

Written evidence from the Down's Syndrome Association (DEG0125)

Executive Summary:

- There is a clear need for current employment support programmes to reflect some flexibility in order for people with Down's syndrome to access them and also for the DWP to work in partnership with specialist providers like the Down's Syndrome Association (DSA), to improve employment outcomes for people with Down's syndrome. Large prime contractors are often unable to meet the needs of people who have Down's syndrome, other learning disabilities and long term health conditions.
- The DSA's employment programme [WorkFit](#) is based on the simple premise that if people with Down's syndrome and employers are given appropriate training and continued support, sustained employment can be achieved. The WorkFit programme is successful - 92% of candidates placed by WorkFit who have been in permanent paid work since 2012, continue to be employed.
- The WorkFit project has delivered and continues to deliver significant impacts for people with Down's syndrome, their families, employers and co-workers/employees. It offers an effective, scalable and evidence-based model for actively supporting people with Down's syndrome into work-related roles and encouraging them and their families to consider paid work as a realistic and feasible option.
- WorkFit operates successfully without the need for job coaches or other third party stakeholders by using a workplace "buddy" system which significantly reduces overall costs and provides a more organic and typical career pathway for employees who have often had their different abilities highlighted and stigmatised.

1. The Down's Syndrome Association

The DSA is a national charity focusing on all aspects of living successfully with Down's syndrome. It has over 19,000 members throughout England, Wales and Northern Ireland. The Association is in contact with over 120 local Down's syndrome support groups and a range of professionals from different agencies. The aim of the organisation is to help people with Down's syndrome lead full and rewarding lives.

2. About Down's syndrome

Down's syndrome is a genetic condition caused by the presence of an extra chromosome in the body's cells. Everyone with the condition will have some degree of learning disability. In addition, there are a number of associated medical conditions which affect some but not all people with Down's syndrome. The number of people in England and Wales with the condition was estimated at 37,090¹ in 2011, many of them are now living beyond the age of 60 and will therefore be of working age for a significant part of their lifetimes.

3. Challenges to halving the employment gap for people with Down's syndrome.

In 2019, statistics were published by The British Association of Supported Employment (BASE) showing that only 5.9% of people with learning disabilities known to social services are in any form of paid work², but it is known that 65% of people with learning disabilities want to work³. WorkFit is therefore a trailblazer in helping to fulfil the government's aspiration to halve the disability employment gap achieve equality for all disabled people by 2025⁴

*"There are mutual gains when people with Down syndrome are included in the workplace. People with Down syndrome involved in such initiatives have a better quality of life and opportunities for development, while the companies that employ them often report significant improvements in their "organizational health. People with Down's syndrome generally have a positive impact on a number of "organizational health: dimensions such as leadership, external orientation (a positive impact on client satisfaction), culture & climate, motivation and coordination & control. This impact has been measured in qualitative and quantitative surveys of organisations that have chosen to hire people with Down syndrome."*⁵

The positive impact people with Down syndrome can have on "organisational health" also reflects on business performance, as it is known that there is a direct, mapped relationship between increased "organisational health" and business performance.

3.1 The DSA believes the most efficient and cost effective way to create sustainable long term employment opportunities for people with Down's syndrome and other learning disabilities is to meet with each individual to understand their specific needs. The WorkFit EDOs (Employment Development Officers) meet with the candidates to discuss their employment aspirations to gain insights into the areas of interest for the individual and understand their career hopes and ambitions. This approach is validated by the fact that 92% of candidates placed by WorkFit, who have been in permanent paid work since 2012, continue to be employed.

3.2 The Work and Health programme currently operates through large prime contractors, some of whom operate within the private sector and have little or no experience of working with people with Down's syndrome or other learning disabilities. Some providers claim that the requirements of the hard to reach groups are far too great and they are unable to help them into employment.

One DSA member was referred by their Disability Employment Adviser to recruitment company Reed, because they offer the Work Programme. At their meeting with Reed they were referred back to the Jobcentre as Reed stated they were unable to provide adequate support to the candidate.

¹ Wu J, Morris JK The population prevalence of Down's syndrome in England and Wales in 2011 Eur J Hum Genet 2013 Sep; 21(9):1016-9. doi: 10.1038/ejhg.2012.294. Epub 2013

² <https://www.base-uk.org/employment-rates>

³ Valuing Employment Now; real jobs for people with learning disabilities, p2, Department of Health, (2009)

⁴ Disabled People in Employment (Aug, 2020)

⁵ McKinsey Report 2018

3.3 Work Choice in its current format, particularly around full-time work, does not meet the needs of people with Down's syndrome, other learning disabilities and long term health conditions. Work Choice currently subsidises employers who take on someone with a disability. WorkFit does not need to do this as it already has employers committed to employing people with Down's syndrome. WorkFit is therefore cheaper to operate than Work Choice, which is currently delivering outcomes of around 60% leading to approximately 12,000 jobs per annum. Assuming continued employment projections, this will not by itself achieve the Government's ambition to achieve 1.2 million new job starters. It is to be seen where the remainder of the jobs will come from but job retention has to be a priority so as to reduce the numbers of people falling out of work. Many people with disabilities are leaving work for various reasons; worsening health, bullying, lack of support, changing job roles, line management etc. Many could be supported to retain their employment if they were offered timely and effective support. The quick response by WorkFit Employment Development Officers (EDO's) to issues in the workplace is often enough to retain and develop their employment.

3.4 The budget for the Work and Health Programme is similar to that of Work Choice. These programmes fail to address the specific needs of people with Down's syndrome and other learning disabilities. The success of the WorkFit programme is proof of the need for a more tailored approach.

3.5 There is a clear need for current employment support programmes to reflect some flexibility in order for people with Down's syndrome to access them and also for the DWP to work in partnership with specialist providers like the DSA, to improve employment outcomes. The following actions by the government would support people with Down's syndrome into employment:

- WorkFit to be recognised by the DWP as a specific provision for people with Down's syndrome and paid directly. Payment should not go through a third party service provider.
- Raise awareness of WorkFit with Job Centre Plus branches in England and Wales
- Extension to Access to Work: people with Down's syndrome will not immediately be able to work for 16 hours or more per week, but this can be achieved for many with support over time. This extension would also be useful particularly in rural areas where transport is not easily accessible.
- Recognition of the long term benefits employment brings to both the mental and physical health and well-being of this group.
- A system that facilitates programmes like WorkFit to work with Disability Confident employers.

4. WorkFit - Connecting Employers and Employees with Down's Syndrome

4.1 WorkFit was launched in England in 2012 to develop and support mainstream employment opportunities for people with Down's syndrome and now also operates in Wales. Employment Development Officers support employers to create work opportunities for people with Down's syndrome and provide bespoke support to each organisation and also to prospective jobseekers. Support to employers includes training for staff and

managers on how to work effectively with people with Down's syndrome, along with on-going workplace support/advice where needed.

4.2 The programme receives no government funding and is dependent on donations from individuals, trusts and corporates. Initially WorkFit was run by one Employment Development Officer (EDO) but the demand from both employers and employees was such that it grew to a small team of staff.

5. The WorkFit pathway

5.1 The website (www.dsworkfit.org.uk)

The WorkFit website is the main public facing aspect of the programme and it is supported by social media presence on LinkedIn, YouTube, Twitter and Facebook. It contains dedicated sections for employers and individuals and facilitates registration onto the programme.

5.2 For employers, the website provides employers with a large range of resources to support their recruitment and selection process, supplemented by additional resources for employment legislation and best practice and case studies.

5.3 For people with Down's syndrome the website as part of the DSA online presence provides information about the different types of work available (volunteering, work placement, apprenticeship and paid work) alongside the DSA Specialist Advisors. It also provides information about the implications of work on their benefits and entitlements along with Easy Read resources to help them to consider choices to support their career pathway. Our YouTube channel provides a range of films showing people who have Down's syndrome at work and also in other activities such as at home with their spouses, with their families, taking part in sport and social activities and many other scenarios. Our various social media channels also raise awareness and celebrate the success of our stakeholders.

5.4 Employer support

Once registered, both candidates and employers meet with an EDO, assigned by geographical regions. For individuals with Down's syndrome this involves ascertaining their job readiness, talking to them about the kind of work they might like to do and establishing their support needs. For employers, the advice will involve helping to establish what roles might be available and suitable for an individual with Down's syndrome. The EDO will offer a range of advice relating to how to support a colleague who has Down's syndrome including what reasonable adjustments might need to be made in the workplace to support the individual, reviewing HR procedures (e.g. ensuring that the staff handbook is accessible) and identifying areas of training required within the company, to name a few. They will also work closely with workplace buddies to support them to fulfil their roles as trainers and buddies/mentors for their new colleague who has Down's syndrome.

5.5 Placing a candidate

Once an employer has been through their bespoke package and a role has been defined, the EDO sources suitable candidates for the role(s) available and puts forward up to three candidates for interview. At this point the employer is provided with bespoke training to prepare them to meet the candidate (s) and facilitate an informal interview. Once a candidate has been selected, the EDO will work with them to identify the right package of

support. Alternatively, an EDO can recommend a candidate based on their Vocational Profile and suitability.

5.6 Once a candidate is placed

The WorkFit model recognises that employers and individuals with Down's syndrome may need further support once a candidate is placed, whether this is to deal with any immediate challenges that arise or to offer support with new issues that arise as a candidate progresses in their role. The EDO is available to support both parties on a seamless and ongoing basis once employment has commenced.

WorkFit Numbers Since January 2012	
people with down's syndrome registered with WorkFit	1135
people with down's syndrome actively looking	724
people with down's syndrome who have secured work through WorkFit	417
Employers registered onto WorkFit	501
Employers trained by WorkFit	454
Employees trained by WorkFit	2,814

All processes are underpinned by the knowledge and expertise of the WorkFit EDO and the DSA who can provide tailored support.

5.7 WorkFit has improved employment outcomes for people with Down's syndrome. Since its inception in 2012, 417 people with Down's syndrome have entered work placements, including paid employment. An independent evaluation⁶ of the development of WorkFit in Wales carried out in 2017 reported on the wider benefits the programme has provided for both employers and employees. This was further confirmed by the independent evaluation⁷ of the delivery of WorkFit in the North of England, planned to be published in December 2020, which highlighted on similar positive outcomes.

6.1 Impact upon people with Down's syndrome who were supported into an employment opportunity through WorkFit

- Interesting and enjoyable jobs
- Increased circle of friends and contacts through work
- Accessing new and more varied social activities through work
- Greater community involvement as a result of activities undertaken during the working day
- Greater understanding of work options available to support future career planning
- Increased confidence about doing their existing job and working with current colleagues
- Almost all of those interviewed for the WorkFit Wales and the WorkFit North evaluations had received no support from other agencies, including minimal input from careers agencies. Often the WorkFit EDO was the only source of employment advice and support.

⁶ Stephen Beyer and Ruth Townsley South West Employment Institute

⁷ Amanda Topps, Amanda Topps Consultancy

6.2 Impact upon employers

- All of the employers interviewed felt confident about being able to support a person with Down's syndrome in the workplace and attributed this to the training they had received from WorkFit
- A flexible approach to in-work support meant that employees who had Down's syndrome had the option to supply their own in-work support to employers if that was their preference – one person was accompanied to work by a PA paid for by her school; one person also had a PA working alongside her, funded through Direct Payments; another person used her Direct Payment hours as a cash payment to cover two hours' support a week provided by her employer
- Employers are very happy with the quality and timing of the training input from WorkFit and appreciate the regular, proactive contact from the Employment Development Officer
- Employers are very positive about their employees with Down's syndrome and have provided excellent feedback on all areas of people's performance at work
- Several employers have commented on the satisfaction of seeing people learn, develop, and grow into their work roles
- All employers would consider employing another person with Down's syndrome, or learning disabilities, in the future, given a vacant position and availability of support from WorkFit or another agency
- Several employers highlighted the positive PR that comes from employing a person with Down's syndrome which has included direct comments from customers and positive feedback on social media.

7. Evidence that WorkFit can support work to bridge the disability employment gap

7.1 WorkFit is a successful and award-winning model, receiving recognition from the British Association of Supported Employers (BASE) and other organisations listed below. The BASE National Awards are particularly highly regarded within the supported employment and business communities across England and Wales and WorkFit has been successful in the following categories:

- Practitioner of the Year – two awards for WorkFit Team members who have actively promoted supported employment and the investment in learning and skills to create real benefits to business and individuals within the workforce
- <http://www.downs-syndrome.org.uk/news/alison-thwaite-wins-award-as-learning-skills-champion/>
- Best Employer Practice – won by different WorkFit employers for the last 4 consecutive years
- David Grainger Award – won by a man who has Down's syndrome who was supported into his job by WorkFit

Further awards that recognise WorkFit:

- Employment Related Services Association (ERSA) Annual Awards 2018

- Cardiff and the Vale Parents' Federation 'Understanding Disability Awards' – joint award for WorkFit and employer Jojo Maman Bebe.

Further details of the awards can be found at:

- <http://www.dsworkfit.org.uk/2019/11/22/best-employer-practice-award-for-xpo-logistics/>
- <http://www.dsworkfit.org.uk/2018/12/10/wiltshire-police-awarded-best-employer-practice-award-for-2018-by-base-british-association-of-supported-employment/>
- <http://www.dsworkfit.org.uk/2018/06/25/workfit-triumph-at-the-ersa-awards-2018/>
- <http://www.dsworkfit.org.uk/2017/12/15/greggs-triumph-at-the-understanding-disability-awards-2017/>

7.2 We are all being asked to live differently due to the Covid-19 pandemic, but for many adults who have Down's syndrome, their jobs independence and social connections have been extremely hard won. Many adults who have Down's syndrome work in sectors that have been particularly impacted by COVID-19 (hospitality, catering and retail). In addition, we have concerns about loss of skills amongst employees, if people are not practising these regularly. We need to recognise that some additional 'catch-up support' will be require to ensure that this group of individuals does not get left behind when these sectors begin to reopen.

The WorkFit model has adapted to meet the needs of our candidates and their employers to support rewarding and sustainable employment opportunities and has lately pivoted the model to continue to deliver to all parties via online platforms as required in line with the requirements of the Covid-19 safety guidelines. The DWP has an opportunity to work in partnership with specialist providers, like the DSA, to improve the employment outcomes for people with Down's syndrome and other learning disabilities.

In summary, independent evaluations of the DSA's WorkFit model over the last four years along with extensive feedback from stakeholders provides compelling evidence of the success of the model in delivering significant impacts for people with Down's syndrome, their families, employers and co-workers/employees and in contributing to the ambition of halving the disability employment gap.

WorkFit in England & Wales offers an effective, scalable and evidence-based model for actively supporting people with Down's syndrome into work-related roles and encouraging them and their families to consider paid work as a realistic and feasible option.

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