exhaustive list).

Any person who is showing significant changes in their behaviour should have a thorough health check from a health professional (e.g. paediatrician or GP). People may not be able to tell you through using spoken language that they are unwell, in pain or that something is wrong for them.

Information about health checks for children, young people and adults can be found [here](#):

- [Health and well-being](#) (see Learning Disability Annual Health Checks 14+ years onwards)
- [You and your baby](#) (see PCHR Insert for birth to 18 years)



## **Education, Health, and Care (EHC) Plans, Statements and Individual Development Plans (IDBs)**

Health and social care service providers should be involved at all stages of the Plan/Statement process. Health has an impact on education therefore the Plan/Statement should explain health issues, particularly vision and hearing, and be clear that education takes these into account as recommended, for example, for seating position, teaching and learning resources, and equipment such as glasses, magnifiers, hearing aids and soundfield systems. Social care should describe services to meet the child's needs.

Information about writing health advice in an EHCP children who have Down's syndrome can be found at the website of the [UK and Ireland Down Syndrome Medical Interest Group](#).

### **Vision**

People who have Down's syndrome are more likely to have difficulties with their eyesight – up to half will need to wear glasses. It is vital that children, young people, and adults have regular eye checks to minimize the effects of any sight difficulty they have.

Even when people are wearing correctly fitted glasses, they will still have poor visual acuity. In practice this means their world lacks firm details and sharp contrasts. This is the case for everyone who has Down's syndrome. Our visual acuity resources tell you what you can do to support students to compensate for their poorer visual acuity.

Vision resources listed below can be found [here](#).

### **Resources**

#### Visual Acuity

- Seeing The World Differently
- Visual Acuity: How I See The World
- Visual Acuity: Think Big, Think Bold
- Visual Acuity – What Is It and Why Does It Matter (Video)

#### Vision General

- Eye Conditions in Children
- Children – Vision, Eye Tests and Glasses
- Adults – Vision, Eye Tests and Glasses

An article contributed to SEN Magazine by the DSA about vision and learning [can be found here](#).

### **Sleep**

Sleep disturbance is common in people who have Down's syndrome and may occur for multiple reasons including Obstructive Sleep Apnoea (OSA).

Symptoms of sleep apnoea include gasping, momentarily stopping to breathe or snoring whilst sleeping. It is recommended for all children who have Down's syndrome to have their oxygen levels checked overnight, whilst asleep, at around the age of six months and then once a year until the age of 5. This is to ensure that their breathing pattern and oxygen levels are normal.

Sleep issues may go undiagnosed because of diagnostic overshadowing and/or people may not realise, or be able to express, that they are experiencing poor sleep.

Sleep resources listed below may be found [here](#).

### Resources

- Managing Sleep Issues in Children
- Sleep Issues in Adults
- Sleep Poster Relaxation Audio

### Hearing

Temporary or long-term hearing loss will affect many people who have Down's syndrome at some point in their lives. Well over 50% of people who have Down's syndrome have significant hearing impairment, which can range from mild to profound. Sensorineural and/ or conductive loss may be present at any age. If undetected it is likely to be a significant cause of preventable secondary disability. The main cause of conductive loss is persistent Otitis Media with Effusion (OME), also known as glue ear.

Children, young people, and adults should have regular hearing checks.

Research highlights the need for audiology and speech and language therapy services to work together as soon as a child is diagnosed with severe, ongoing hearing difficulties (further information is available at the research link below).

Hearing resources listed below may be found [here](#).

### Resources

- Hearing (Children & Adults)
- Supporting Adults to Have Hearing Tests – Tips for GPs
- Supporting Adults to Have Hearing Tests – Tips for Carers
- Hearing, Learning and Down's Syndrome - Summary of research into early hearing loss and language abilities in children.
- Nasal Congestion/Catarrh

An article contributed to SEN Magazine by the DSA about hearing and learning [can be found here](#).



## Pain

Pain is experienced differently by people who have Down's syndrome; individuals are more sensitive to pain and may have a magnified pain response that lasts longer. Even articulate people who have Down's syndrome are known to have difficulty expressing the extent of their pain and locating it on their body. In an education context, if students exhibit challenging behaviour, it could be that they are in pain and unable to communicate this verbally.

Any person who is showing significant changes in their behaviour should have a thorough health check from a health professional (e.g. paediatrician or GP).

## Neck instability

Underlying neck instability is more common in people who have Down's syndrome than in the general population. This causes concern because although significant damage caused by neck instability is rare and most people have mild early warning signs, it can be devastating and result in paralysis and in extreme cases, death.

Parents, carers, and educators should be constantly aware of the warning signs (symptoms) which might indicate that a person who has Down's syndrome is at risk of neck instability. If it is suspected that a person who has Down's syndrome is showing any of the signs or symptoms listed here (A), (B), the person may have a problem with neck instability and should be seen by a Doctor for medical assessment.

Even minor impact involving the person with these symptoms may cause spinal damage (e.g. tripping up or a jolt).

### These are the warning symptoms of neck instability:

A) Warning symptoms:

These are the warning symptoms of neck instability:

1. Pain anywhere along the neck
2. A stiff neck which doesn't get better quickly
3. Unusual head posture ('wry neck' or torticollis)
4. Alteration in the way a person walks so they may appear unsteady
5. Deterioration in a person's ability to manipulate things with his/her hands.

B) Poor neck control

Difficulty holding the head up.

1. Holding the head at an unusual angle
2. Difficulty nodding or looking up and down and/or difficulty turning the head in certain directions.

Neck instability resources listed below can be found [here](#).

### Resources

- Neck Instability in People Who Have Down's Syndrome
- Knowing About Neck Problems (Easy Read)

## Supporting Pupils with More Complex Needs

The DSA is committed to children and young people having the option to attend local community schools and colleges however complex their needs may be.

Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education. Pupils who have Down's syndrome alongside long-term and complex medical conditions may require ongoing support, medicines, or care while at school to help them manage their condition and keep them well.

### **Education, Health, and Care (EHC) Plans, Statements and Individual Development Plans (IDBs)**

Health and social care service providers should be involved at all stages of the Plan/Statement process. Health has an impact on education therefore the Plan/Statement should explain any additional or complex health issues and should be clear how education settings takes these into account. Social care should describe services to meet the child's needs.

Information about writing health advice in an EHCP children who have Down's syndrome can be found at the website of the UK and Ireland Down Syndrome Medical Interest Group

At the DSA, we have a wealth of resources available to help families and educators learn more about conditions that may sit alongside Down's syndrome. We also hold regular complex needs (including Autism) support group meetings for parents and family carers. The meetings enable parents to share information and experiences and help to guide our work.



If you have any questions about health issues, you can call DSA's Helpline (Tel: 0333 1212 300) or email using [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk). If an information officer is unable to answer your question, they can make a referral to the medical advisers at the UK & Ireland Down Syndrome Medical Interest Group (DSMIG).

Below is a list of DSA and other resources that can be found [here](#).

## Resources

- Leave No One Behind in Education – DSA Journal
- Autism
- Supporting Communication: Dual Diagnosis of Autism and Down's Syndrome
- ADHD
- Development and Attention
- Anxiety and Stress
- Leukaemia
- Epilepsy
- Epileptic Spasms
- Down Syndrome Medical Interest Group Topics
- DFE Guidance – Supporting Pupils with Medical Conditions
- Parent Stories
- Social Care Support for Children (England)

Support for parents/family carers (not professionals)

- DSA Online Support Group
- DSA Closed Complex Needs and Autism Facebook Group
- Listening Service for Parents and Family Carers

## Early years education

Education for babies and very young children does not have to mean any kind of formal setting or provision. As is the case for any baby or young child, education starts in the family home. The most important experiences for a child who has Down's syndrome come from being a member of a happy, loving and active family and from doing all the things that families do. In the first months of life it is important for parents to have fun talking to their baby and interacting with them, showing them the world, and responding to the many ways that they communicate with them.

Children will develop through enjoyable opportunities for interacting, moving and playing in their first years of life. So engaging them in activities and enabling them to take a full part in family life will make for a very positive and nurturing beginning.



We offer webinars on aspects of early development and a range of online meetings for parent carers to advise on and demonstrate activities to support speech, language and communication, play and learning.

All families should receive early intervention services to help guide their child's development. Although children's needs vary, families should expect to engage with speech and language therapy, pre-school advisory and physical therapy (physiotherapy and/or occupational therapy) services during their children's early years. However, it is important to remember that most learning will probably occur at home, from family members, between visits to/from professionals.

The DSA offers subsidised speech and language therapy assessments to members of the DSA.

Most children who have Down's syndrome attend mainstream early years settings with their typically developing peers. This gives them the opportunity to develop social relationships and learn new skills in an inclusive environment.

There is no hard and fast rule about how much extra help a child will need at nursery or pre-school. Some children who have Down's syndrome manage well within what the setting generally provides; others may need additional support. The setting should work very closely with parents/carers, as they know their child best. It will also be helpful for the setting to get advice from other professionals such as a speech and language therapist or educational psychologist. The local authority may also have early years advisory staff for special educational needs, for example an early year's inclusion officer (INCO) or area SENCO (special needs co-ordinator) covering a cluster of early years settings.

## Lorni's story

I was born in 1990. When I was 10 weeks old, I had my first physio session. I joined a special needs baby group called Springboard when I was four months old. I had different sessions like music therapy and physio sessions.

I also had Portage once a week. This helped me learn to talk when I was little. This was when I was about three years old.



When I started physio I did learning-through-play activities. I went to a specialist playgroup, and I had a special helper who played with me. This was nice.

I then went to New Road Nursery, and I had a special helper there too.

I went to Primary school, and I had 15 hours of support per week. I had a very nice support person. She helped me with Numicon, and I learnt how to use the different shapes.

I then went to secondary school and when I was there, I had 20 hours of support per week.



## Early Years Foundation Stage (EYFS) England

The Early Years Foundation Stage (EYFS) covers the education of children aged 0-5. It is a statutory framework setting out standards for the learning, development, and care of all children 0-5 years old (up to the end of Reception year in school). The guidance must be followed by OFSTED registered childminders, nurseries, and pre-schools, to ensure that children learn well, are healthy and are kept safe.

The framework states that Early Years providers must have arrangements in place to support children with SEN or disabilities. There are universal progress checks at age 2 and at the end of Reception Year. Providers have a duty to identify and meet the special educational needs of children with Special Needs and Disabilities.

## Wales

In Wales there is the Early Childhood Play, Learning and Care Framework which contains resources and guidance for childcare, play settings and schools on early childhood play, learning and care for 0 to 5 year olds.

This may be downloaded [here](#).

## Northern Ireland

In Northern Ireland there is the Learning to Learn framework for Early Years Education and Learning.

This may be downloaded [here](#).

## Support in early years education

### England

All schools and early years settings (preschools / nurseries) must provide additional help for children who need it. It is particularly important that early year's settings do not delay in making provision for children with SEND. The process for giving additional help is set out in the [SEND Code of Practice](#). Chapter 5 sets out the actions early years providers should take to meet their duties in relation to identifying and supporting all children with special educational needs and disabilities.

If a child needs more help than the setting can provide from their own resources, parents should consider asking for a statutory Education, Health and Care (EHC) Assessment which may lead to an Education Health and Care (EHC) Plan (in England). If they haven't done so before, we suggest that parents start the process at least a year before their child starts school.

### Wales

The Additional Learning Needs (ALN) Code for Wales describes the statutory system in Wales for meeting the ALN of children and young people. It is aimed at ensuring that children and young people's ALN needs are identified early and addressed quickly to enable them to achieve their full potential. [The ALN Code may be downloaded here](#).

### Northern Ireland

In Northern Ireland there is a Code of practice that addresses the identification, assessment and provision made for all children who may have special educational needs at some time in their school careers, or even earlier.

[The Code can be downloaded here](#).

Below is a list of DSA and other early years resources; these may be found [here](#).

## Resources

- Early Years Factsheet
- Lorni's Story
- DSI International Guidelines for the Education of Learners with Down Syndrome – Early Years
- How Do I Decide Which School Is Right for My Child? (video)
- Advice For Parents Entering the Education System (video)
- 'All About Me' Personal Books
- Education, Health, and Care (EHC) Needs Assessments
- Education, Health, and Care (EHC) Plans
- Transition From EYFS Into Year 1
- Supporting Early Communication
- The Role of the Speech & Language Therapist for Babies and Pre-Schoolers
- Speech and Language Therapy Activity Videos
- Activity Tutorials
- Developing Language at Mealtimes
- Straw Drinking Advice
- Biting and Chewing
- Supporting Motor Skill Development
- Early Years Foundation Stage (DfE)
- Portage Home Visiting (NPA)
- Finding Childcare (Contact)
- Guide to Childcare for Children with SEND (Coram)
- Transport for Under 5s (IPSEA)
- Help with Childcare Costs (UK Gov)
- Developing Early Skills (Down's Syndrome Scotland)
- Early Years Guide (Down Syndrome Australia)

Listen to Me – Childhood Communication [may be found here](#).

Learning at Home resources [can be found here](#).



## Back to school

We recognise that the back-to-school period can be a stressful time for children, parents, carers, and teachers alike. Planning will hopefully ensure that a child has a smooth transition. The resources listed below may help you to prepare for a child who has Down's syndrome to start school, change school or move to a new classroom or teacher.

All these resources may be found [here](#).

### Resources for parents and carers

- Back to School Checklist
- Making A Transition Book
- Making A Holiday Book
- All About Me – Personalised Books
- What Should I Expect from My Child's School
- Becoming School Ready – Transition from Reception to Year 1
- How to Build a Relationship with Your Child's
- School Transport Factsheet
- Education Health and Care (EHC) Plans
- Education Health and Care (EHC) Plans - Annual Reviews (Video)
- Advice for Parents Entering the Education System (Video)
- Parent/Carer Wellbeing
- Our Listening Service for Family Carers Facing Difficulties

### Resources for educators

- Back to School Checklist for Educators
- About Down's Syndrome
- Early Years Factsheet
- Primary Factsheet
- Secondary Factsheet
- Further Education Factsheet
- Supporting Children to Learn
- What Works to Support Children and Young People Who Have Down's Syndrome (Video)
- How to Include Learners with Intellectual Disabilities in Your Classroom (Video)
- Vision and Learning
- Seeing The World Differently – Explaining How Vision Impairments Affect Children Who Have Down's Syndrome
- Strategies For Supporting Vision Impairments
- Hearing and Learning
- How to Include Learners with Intellectual Disabilities in Your Classroom (Video)
- Visual Acuity – What is it and Why Does it Matter (Video)

- Recommendation for the Inclusive Education of Pupils Who Have Down's syndrome – Introducing the International Guidelines for the Inclusive Education of Learners with Down Syndrome
- Early Years and Primary Education Training
- Secondary Education for Learners 11-16 Years Training

## Behaviour

Behaviour refers to everything that people do. We all react to situations and communicate through our behaviour.

DSI International Guidelines for the Education of Learners with Down Syndrome remind us that:

*'Critically, challenging behaviour is not in itself a characteristic of Down syndrome, and the underlying cause or motivation needs to be addressed.'*

Behaviour can be positive, helpful, and useful to the person.

For people who have difficulties with other forms of communication, such as pupils who have Down syndrome, behaviour – the things that they do – can be the most effective form of communication. A person who has Down's syndrome will usually be stronger in receptive language (understanding) than expressive (verbal) language skills. This can lead to frustration when they can understand but are not able to tell people what they need or want.

An important part of understanding behaviour is to look at the environmental factors and by this we mean more than the physical environment. We need to look at other people and their behaviour including ourselves as a supporter and consider the rules and expectations and whether they are realistic and consistent. A learner's health, emotional wellbeing, social inclusion, relationships and experiences at home, school and in the community are all important factors to consider.

Below is a list of DSA and other resources about managing, changing and supporting behaviour positively; these can be found [here](#).

## Resources

- Using Positive Behavioural Support as a Model of Change with People Who Have Down's Syndrome
- Understanding and Supporting Behaviour Change in Children (Webinar)
- Understanding Behaviour Resources
- DSI International Guidelines for the Education of Learners with Down Syndrome: Encouraging Behaviour for Learning
- Tips for Behaviour Management
- Supporting Emotional Wellbeing
- Sleep
- Gastrointestinal and Diabetes

- Supporting Motor Skill Development
- Mental Wellness in Adults with Down Syndrome (McGuire/Chicoine)
- Managing Behaviour (NDSS)
- Behaviour & Down Syndrome: A Practical Guide for Parents (Stein)
- Seven Key Questions About Positive Behaviour Support (BILD)
- Positive Behaviour Support (CQC)
- Behaviour in Schools Guidance (DfE)

Listen to Me – Childhood Communication [may be found here](#).

## Friendships

Friendships and social relationships are important for all children. Positive social relationships are important to mental health. This is true for everyone, including children and young people who have Down's syndrome.

Friendships and meaningful relationships with similar-aged peers are important to them in the same way that they are for anyone else. If a learner does not have any friends, they can feel isolated and as though they do not belong.

It is therefore important that you do not assume that learners who have Down's syndrome do not want to make friends or that they do not have the ability to do so, for instance, because of their developing communication and social skills.

It may just be that they – and importantly their peers – need some additional support in developing those relationships in a way that works for everyone.

Below is a list of DSA and other resources about friendships; these can be found [here](#).

## Resources

- Being part of a Circle of Friends at School: Catherine's Story (Video)
- Circle of Friends Meetings: Molly's Story (Video)
- Hand in Hand: Forging Bonds and Friendships Together
- My Friends My Community (Videos)
- Relationships and Sex
- Our Voice
- Let's Talk: Natty, Friends and Friendship
- Let's Talk: Bullying - Supporting Children and Young People Who Have Down's Syndrome



- Bullying (Easy Read)
- Learning About Down's Syndrome – Resource for Children (includes a presentation and guidance notes)
- Learning About Down's Syndrome – Resource for Young People (includes a presentation and guidance notes)
- Local Support Groups
- Supporting Friendships (Choice Support)
- Friendships and Social Relationships (NDSS)
- Making Friends (Contact)
- Bullying (Contact)
- Anti-Bullying Alliance
- Circle of Friends (Inclusive Solutions)
- Circle of Friends Resources and Training (Inclusive Solutions)

Listen to Me – Childhood Communication [may be found here](#).

## Inclusive homework

Homework provides learners with opportunities to revisit the work that they have done in school, and for parents to see what is being learned. It can help learners develop positive study habits and to develop independent learning skills. However, for pupils who have Down's syndrome it can also provide additional challenges.

It is important to link homework to classroom work, and that teachers modify homework to meet the individual learner's abilities and learning requirements. Homework should be seen as an integral part of learning, rather than an extra piece of work. Homework definitely should not be used as a punishment or penalty for poor performance in the classroom by a learner who has Down's syndrome or just to catch up on work they have not completed in the dedicated time allocated.

Homework for learners who have Down's syndrome should be differentiated to ensure that they can be successful in their homework, with minimal support from their parents. Always start with what you know they can do, to ensure that they can succeed.

School or college might also consider providing the pupil who has Down's syndrome opportunities to attend a homework club so that they can complete their work with support from their regular learning support staff, to reduce the demands placed on the family.

It is important that clear communication channels are put in place with the learner's parents, to discuss expectations about homework and for them to provide feedback on how the child or young person approached their home learning and what support was provided. Homework can provide a useful opportunity for parents to support pre-teaching (e.g. of topic vocabulary) or over-learning of content taught in lessons. It also allows for more real-life experiences to be incorporated into learning, for instance visits or taking part in activities instead of just writing about them.

A resource about inclusive homework is available [here](#).



## Transitions for all ages and stages

Whichever transition it is you are planning for; it is important to start early. This might be a transition to starting school, a transition from one school to another, or transitioning from education to adulthood and employment or social care.

These processes always take longer than you think, as they tend to involve a wide range of people. Ideally someone from the setting you are transitioning from or to will take on the responsibility for co-ordinating the transition process so that the learner who has Down's syndrome and their parents are not having to co-ordinate the paperwork and meetings.

It is important that children and young people who have Down's syndrome can be as involved as possible in decision making processes too. Transition goals should reflect their interests, abilities, and hopes for the future. Their individual transition plan should outline specific objectives to help them achieve those goals.

Below is a list of DSA and other resources covering a range of transition scenarios; these may be found [here](#).

## Resources

- DSI International Guidelines for the Education of Learners with Down Syndrome - Transition Planning (Extract)
- Transition Planning: How do I Choose What's Right for my Child?
- Education, Health, and Care (EHC) Needs Assessments
- Starting School
- Primary School
- Becoming School Ready (from Year R to Year 1)
- How Can Parents Make the Right Decision on Secondary School? (Video)
- Secondary School (including useful questions to ask)
- Transition to Secondary School
- Teenagers...What Next?
- Easy Read: Listen to Me - Thinking About 13+ Transition.
- Further Education
- 31 March Deadline for Post 16 Education Health and Care (EHC) Plans
- Fostering Independence (DSI)
- Supporting Teenagers
- Making Everyday Decisions Post 16
- Planning for Adulthood and Transition
- Social care – Child in Need and Transition Assessments
- WorkFit
- DSI International Guidelines for the Education of Learners with Down Syndrome
- Preparation for Adulthood (NDTI)

- School Visits for Pupils with SEND (BBC Bitesize)
- Choosing a School for Pupils with SEND (BBC Bitesize)
- Choosing a Mainstream School for a Pupil who has Down's Syndrome (BBC Bitesize)
- Starting School for Pupils with SEND (BBC Bitesize)
- Starting Secondary School for Pupils with SEND (BBC Bitesize)
- Finding the Right School (Contact)
- Applying for a School Place (Contact)

## Planning for independence

As young people who have Down's syndrome enter their teenage years, it is important to start planning with them for adult life.

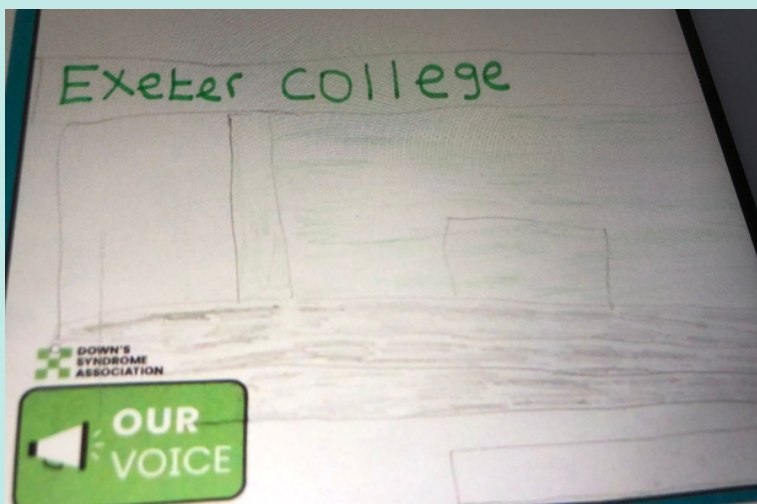
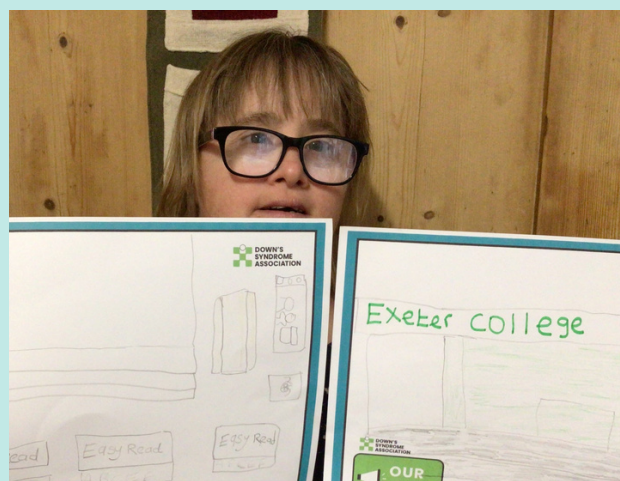
This certainly isn't a one-off event – they will need to revisit their plans as they get older, and circumstances change.

It is important to start thinking and talking about the future as a family, and to think about how the young person's education setting can support this. The Year 9/14+ transition/annual review is a good time to begin finding out about what is available (care and support, work, leisure, housing).

### Emma's experience of further education

I went to Exeter College. It was quite good.

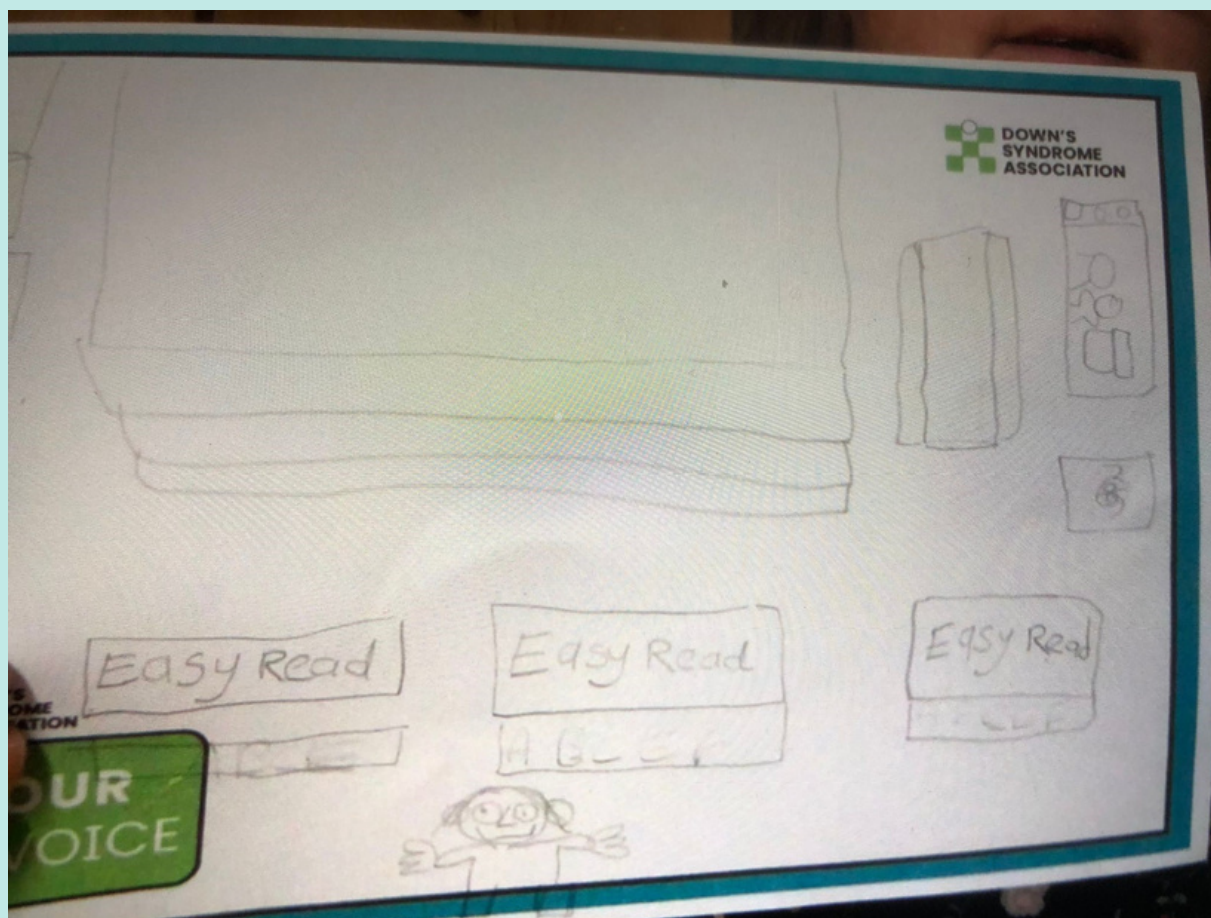
This is the inside, with the classrooms, the canteen up the steps, the bench, Student Union bar, and drama room.



 DOWN'S SYNDROME ASSOCIATION



I did the 3-year Catering course, that's me in the picture.  
There are three Easy Reads here.



It is time to start developing a person-centred plan with the young person and the people who care about them. A person-centred plan is a plan that revolves around the person, what they like and don't like, and what they want, both now and in the future; this will provide vital information about the wishes and needs of the young person who has Down's syndrome and the support they will need to achieve them. The plan will develop as they grow into adulthood.

Good support is responsive to the needs and wishes of the individual. The level of engagement a young person can contribute to planning their support will be different depending on their individual needs. Some young people may have family and people who know them well taking the lead in designing their support, based on what they know of their interests, likes and dislikes. Others who are more able to communicate their needs and aspirations are likely to be able to have more influence over planning their own plans. Whatever the person's ability they should be at the centre of the support planning process and as much weight as possible should be given to their wishes.

### **Decision making post 16**

It is important for families to understand the legal framework around decision making for young people once they turn 16. It can come as a surprise to some parents to discover that they do not have the automatic right to make decisions for their older teenagers and adult children with Down's syndrome.

When a person turns 16, under the Mental Capacity Act (2005), the starting point is to assume they have capacity to make decisions for themselves. The law says a person must be given relevant information in an appropriate format and time to understand it before a decision on their capacity is made. This may mean that over a period of time pictures, symbols, diagrams, videos, sound clips, verbal conversation, or other formats that the person normally uses to communicate are used to help the person to understand the options open to them. This is known as supported decision making.

The Mental Capacity Act (2005) states 'a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made'. This means capacity must be assessed in relation to every decision that needs to be made, at the time it needs to be made. Therefore, it is not possible to assess overall capacity and make blanket decisions on a person's behalf based on the fact that at a particular time they were found not to have capacity.

Never assume that someone does or does not understand and that they can or cannot do something. Have high but realistic expectations. You need to keep re-thinking about what is possible for the young person as they grow and develop. Some days all might go really well, some days they may not be able to do things as well as yesterday and tomorrow they might well do something you didn't know or think they could do at all.

Below there is a list of DSA and other resources about education and developing independence; these may be found [here](#).

## Resources

- Developing Independence and Preparation for Adulthood (Two-part Video)
- Who decides? Decision making from 16 years old (Video)
- Further Education.
- Education Rights Post 16
- Planning for Adulthood and Transition
- Making Choices and Encouraging Independence
- Supporting Teenagers
- Growing Up: Thinking About Being an Adult (Easy Read)
- DSI International Guidelines for the Education of Learners with Down Syndrome - Lifelong Learning
- Angharad: Preparation for Adulthood
- Emma: Going to College
- Tanzie: Travel Training (video)
- Catherine: About Dreams (video)
- Samuel: My Job as a Swimming Coach
- Preparation for Adulthood Tools (NDTI)
- Thinking Ahead Guide (Together Matters)
- Community Circles (Helen Sanderson)

## Mental Capacity

- Making Decisions Post 16
- The Mental Capacity Act FAQs
- Mental Capacity and Decision Making

## Relationships and Sex Education

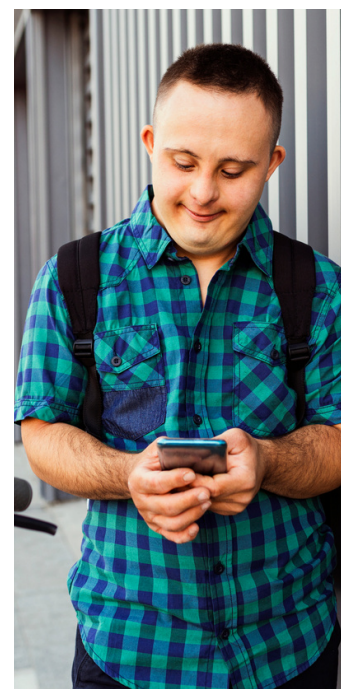
- Puberty and Sexual Health
- Relationships and Sex Education

## Money

- Bank Accounts and Managing Money

## Employment and Work Experience

- DSA WorkFit
- DSA WorkFit Easy Read
- H&M and WorkFit (A Case Study)
- WorkFit Video
- Reece's Business (Video)
- Supported Internships (NDTI)
- Work Experience That Works (Council for Disabled Children)



For additional information, support and training, visit our website, email us or call our Helpline.

Our Helpline is open **Monday to Friday, 10am - 4pm** and can be reached on **0333 1212 300**.



## CONTACT US

### Down's Syndrome Association

Langdon Down Centre,  
2a Langdon Park, Teddington,  
Middlesex, TW11 9PS

**t. 0333 1212 300**

e. [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)  
e. [training@downs-syndrome.org.uk](mailto:training@downs-syndrome.org.uk)  
w. [downs-syndrome.org.uk](http://downs-syndrome.org.uk)

© Down's Syndrome Association 2023