Cyflwynwyd yr ymateb hwn i'r Pwyllgor Plant, Pobl Ifanc ac Addysg ar Llwybrau at addysg a hyfforddiant ôl-16

This response was submitted to the Children, Young People and Education Committee on the Routes into post-16 education and training

RET 16
Ymateb gan: Cymdeithas Syndrom Down
Response from: Down's Syndrome Association

DOWN'S
SYNDROME
ASSOCIATION

Response from the Down's Syndrome Association

January 2025

Introduction

The Down’s Syndrome Association (DSA) submits this evidence to the Children, Young People and Education Committee. We have drawn on our experience of engaging with families of young people who have Down’s syndrome and supporting people who have Down’s syndrome into employment in Wales to inform our response.

We would be happy to provide oral evidence to this inquiry.

The Down’s Syndrome Association

The Down's Syndrome Association is a national charity focusing on all aspects of life for people who have Down’s syndrome. We have over 50 years’ experience of supporting people who have Down’s syndrome, families/carers, and professionals working with them. We have around 20,000 members throughout England, Wales and Northern Ireland. We provide direct support to 70 affiliated local support groups and a range of professionals from different agencies. The aim of the organisation is to help people who have Down’s syndrome lead full and rewarding lives.

We are the lead provider of information, advocacy, support and training to anyone with an interest in Down's syndrome. We are a membership-led organisation, with our membership comprising primarily the family-carers of children and adults who have Down’s syndrome and a growing membership of adults who have Down’s syndrome aged 18+. We are well placed to reflect the needs and views of people we seek to serve. The Down’s Syndrome Association provides lifelong support, in the form of information and advice for people who have Down’s syndrome and their parents and carers. Our free Helpline offers tailored information, advice and support.

The Down’s Syndrome Association has had significant involvement with policy makers across Wales, since the inception of the Welsh Assembly (now the Senedd) in 1999.

- We are part of a consortium of learning disability charities in Wales who meet monthly with representatives from the sustainable social services team at Welsh Government and relevant professionals from Public Health Wales.
- We are members of the Welsh Government Learning Disability Ministerial Advisory Group and meet quarterly with the relevant minster.
- We helped to write the current Learning Disability Action Plan for Wales.

- We were founder members of TSANA, the third sector alliance of charities supporting children who have Additional Learning Needs (ALN) and respond to all relevant policy consultations relating to education provision in Wales.
- We sit on the Antenatal Screening Wales Advisory Group, providing expertise and lived experience of supporting new and prospective parents who have a child who has Down's syndrome.
- We attend the Wales Cross Party Group on Learning Disability.
- We participate in the Wales 'community of practice for professionals supporting children who have a learning disability'.
- We helped shape the Wales Dementia Action Plan in 2018.
- We are members of the British Association for Supported Employment (BASE)

We have a commitment to inclusive participation and work closely with a diverse group of individuals who have Down's syndrome called "Our Voice", who come together regularly to help shape and inform our work.

The Down's Syndrome Association's WorkFit programme was established in 2011. It is a highly successful employment programme, which engages with a range of employers to support candidates who have Down's syndrome into a variety of suitable jobs. We know that people with learning disabilities still face significant challenges in entering the workforce – despite 86% of people with a learning disability saying they want to work, the proportion of adults with a learning disability in paid employment has decreased over time, from 6.0% in 2014/15 to a low of 4.8% in 2022/23.

Operating across England and Wales, the DSA WorkFit programme supports anyone who has Down's syndrome and who wants to work, to fulfil their career ambitions and potential. We bring the following core values to this work:

- We support all people who have Down's syndrome to fulfil their career ambitions.
- We promote the skills and abilities of people who have Down's syndrome and focus on the positive contribution they can make in the workplace.
- We source real jobs (with wages paid at the going rate for the job, with the same terms and conditions as colleagues).
- We have a zero-rejection approach - everyone can work, in the right job and with the right support.

The success of the DSA WorkFit programme is based on a person-centred approach for our candidates, and bespoke advice, resources and training for each employer. To place candidates, we work directly with employers and prospective candidates during the recruitment process, working to ensure jobs are tailored to suit both the needs of the business and of people who have Down's syndrome. As a result of this bespoke support, employers have a greater awareness of Down's syndrome and feel more confident to support a person who has Down’s syndrome in work.

About Down’s syndrome

Down’s syndrome is a genetic condition, caused by the presence of an extra chromosome 21 in the body’s cells. People who have Down’s syndrome will have some level of learning disability. This means they will have a range of abilities. Some people will be more independent and do things like get a job. Other people might need more regular care.

In addition, there are several associated medical conditions, which affect some, but not all, people who have Down’s syndrome, meaning the services that they access from the NHS and social care settings are of paramount importance to their wellbeing. It is recommended that people who have Down’s syndrome should have extra health checks in early life, and regular health reviews throughout their lives.

We estimate there to be around 40,000 individuals living in the UK who have Down’s syndrome.

Response to the inquiry

Quality and nature of information provided to learners

With the introduction of ALN reform, Careers Wales Advisors no longer hold statutory roles in guiding learners with complex ALN towards further education and training at mainstream and specialist FE colleges. There doesn’t appear to be a one-stop-shop for learners who have Down’s syndrome and their families across Wales to access information about post-16 provision and training options, especially within the specialist sector, where some provision, due to the specialist nature may be located outside of Wales.

Specialist organisations (eg. Natspec) provide this information, but not all families are aware of these organisations.

Learners who have Down’s syndrome are not provided with suitable information about apprenticeships and supported employment opportunities.

It is important that learners who have Down's syndrome and their families can easily access information and guidance on a wide range of post-16 options. Local mainstream and specialist schools and colleges must start talking to learners who have Down’s syndrome about working towards career options early, and certainly no later than 14 years old. They should also be expected to source high quality and well supported work experience placements and taster sessions including and beyond the traditional sectors of retail, catering and hospitality. We believe that young people should be encouraged to explore a range of different roles, and to develop transferrable skills to enable them to become attractive work candidates for employers.

Quality and nature of information provided directly to learners by Careers Wales.

Based on feedback we have received, we believe that the provision of information to learners who have Down’s syndrome is patchy at best and generally inadequate. The Careers service appears to have low aspirations for learners who have Down’s syndrome and rather than exploring opportunities to move into supported employment, they focus on encouraging more education.

Referrals direct from Careers Wales to the DSA WorkFit programme have been very low (estimate to be 2 over a period of roughly 10 years). This is despite a DSA WorkFit Officer presenting information about WorkFit to Careers Wales on several occasions in different locations and in different formats. We do not believe that the Careers Wales service is telling all families of young people who have Down’s syndrome about the employment opportunities afforded through the DSA WorkFit programme.

We would recommend that Careers Wales provides information about DSA WorkFit to all learners who have Down’s syndrome.

The extent to which employers are able to engage directly with learners in schools, for example at careers events.

The DSA WorkFit team has attended many careers events over the years, and they have only on occasion had employers present, and then not in large numbers. The events we have attended tend to have a greater number of providers of employment support or education providers (residential or complex needs etc), rather than offering opportunities for direct engagement between learners and employers. Of course, it should be noted that Wales doesn’t benefit from the same range of big organisations and employers as England. Local authority/public sector is the main employer in rural Wales, which can lead to fewer opportunities being available to disabled people.

There is low awareness of future work opportunities for people who have Down’s syndrome, amongst schools (especially mainstream), further education settings and careers advisors.

We also understand from families that careers events, jobs fairs and work experience opportunities can be overlooked within the special school environment.

We recommend the development of careers events specifically targeted towards students who have additional needs, to enable them to explore opportunities for supported employment. We would be happy to attend such events.

To what extent careers support at pre-16 is resulting in positive or negative outcomes post-16 e.g. young people finding themselves not in education, employment or training (NEET).

We are aware of two recent cases whereby a young person who has Down's syndrome has found themselves not in education, employment or training (NEET) due to the very slow process of the Welsh Government agreeing funding for placement of these young adults into specialist residential colleges. There was a delay of several months between leaving secondary education and funding for their college provision being agreed. During that time, they were effectively NEET. They were unable to start their college courses at the same time as their peers, missing out on important opportunities for building relationships and engaging in induction activities.

This could be prevented by ensuring that planning for further education opportunities commences earlier and that funding decisions are made in time for the placement to be agreed in enough time for the young person to start their course at the beginning of the academic year.

Whether work experience opportunities for learners of compulsory school are operational, effective and meaningful and any barriers in that regard.

Based on our engagement with families and people who have Down's syndrome, we believe that learners who have Down's syndrome have fewer opportunities for meaningful and relevant work experience. Employers are often not well supported by education settings to welcome learners who have Down's syndrome into their business for work experience opportunities. Work experience is often limited to artificial situations, such as the college shop or café.

We also understand from families that careers events, jobs fairs and work experience opportunities can be overlooked within the special school environment.

We want to ensure that more young people who have Down's syndrome who are leaving education are work-ready, and that they have the transferrable skills and knowledge of how to approach employment across a range of roles and settings. Offering a range of suitable work experience opportunities will ensure that they can choose from a range of employment roles.

Are some groups of learners disadvantaged by the current system (e.g. pupils from low-income households, learners with travel needs)?

We know that funding for transport to education is a major concern for many families of learners who have Down’s syndrome. It is often decided that it is the responsibility of families to fund this transport, or students are given a bus pass. This fails to recognise the needs of learners who have Down’s syndrome to be able to access travel support and training, and the support they need to travel to a setting is not sufficiently taken into account. Furthermore, specialist colleges are unable to include transport costs in their fees and parents often do not have the financial resources to cover the full costs of transport, which leaves learners unable to commence their study programmes.

A post-16 transport policy should be in place to ensure learners who have Down’s syndrome and other ALN are not discriminated against by the nature of their additional learning needs and learning provision.

For learners whose first language is Welsh, there are limited opportunities to continue education/training in specialist provision through the medium of the Welsh language.

Is there any regional variation in the information and support provided about post-16 across Wales? Are there any particular challenges facing learners in rural areas? Are there any other equality issues?

The default position for local authorities across Wales, guided by the Welsh Government, is for provision to ‘local first’. However, in many areas, especially in smaller rural areas, specialist provision to cater for the needs of students who have Down’s syndrome does not exist locally.

We know of several families where the learner who has Down’s syndrome has been educated successfully in mainstream education to the end of secondary school, who then face very limited options available to them for post-16 education. As a result, the most resourced and informed parents will often look further afield at residential colleges for their young person. This often results in a challenge to secure funding for appropriate provision further afield, especially if this this a residential provision.

Residential colleges may offer specialist vocational courses that are not available at local colleges, as well as opportunities to develop independence skills and confidence. Such provision takes the young person out of their local communities. There are also limited spaces in such residential colleges, meaning that not every young person who has Down’s syndrome will have the same exposure to these opportunities.

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 like to see better access to opportunities to support people to prepare for adult life and their chosen vocations.

We recommend that a review is undertaken of the specialist residential provision, to understand what they are offering in terms of supporting learners move towards both employment and independent living, and how this can be replicated within local communities.

How effective is the Welsh Government’s approach to support participation in the full range of post-16 education and training options?

There is a discriminatory approach in place across Wales where the direction from Welsh Government is for pupils who have ALN for provision to be local (which does not always meet the individuals’ needs).

Furthermore, the ALN Code asserts that a two-year limit on further education is the standard. However, many learners who have Down’s syndrome will need to have more time to embed skills, to work towards employment and to develop independent living skills. They should not be prevented from undertaking three-year vocational programmes in line with their aspirations and life goals.

Please see the Case Study at the end of this submission for an example.

Outcomes from Dr Hefin David MS’s ‘Transitions to Employment’ report.

Only a small part of the report focuses on pupils who have ALN and Engage to Change seems to be the focus. We are not aware of many people who have Down’s syndrome accessing and benefiting from Engage to Change.

Engage to Change and Learning Disability Wales (LDW) have spoken a lot about the need for job coaching for all ALN learners in Wales. The DSA WorkFit model provides an alternative approach to supporting employment for people who have Down’s syndrome which removed the need for job coaches. DSA WorkFit offers an effective, scalable and evidence-based model for actively supporting people with Down’s syndrome into work-related roles, encouraging them and their families to consider paid work as a realistic and feasible option. Further information is available at https://www.dsworkfit.org.uk. Examples of case studies of people who have Down’s syndrome who have been supported into work in Wales can be found https://www.dsworkfit.org.uk/category/wales/.

Case study

S is a young lady who has Down’s syndrome and who has hopes and dreams for independence, relationships and employment, however she requires longer to learn the skills for independence and needs to learn in a real life setting to be able to understand and embed this learning. Like most young people, S is resentful of parental advice and boundaries offered and as a result is very motivated to go away to college and learn alongside peers. S's mother believes that with the support offered from the right environment, S can lead a reasonably independent, fulfilling life, contributing fully to society, including through employment.

The local college stated that they could meet S’s educational needs but could not keep her safe. The local college also could only offer a 3-day course, from 10am-3pm, with lessons in a classroom without the real-life application that S needs.

Following significant research, the family identified Foxes Academy in Somerset, which is a specialist residential college and training hotel for young people with learning disabilities. Over three years, the young person works, trains, lives, and learns life, social and industry skills. These extend to the residential environment (the area where S has the greatest educational need). There are currently no similar facilities in Wales.

Foxes provisionally accepted S to start in September 2024, however the family turned to the Down’s Syndrome Association as they were unable to secure the funding for her to attend through the collaboration of public bodies. Also, they raised concern that the ALP for Wales only provides for courses of a 2-year duration (unless exceptional circumstances), whereas Foxes is offering a 3-year programme. The family were seeking opportunities for S to engage in further education and training tailored to her specific needs and aspirations, with a chance to learn independent life skills in context, in an outcome driven environment. The family feel that S’s opportunities are limited by the lack of appropriate provision in Wales and the limit of 2 years duration for education programmes.