

The Invisible Workforce

A Report by the Down's Syndrome Association



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Foreword

In 2006 the Down's Syndrome Association was given a marvellous opportunity to run a national employment campaign. We were able to design and produce a poster featuring a man with Down's syndrome asking employers to give him a job. The poster then appeared on thousands of advertising sights mainly in London but it did eventually reach other parts of the UK. The most talked about site was the 'Torch' on the M4 at Hammersmith where it was featured for approximately three weeks. We then followed up the poster campaign with a direct mailing to employers in different parts of the UK.

The stark reality of a large image of a man with Down's syndrome asking them to consider including someone like him in their workforce seemed to come as a complete surprise to most employers. There was a huge amount of interest in the campaign and for a few weeks our information lines were 'red hot' with requests from companies for us to find someone for them.

Unfortunately, we found that there were so many barriers in place to finding and employing someone with Down's syndrome that most employers just gave up out of sheer frustration.

Following on from this experience, we decided to send out a questionnaire to our members with Down's syndrome, their families and carers to see what was really happening for them. The results of our findings were similar to those we encountered with the employers. Once again

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the complexities of finding a paid job and being able to travel to that job independently seemed to be really difficult to achieve for most people. Only those who had a tremendous amount of support from their families/ carers were successful.

I'm delighted that the Government is trying to find better ways to make it easier for people with learning disabilities to find and keep a job but I think that we still have a very long way to go to achieve that. I hope that the findings in this report will be of some help towards a better understanding of what is actually happening in reality together with some useful suggestions.

Finally, it is absolutely right that we do everything we possibly can to support people with learning disabilities to find paid employment. However, it is important to remember that there will always be people with learning disabilities for whom paid employment will never be a realistic option. Our survey shows that there are a significant number of people with Down's syndrome who are working as volunteers or are using a day service and they believe that they have a 'real' job. It is imperative that this group of people will continue to be provided with meaningful daytime activities and that they are not penalised financially due to their inability to take up paid employment.



Carol Boys

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Employment issues in context

In December 2006, the Down's Syndrome Association (DSA) began an awareness-raising campaign to highlight the barriers that people with Down's syndrome (DS) face when trying to secure employment.

Our principle campaign tools were:

- **Dec 06 – March 07: awareness-raising advertising campaign.** Our advertising posters (see appendix A) were displayed on roadside billboards, in national rail and London underground stations and in health clubs, malls and cinemas throughout the UK. It was also displayed twice in the Guardian newspaper.
- **March 2007: direct-mailing campaign.** We approached just over 1000 companies in London, and some in North-west England, encouraging them to think about their own attitudes to employing someone with Down's syndrome (see appendix B).
- **June 2007: survey** among members of the DSA with Down's syndrome of working age, to find out about their employment experiences (see appendix C). The response rate was 30%. We used the results of this survey to further highlight our employment campaign during our annual Awareness Week.

The following report is based upon the responses we had to our awareness-raising campaign (both the posters and the direct-mailing) as well as the results of the employment survey among our members. We have also drawn upon our experience over the past year of dealing with employment enquiries on our helpline.

The principle aims of the campaign were:

- To encourage employers to think about employing people with DS.
- To raise awareness among the general public that many people with DS can and do make a significant contribution to a workplace, with the right support.
- To highlight the barriers that we know exist for people

with DS trying to secure employment.

A year on, we believe we achieved these aims with reasonable success. However, since the start of the campaign, two significant things have happened:

1. There has been a noticeable effort on behalf of various government departments to prioritise supporting people with learning disabilities into employment.
2. The process of our campaign has taught us a great deal more about employment issues – we believe that an evaluation of our findings and experiences throughout 2007 can now make an important contribution to this wider debate about employment.

During 2007, the following Government documents were published which all had a significant statement to make about employment:

- The **Welfare Reform Act** highlighted the increasing focus upon supporting people into work and off benefits, including those with learning disabilities.
- **'Public Service Agreement 16: Increase the proportion of socially excluded adults in settled accommodation and employment, education or training (EET)'** – this document was based upon the aim to increase the proportion of vulnerable adults in housing and EET, and outlined the delivery strategy for achieving this.
- The Green Paper **In Work, Better Off: Next Steps to Full Employment** outlined how the government plans to achieve full employment, by improving job prospects for those who are most disadvantaged in the labour market.
- **Valuing People Now** placed a significant focus on increasing 'real work for real pay' in the section entitled 'what people do during the day'.
- **Full employment and world class skills: Responding to the challenges** only touched briefly on people with disabilities, but stated: *"DWP needs to explore ways to assist disabled people...to find and sustain work."*

We agree that local partnership working is vital and ask DWP to clarify its role and responsibilities in brokering local relationships..."

- **Reducing dependency, increasing opportunity: Options for the future of welfare to work** provided a review of progress of the 'Welfare to work' programme over the last ten years, and outlined where changes still needed to be made to meet the Government's aspirations of full employment.
- The **Public Consultation on Improving Specialist Disability Employment Services** lays out the proposed plans for improving existing specialist employment services and offers the chance for public feedback.
- The **Comprehensive Spending Review** announced that a new Green Paper would be written that would spell out the reforms within Adult Social Care. This will affect adults using support services to find a job, as well as those who do not work and rely on care services to support them with other meaningful activities.

The DSA welcomes the Government's renewed focus on employment issues for people with learning disabilities. However, this renewed focus alongside the results of our employment campaign raises some concerns:

- 'Real work for real pay' is a desired and appropriate aim for some people with Down's syndrome, and should be encouraged. However, this should not be the only option available. The focus on employment should be seen as a way to improve job opportunities for those who choose to take this route, rather than something that limits options for others. Expecting

everyone with Down's syndrome to engage in paid work is neither desirable nor appropriate.

- There seems very little recognition so far of the huge diversity among people with Down's syndrome. The employment agenda needs to reflect this diversity, in terms of the range of support needed and the types of activities available.
- Paid work without the right preparation or support could have serious consequences for both employer and employee, which could have a negative impact on the progress made in employment issues so far.
- There are still numerous and very real barriers to paid employment for those adults with Down's syndrome who are trying to follow this path. The wealth of initiatives has not yet been transformed into practical solutions.
- For those employers who do want to employ someone with Down's syndrome, too many are put off by the seemingly long and complex process involved in recruiting someone if they use a third party employment agency. It is important that changing attitudes are supported by real and practical information about how to turn a vision into reality.

Overall, it seems that the two key challenges are:

- Helping secure 'real work for real pay' for those who want it and for those who are able to follow this route.
- Ensuring the right support is available for those who want, or need, to do meaningful activities other than paid work.

What are the reasons behind encouraging employment?

There seem to be two starting points from which the debate about employment is being addressed.

The first is:

"We need to reduce unemployment levels, therefore we must encourage people off incapacity benefit and into work."

The second is:

"People with learning disabilities should have the same options open to them as everyone else, and employment should be one of these. We must ensure that adults with learning disabilities have the support they need to undertake the daytime activities that they choose, and ensure that they understand the full range of options available."

The DSA believes that any useful and meaningful progress in employment can only come from the second starting point. We are concerned that in some circumstances people may cite 'encouraging independence' as the reason behind promoting employment when in fact they are more concerned with reducing unemployment. In other cases, the needs and wants of the individual are the genuine starting point, but they become lost in striving for a reduced number of people on benefits.

These are just a sample of some of the responses we received from parents/carers when asked to comment on their dependant's experiences of employment:

"As his mum I have seen a fantastic difference in him [since starting paid employment]. His confidence has increased enormously, he travels independently on public transport."

"Her [paid] job is very important to her. It helps to give focus and purpose to her life and has given opportunities for a wider circle of friends and acquiring skills related to the job and to normal adult social life."

"I am very worried that the government will put pressure

on recipients of Incapacity Benefit to get paid work. Kitty will probably end up stacking shelves [instead of her current voluntary role at a children's nursery] as the nurseries cannot afford to pay her. She cannot do the same as a paid nursery assistant but what she can do is much appreciated."

"This form [the DSA employment survey] is not really relevant to Jeremy but MacIntyre Care have an excellent day centre at Ampthill where Jeremy receives a lot of stimulation and enjoyment. He is more able there than at home."

"Em puts her heart and soul into her [voluntary] job and loves going in. Her mum and I [carer] put money in an envelope at the end of the month – her 'wages.'"

"What my son does is enriching his life. He is happy with his one day [of voluntary work] and doing other things on other days."

"Lucy's 'work' is provided by social services – they are very good at person-centred planning. She only gets 80p a day in order to keep her benefits, as she has no concept of the value of money. It works very well."

"Something seriously needs to be done as too many people with Down's syndrome are just sitting at home. 'Stepping Stones' is ideal for the higher ability person and [the local] Adult Resource Centre is ideal for the profoundly disabled but there is nothing for those who are 'in between' and my daughter falls in this category. Facilities are desperately needed to occupy their time, but not necessarily in a job placement."

Within only this small selection, it is clear that there is an enormous range of needs, desires and difficulties to face. It seems obvious that if these are going to be met, there must be a range of solutions.

The recent Government protocol 'Putting People First' emphasises that the new direction in adult social care must be led by the individual. This is also arguably the way forward when considering employment. Rather

than aiming to meet 'percentage targets' for paid employment, one must look at what the individual wants and needs and be led by that. (Interestingly, great emphasis was put on the concept of 'personalisation' in 'Valuing People Now' but this seemed to be somewhat in opposition to the emphasis on employment as a replacement for day services rather than as another equally accessible option.)

Of course, there is no point asking individuals what they want if there are no services, or funding, to provide them with that. 'Personalisation' must NOT be seen as an excuse for poor quality services or

for not making support available.

When we surveyed our members with DS of working age, 49% of respondents were not in any sort of 'employment', either paid or unpaid. This means that nearly half of the population of people with Down's syndrome face adulthood without paid work, a work placement, voluntary work, or working opportunities through day services or support packages.

The more genuine choice there is, the less likelihood of people with Down's syndrome entering adulthood with the only viable option being to sit at home and do nothing.



Securing paid employment: the main barriers

For an increasing number of people with DS, the option that they will want to go for is paid employment, yet there are still too many barriers in this field. The following themes emerged time and again during our focus on employment:

• Understanding the concept and world of work

“She would like to try different types of work to find out what she likes.” (DSA survey response)

For many teenagers leaving education, the concept of work is a very abstract one. For those teenagers with learning disabilities, who may find it particularly difficult to process abstract ideas or relate one concept to another, getting to grips with what they might like to do can be a real problem.

The DSA recently ran a small project in which a group of adults with Down’s syndrome were filmed talking about their experiences of work. It was clear from these interviews that the majority of these adults had trouble imagining what work they might like, or might be good at, when taking into account their strengths and weaknesses and likes and dislikes. For example, one man wanted to “work in an office” – when asked what this would entail, or in what sort of field, he could not respond. He clearly had a passion for football, and when it was put to him that maybe he could do administrative work for a football club, he was adamant that this would not count as office work as it would be at a football ground.

56% of our survey respondents who were in no sort of employment at all had done work experience – clearly the current practice of work experience is not leading onto further meaningful activity.

Improving work experience opportunities is crucial in supporting people with DS to have a taste of what working involves, what sorts of jobs are out there, what they are good at and what they like. Far too often, work experience in schools comprises of a week at a shop or in a garden centre, and from this young adults are expected to make choices about what they would like

to spend the majority of their time doing. People with Down’s syndrome would benefit much more from a regular timetabled work placement in a range of situations. The flexibility that comes in Key Stage 4 can accommodate this, and work experience could be built into the weekly timetable. This would give real, direct experience of a range of work situations. Expecting people with Down’s syndrome to transfer skills from one type of work to another is unrealistic.

Mishandling work experience placements can have devastating consequences not only on limiting future choices but on confidence to approach the world of work:

“Miriam is terrified of an official work place as her school was very bad and handled work experience in a very tactless way, with little preparation. I used to see other pupils near my home being humiliated by staff. I complained to the headmaster, but to no avail. Miriam suffered something similar and has never got over it.” (DSA Survey Response)

The DSA also speaks regularly to young people who do not have clear understanding of the responsibilities of working and keeping a job. It can be difficult for an individual who sees other peers taking a more leisure-based approach to their daily activity, to understand that if they have chosen the option of paid work then they have to see it as a proper commitment. While choice is vitally important, there also have to be boundaries within each option.

• The role of schools

Alongside securing more useful and relevant work experience placements, schools and Further Education colleges have a vital role to play in making the transition from education to employment a much easier one.

Not only must there be a focus on making FE courses more relevant, but it is vital that staff working within schools understand the needs of the individuals they are working with. We recently had a call from the mother

of a very able, bright, outgoing young man. The Head of the Special Needs Unit at her son’s FE college had told her *“you are setting him up to fail if you get him a job.”* The young man was given the option of litter-picking or washing cars as his ‘work experience’. The DSA agreed to take him on to do work experience one day a week, which he thrives upon. He is a reliable and hard worker, undertaking a variety of basic admin tasks such as stuffing envelopes, franking and labelling mail – tasks that are common in many organisations. Clearly, he is able and willing to work, but if someone responsible for SEN takes such a negative line, the chances of him being supported into employment seem slim.

The DSA also believes that thinking about ‘transition’ from childhood to adulthood needs to be done earlier – it is too late to start the process of considering options in the final months of FE college. The 14+ Transition Review should be the time at which work experience options begin to be planned.

The DSA is encouraged to see the move towards more joined-up thinking through the strategy ‘Progression through Partnership’, and our members will be watching closely to see how this develops in the next few years.

• Attitudes of employers: fear, ignorance, misunderstanding or discrimination

There is no doubt that attitudes towards employees with learning disabilities have improved in recent years, as this sample of responses from our survey testifies:

“The positive attitude of the people she works with has helped us to overcome hiccups. I’m sure the outcome may not have been so good if the attitude had been different.”

“I enjoy jobs that I do and the people that I work with are kind and supportive to me and I love working with them.”

However, there is clearly still a lot of work to do in this area. For many people, the experience has certainly

not been as positive:

“The staff seem uneducated about people with learning disabilities. They are nervous about letting her work on her own.... As Camilla recently told me, she can do the jobs she is given, it is the staff who need the support and educating.”

“Initially our job centre was excellent and pro-active, but most employers weren’t interested in someone with special needs. We know Jo is lucky – none of her friends are employed.”

There are two key issues for employers: HOW should they recruit and retain someone with Down’s syndrome, and WHY? Clearly, most employers will consider the WHY before they get to the HOW.

When employing anyone, employers will always be asking themselves: what’s in this for me? At present, it seems to be either a social responsibility or the hope of an image-boost that sways employers. This may not always be enough to persuade an employer to pay someone’s wages.

It is vital that we reach employers who have the resources but not the motivation to employ people with DS, and provide greater incentive for positive discrimination. Possibilities for doing this include:

1. Educating the employer so that they see past the disability and recognise the strengths of the individual. This requires awareness-raising to change attitudes, which was the starting point of the DSA’s employment campaign. Many of the responses of those people from our survey who were in employment outlined not only what the employee was gaining but what the employer was gaining:

“David is a good time-keeper...”

“Dougal has hardly had a day off sick in ten years...”

“Michael is really appreciated by customers...”

“He works hard, aims to please...”

“Her accuracy and work output are top level.”

"I enjoy meeting the customers and love it when I have to use my sign language."

2. Providing some sort of nationally-recognised (and possibly financial?) award to employers who not only employ someone with Down's syndrome, but who do so successfully – e.g. based on an evaluation by the employee.

The prospect of employing someone with Down's syndrome can be daunting for an employer who previously has had no links with the world of learning disabilities. It is crucial that information is provided about:

- Where to go for help in finding suitable candidates.
- How to adapt traditional recruitment processes so that they are accessible for people with Down's syndrome (one survey respondent told us: "He tried to apply to a supermarket – he could do shelf-stacking because he understands sell-by dates and is neat and tidy – but they insisted on his filling in a psychological profile, which is beyond me let alone him.")
- What extra support someone with Down's syndrome may need once they start the job, and what providing that will entail.
- How to help the employee progress in their role (which may not be the same process for supporting career-progression among other staff).
- How to support other staff in working with the employee.
- What reasonable adjustments need to be made, and equally what is unreasonable behaviour on behalf of the employee (many employers have told us that they are afraid of the consequences of what might happen if a work placement for someone with a learning disability goes wrong, so avoid hiring the person in the first place).

Many employers don't know where to go to find this information. It is important that training for employers

is publicised at every opportunity – e.g. the DSA offers bespoke training to meet the specific needs of staff and employers.

It may also be useful to use a successful employer as a 'model' for other companies, to show them not only that it is possible to employ someone with DS, but the logistics of achieving it.

• Transport

Time and again, our survey respondents cited an inability to use public transport as a key reason why they could not work. If the Government is expecting more people with Down's syndrome to work, they need to recognise that relatively few can travel independently, and this is a serious practical issue to address.

Many people would benefit from a focus on travel training at school and college – again, there is a need to start this earlier (where appropriate) rather than leave it to the time when an inability to travel really limits opportunities.

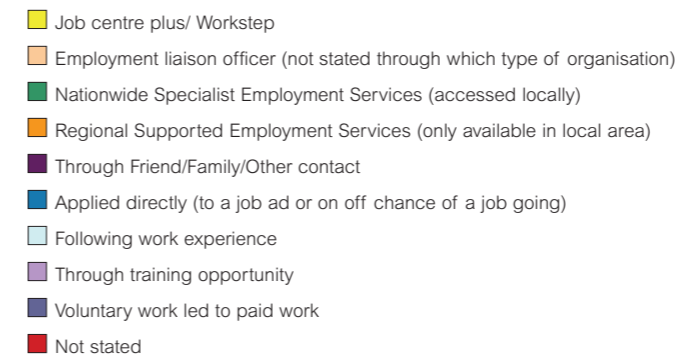
For many adults, travelling independently may not be an option, and suitable systems, with the funding to support them, need to be in place so that this does not prevent people from working.

Among the DSA survey respondents, only one mentioned Access to Work as a way of getting support for transport. We do not know whether the lack of use of services such as these is due to insufficient information about them, whether the services themselves are not functioning efficiently, or whether fewer people are unable to access them as funding is reduced.

Another serious issue related to travel is the vulnerability that people feel when using public transport. Through calls to our helpline, we have come across adults who might be capable of travelling independently, but who feel too vulnerable to do so based on experiences of bullying, hate-crime or discrimination aimed at them or their peers.

• The limitations or inefficiencies of Specialist Disability Employment Agencies

A chart to show how people found paid employment



This is just some of the feedback we received from our respondents about using specialist employment agencies:

"No support available and no supported placements available for the type of work wanted (working with animals)."

"Andrew would like to work and is very able. The Social Services here would not help us to find either work or leisure ideas for him to do."

"Tried Shaw Trust – no opportunities, no support, no encouragement."

"Our local authority has NO training for young people with learning disabilities and there needs to be a training scheme set up to help find work for them."

"Went to job centre and was told there were no suitable jobs."

"I'm finding it very difficult to get a paid job, I believe because of my learning disability. All the agencies want to do is help with interview technique which I have done a few times, and tell you about vacancies where you don't have a chance against an able bodied person."

None of them can actually help you get a job."

There seems to be a missing link between the adults with DS who want a job, and the employers that would like to hire them. Given that potential employers appear to be few and far between, the recruitment process needs to be made as simple as possible.

In some cases, it seems that the employment agency staff may not be equipped to carry out their jobs properly. The DSA had a helpline call from a distressed mother recently who told us that the learning disability adviser at the local Job Centre Plus had told her "I never place anyone with Down's syndrome because they all have a tendency to be too cuddly".

This is clearly not acceptable, and it is vital that all staff working for Job Centre Plus or similar independent organisations receive appropriate training and that their work is monitored.

Staff must also be aware of the learning profile and capabilities of people with Down's syndrome. One young lady with DS attempted to secure a job through Shaw Trust. She was more than capable of the role, but Shaw Trust set up a telephone interview, which, given her communication difficulties, meant that she was unable

to prove herself as the bright and capable woman she is. Consequently, she was not offered the job, and Shaw Trust did not find her any further opportunities. Eventually, her mother found her a similar role by knocking on doors of companies, and she now thoroughly enjoys her job.

It is not only potential employees who find the current support services inadequate – too many employers who have approached them have been met with closed doors. One man, who had recently employed someone with Down's syndrome and who wanted to employ someone else, asked for help from a specialist employment agency, and was told that they could not find him a candidate with Down's syndrome. When he tried to persist, he was told that he was being discriminatory by only wanting to recruit someone with DS. It seems baffling that a specialist employment agency is not open to practising positive discrimination.

In the instances where specialist employment services do have the staff and resources to work efficiently, they still face the problem that many employers either don't know very much about these services, or are reluctant to use them. The idea of having to go through various organisations and involve social workers to employ just

one member of staff is a real barrier to employers. The awareness that was generated by the DSA's poster campaign and direct mailing led to several calls from potential employers who wanted to employ someone with Down's syndrome. However, the DSA was only able to signpost them to relevant support services in their area – we are not an employment agency ourselves. Typically, when we told the caller this, they were put off by having to go from one organisation to the next:

"Our HR department is very stretched. I had hoped you have some candidates handy. We will look at it ...when it becomes more quiet." (HR director of company in Acton)

"We are sure that there must be lots of people with DS in the area who want to work, but it seems impossible to link up with them." (Head of HR at company in Watford)

Of course it is the responsibility of employers to learn about these processes and put them into practice where possible – particularly public sector organisations who are bound by the 2006 Disability Equality Duty act – but there is a clear need for simplifying and improving these services so that they are more accessible for employer and employee alike.

"He is a very able, willing and capable individual and it appears that if he does not want to do gardening or catering then there are no opportunities for him." (DSA Survey Response)

There is an added difficulty in finding employment opportunities in light of modern working practises that are heavily technology-based, as there appears to be a shortage of what were once seen as 'typical' options. Tightening of various workplace rules and regulations means that increasingly, everyone has to be able to read health and safety warnings, or to carry out their own risk assessments... This will be beyond the abilities of most people with Down's syndrome, and therefore discriminates against them in the workplace.

This shift in job types means there is a risk that people with Down's syndrome face even more reduced opportunities, as they are pigeon-holed into the only jobs that employers believe they are capable of, based on presumptions and stereotypes.

Over half of the paid jobs undertaken by our working survey respondents were in the retail or catering sectors (29% retail and 25% catering).

Rather than pushing people into jobs that they might not necessarily want to do, there is an urgent need to think more creatively about job opportunities.

This should come from a person-centred approach, matching the strengths of the individual to appropriate jobs.

For example, our Information Team spoke recently to the mother of a young man with Down's syndrome whose frustration with his living situation had led to severe behavioural problems. Various unsuccessful attempts were made to "calm him down", until eventually it was recognised that it would be more appropriate to 'channel' his anger: he was given a job at a recycling plant where he was responsible for breaking up all the materials – destroying things to his heart's content! He excelled in his role, and his behaviour at home improved dramatically.

• The practicalities of the day-to-day role

"Russ is very happy at work, but has problems from time to time as his managers overestimate his ability to understand instructions – and don't realise he won't always ask when he doesn't understand. [The company's] strict policy on leave is difficult as they don't always realise he has to holiday with us." (DSA Survey Response)

Starting a new job is a daunting prospect for anyone. If there are communication difficulties between employer and employee, it can be enough to make either party want to give up before they've really begun.

It is important that greater emphasis is placed on providing practical tools to facilitate communication between all involved parties. It would be useful to have some sort of template that parents/carers, employer and employee can use to aid understanding of the job and all that it entails. For example, the DSA has produced a template that all parties can complete and keep a copy of so that everyone is agreed on what the expectations are (see appendix D). We also have visual timetable software, originally created for use in schools, but that could be easily adapted for use in the workplace (see appendix E). These sorts of tools can help to overcome a common difficulty for people with DS of dealing with the unexpected, and can make the employment process a much more positive experience for all involved.

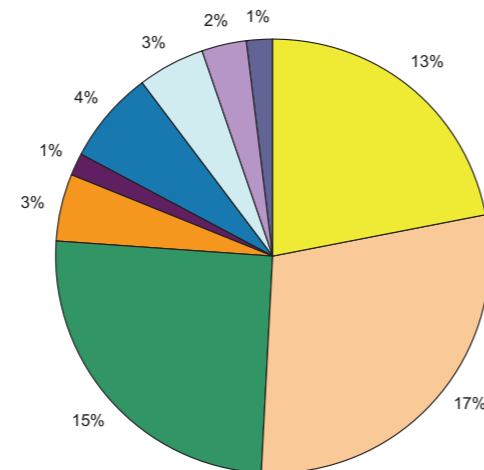
One case which the DSA was informed of involved a young lady who worked as a kitchen assistant. Her job was to prepare the first part of the food then pass it onto the chef. When the chef was absent on one occasion, no-one informed her and after she did her usual tasks she was left waiting for four hours as she was not sure what to do next. When she was finally told that the chef was not coming, she was so embarrassed that she ran out of the kitchen, knocking over a pan as she went. It was then decided that she was a health and safety hazard and she was dismissed.

Employers and staff need to understand exactly what an employee with DS is capable of, and understand that their reactions to certain situations may be different to other peoples.

• Types of jobs available

A chart to show in which sectors people in paid employment work

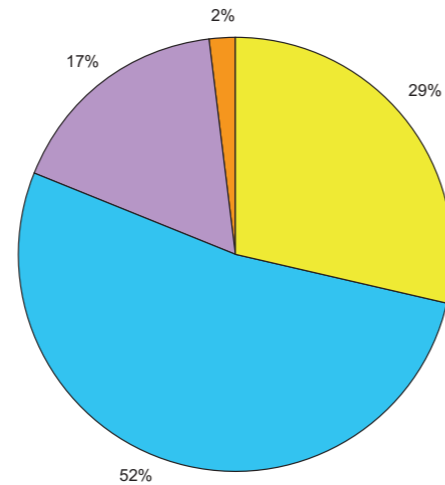
- Administration
- Retail
- Catering
- Cleaning
- Care Work
- Outreach
- Manual labour
- Arts
- Reception
- Horticulture



• Working hours

A chart to show how many hours people in paid employment work per week

- Less than 7 hours
- 7-21 hours
- More than 21 hours
- Doesn't say



Within our survey, out of the 59 paid jobs that were undertaken (some by the same person) 82% of them were done for under 21 hours a week. Of the people who worked more than that, although not all answers were clear, it seems that very few work full time.

For the majority of people, the amount of time that they worked (some as little as 3 hours a week) suited them. They did not desire a full-time job: some wanted time to do other things, some simply felt unable to work for longer than they already did, and even had to reduce their hours:

"It hasn't all been plain sailing especially early on. Joe had trouble staying on task, even staying awake, but working with the store we adjusted his times etc to achieve the desired results."

"The tiredness factor is very noticeable and I really don't think that Karen would have enough energy to sustain either longer hours or regular days doing the same thing – the balance of the variety and short days seems to suit her best."

• Wages and benefits

It is clear to the DSA that facts need to be faced: the vast majority of people with DS are never going to earn enough to be able to live without benefits. This should

not be something that the Government is aiming for. It is unrealistic to expect most people with DS to work for a wage much above the minimum.

The wages issue is clearly tied in with issues surrounding working hours. Of the few respondents who said that they would like to work longer hours, most could not do this as it would affect their benefits. This is the classic benefit trap. If working for longer meant losing benefits, then they were always financially worse-off. There was a major concern about having to choose between paid work or no work at all, and therefore losing the non-financial benefits that work can bring:

"Jonathan has had to cut down his hours because of the basic wage and permitted earnings rule. The £20 permitted earnings has never been increased to fall in line with the minimum wage."

"David had a 2 1/2 day a week job at a garden centre which he had to leave because of the ridiculous implementation of the otherwise sensible minimum wage regulations."

"[A small company] tried to put him on the payroll in his own right but no way could be found to pay him for the work he does. His mum sends his 'wages' which we pay ourselves."



"Rebecca loves her day at [large company], but friends tell her she should be paid. Why does the Government insist on minimum wages? Its short-sightedness has shot people with disabilities in the foot; an employer cannot afford to pay someone for more than their level of work is worth."

The debate surrounding wages also reflects the aforementioned problem of persuading employers WHY they should employ someone with DS. Many employers will feel that they cannot afford to pay someone for a role that would only really be filled in the name of social responsibility.

Another problem that the benefits system caused for some people is that if they had a job for a while, came off certain benefits and then left their job for whatever reason, they had such a struggle trying to re-claim benefits that it put them off ever trying to gain employment again.

Working out issues around wages and benefits is incredibly complex, and warrants a report of its own. At this stage, the DSA is calling for recognition of the fact that changes need to be made to enable people to work the hours they want – from none to nearly full-time – without ending up losing money, and a fair debate about how the system can be changed to reflect this.

Recommendations concerning paid employment



It is clear that there are still too many barriers to supporting people with Down's syndrome into employment if they wish to work. Some of the key recommendations that the DSA makes to start to address this include:

- Starting the process in schools – get teenagers thinking about what work “means”, what they could do, having as many different tastes of the world of work as possible etc, from a much earlier stage. Plan ahead! Build these plans into Key Stage 4 provision.

- Improve Specialist Disability Employment Services – the current DWP Public consultation should start this process.
- Provide a model framework based on companies who have employed someone with DS successfully, so that other companies can benefit from their experience.
- Think more creatively about the types of roles available – and communicate these to people with DS who may not have heard of them before.
- Create and disseminate clear information for employers about how to recruit someone with DS and what may be involved. Publicise the training that is available for employers. It would be really useful to have a one-stop website that contains all of this sort of information in one place.
- Recognise successful employment placements, and motivate employers by rewarding good practise.
- Provide a ‘practical package’ for employers, employees/job-hunters and parents/carers that facilitates communication between all parties and promotes a good working relationship.
- Recognise the real limitations caused by an inability to travel independently and put efficient, affordable systems in place to overcome this.
- Re-evaluate the benefits system to ensure that those who do want to work are able to do so and that those who can't are not victimised.

Supporting people into options other than paid work

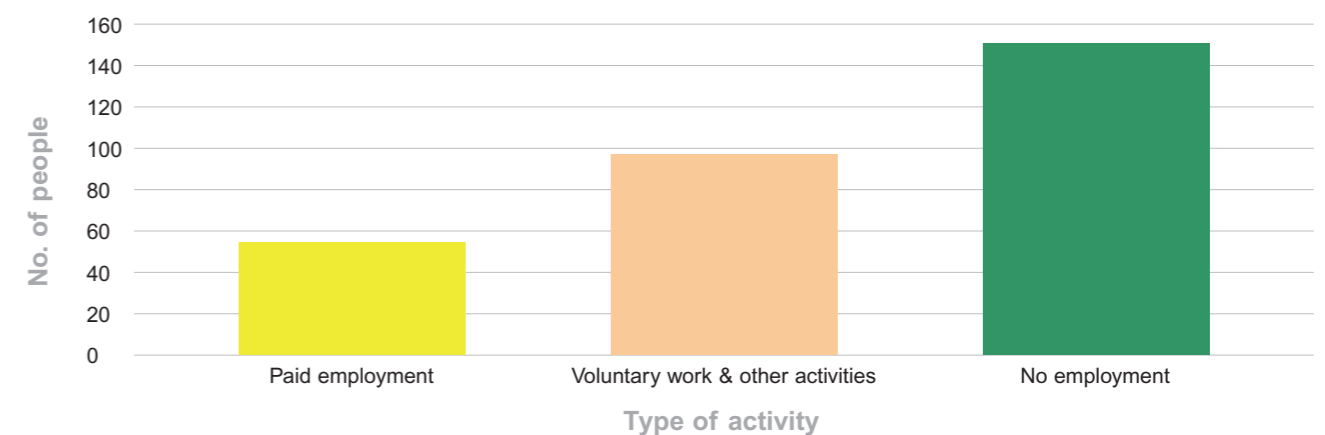
There is a significant number of people with Down's syndrome who either do not want to undertake paid employment or for whom paid employment is not the most suitable option. There is also a large group of people who would like to undertake some sort of paid employment, but only on a very part-time basis, or at some point in the future once they have developed other areas of their lives.

There currently appears to be a distinct lack of recognition of, or support for, other meaningful activities for these people. These can include long-term work experience, unpaid 'social firms', community projects, day opportunities

and volunteering, many of which provide the same benefits as traditional paid employment (increased self-esteem, social networking, learning and using skills etc).

There has been increasing emphasis in recent years on the 'transition crisis' – ie the fear that when people with DS come out of education, they suddenly find they have nothing to do. At the time that they should just be beginning the exciting new phase of their life, they find themselves stuck at home with a decreasing social circle and little idea of where to turn. While 'real work for real pay' answers this problem for some, other choices should not be seen as inferior if paid work is not an option.

A chart to show how many people access other meaningful activities compared with those in paid or no employment



Many of the other options available can be considered as part of a wider debate about Adult Social Care, and it is not necessarily appropriate to go into detail here about what other possibilities there are – the important thing is that there ARE other options. There needs to be an increased range of other activities/opportunities with straightforward access for people with DS, in addition to a differentiated range of support levels to achieve success.

A noticeable trend that came out of our survey was that many of the people who did voluntary work, community

projects or simply had responsibilities within their day services considered themselves to have 'work'. It did not matter to them that they were not paid or that others would not consider their activities 'a real job' – they got out of it what they wanted to – primarily a sense of self-worth and a chance to meet other people.

People with DS and their carers not only need better information about what alternatives there are, but these alternatives need to be of a high standard and have the same priority given to improving them as paid employment does.

Conclusions

- If 'real work for real pay' is an appropriate aim for an individual with DS then it should be actively encouraged and supported. Adults should be able to engage in paid employment as a genuine choice and with the appropriate support.
- However, it needs to be recognised that paid employment is not the only option available, and those that do not take it should not be marginalised or have a reduced quality of life.
- The overall transition period from childhood (and child services and education) to adulthood (and adult services and possibly employment) needs to be given much greater consideration. There is a need to start thinking about the process much earlier, as well as ensuring that all the services assisting the process are of the highest quality possible and are working together. The 14+ Transition Review should be a fundamental part of the process.
- Employment opportunities need to be considered from the point of view of the individual concerned, rather than from a desire to reduce the unemployment rate and the number of people on benefits.
- Without the right support at each stage of the employment process, experiences for both employer and employee could be very negative, and could actually discourage either party from trying again.
- There are still many improvements needed to support people into employment, particularly in the areas of:
 - 'de-mystifying' the concept of work
 - the role of the school
 - transport
 - specialist disability employment services
 - types of job available
 - supporting all involved parties to understand the practicalities of work
 - wages, benefits and working hours

Appendix

Appendix A

Poster A – displayed at 1639 sites throughout London and the UK, for a minimum of one month, as well as twice in the Guardian newspaper (approx daily circulation of 364,000).

Poster B – displayed on the M4 'Torch' for one month.

All costs, from design to advertising space, were donated as gifts in kind to the DSA.

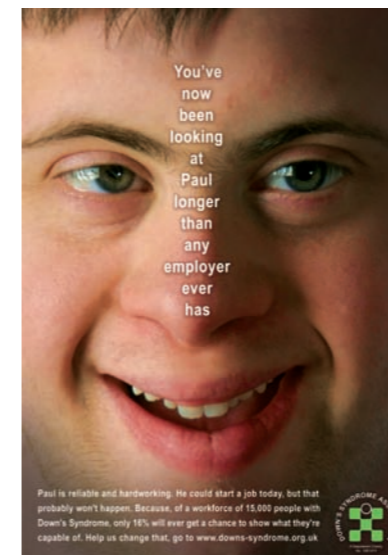


Table of coverage

Media Location	Media Size	No. Panels	Dates	Audience	Cover	Freq
Roadside	6 sheets	70	18/12/06 - 31/12/06	Ads	33%	3
Roadside	6 sheets	200	01/01/07 - 14/01/07	Ads	58.40%	5.7
National Rail	4 sheets	200	18/12/06 - 31/12/06	UK Rail Users	50.70%	4.5
National Rail	6 sheets	100	18/12/06 - 31/12/06	UK Rail Users	54.60%	3.3
London Underground	4 sheets	750	18/12/06 - 31/12/06	LU Users	91.30%	68
				LITV	23.30%	
"The Torch" - M4		1	18/12/06 - 31/12/06	Ads	2mil	
Health Club / Cinema	6 sheets	200	01/01/07 - 14/01/07	Ads	n/a	n/a
Mall	6 sheets	100	18/12/06 - 31/12/06	Ads	n/a	n/a

NB: It was not possible for the Health Club/Cinema/Mall panels to run cover & frequency, but overall the table gives a good indication of who will have seen what.

Key results from our survey

As most of our questions required qualitative rather than quantitative responses, it was not always possible to draw

statistics for every question. Where possible and relevant, we have analysed the data in statistical format here:

Results from those in paid employment

*Note: There are 56 people in paid work, but some have more than one job, hence the different numbers for top 2 tables.

Hours worked per week	No. of people
Less than 7 hours	17
7-21 hours	31
More than 21 hours	10
Doesn't say	1
Total in paid employment	59

Work sector	No. of people
Administration	13
Retail	17
Catering	15
Cleaning	3
Care Work	1
Outreach	4
Manual labour	3
Arts	2
Reception	1
Horticulture	0
Total	59

Age	No. of people
18-24	15
25-34	28
35-44	10
45-54	2
55-60	0
Not specified	1
Total	56

Gender	No. of people
Male	32
Female	23
Not specified	1
Total	56

Where did you find job	No. of people
Job centre plus/ Workstep	4
Employment liaison officer (not stated through which type of organisation)	3
Nationwide Specialist Employment Services (accessed locally)	8
Regional Supported Employment Services (only available in local area)	6
Through Friend/Family/Other contact	11
Applied directly (to a job ad or on off chance of a job going)	7
Following work experience	9
Through training opportunity	5
Voluntary work led to paid work	1
Not stated	2
Total	56

Results from those in no sort of employment/day activities

Would you like to work?	No. of people
Yes	93
No	40
Specifically stated as not able to	7
Not stated	12
Total	152

Done work experience	No. of people
Yes	86
No	56
Not stated	10
Total	152

Have tried to get a job	No. of people
Yes	31
No	113
Not stated	8
Total	152

Age	No. of people
18-24	70
25-34	47
35-44	20
45-54	6
55-60	7
Not specified	2
Total	152

Gender	No. of people
Male	82
Female	66
Not specified	4
Total	152

Results from those in voluntary or other activities

Types of activity	No. of people
Voluntary work	57
Social firm/supported businesses (unpaid)	6
Day opportunities (unpaid or minimal pay)	25
Organisations providing work 'experience' placements (unpaid)	8
Community projects (unpaid or minimal pay)	3
Total	99

Notes: Day opportunities refer either to specific 'work' responsibilities within the individual's residential care

or college (e.g. helping on a farm where their residential college is based, regular kitchen duties in their canteen

etc), or unpaid placements run by social services (e.g. gardening, special cafes etc).

Organisations providing work placements are those locally-run charities or community services that have been set up to help people with learning disabilities experience the world of work, either in real work placements or in specifically set-up projects.

Appendix D

This is an example of a completed work-support form to aid communication and understanding between employer, employee and parent/carer. This is by no means a

Community projects are those which have been set up by the local community to encourage inclusion and participation among all residents – usually for a specific period of time.

It was not always clear from the nature of the responses exactly which category the activity would come into – interpretations had to be made in occasional circumstances.

hard-and-fast template, but gives a good idea of the sorts of things that may seem obvious to parents but aren't as clear to employers.

Example - Working with Sarah

Sarah Jones
 Name of work Placement: Bill's Book Shop
 Address: 112 Oxford Street, London
 Contact number in case of illness etc: 0207 555 1234
 How does she travel to work: Bus & Train
 What day/s does Sarah attend: Monday, Wednesday and Friday
 What time does she start? 9.00am
 What time is break? 10.30am & 1.30pm
 What time is lunch? 12.30pm
 What time does she finish? 3.00pm

To be completed by parent/carer with Sarah's help

Strengths:
 Sarah enjoys the company of other people and works well with others.
 Sarah enjoys routines and works best when she knows which jobs are hers and when they should be done. Sarah likes to complete one task before starting another where possible.
 Sarah will need some jobs that involve sitting down as she can't stand for long periods.
 Sarah works well from a clear timetable and a visual (written or picture) clue will help her stay on task.
 Sarah can be polite and charming and is pleasant to customers.
 Sarah is well presented and happy to dress appropriately for work.

Things that will help her:
 Encourage Sarah to keep to time by reminding.
 Give Sarah one task at a time, set a time for it to be completed.
 Sarah will need somewhere to keep her valuables (purse, phone, MP3 player etc) during work time as she can easily lose things and is vulnerable.

Let Sarah know what the rules are, write them down at the back of this booklet so she can read them and have them reinforced at college and at home.

Be clear about any staff perks (free meals etc) and staff discounts on purchases etc. Write them down as well.

Sarah's parent will inform you of any appointments or absences due to illness holidays etc.
 If Sarah says she is unwell it may be that she needs distracting with another task. Sarah can use avoidance techniques but is very willing to keep to task once things are clearly explained.

Sarah is a very sociable and chatty young lady who may need reminding when to chat and when to work. She is very keen to make a success of her work placement and will at first need support to learn all the routines and tasks.

To avoid problems:
 Bring up any difficulties or misunderstandings as soon as possible so that they can be discussed and dealt with. Call the college or Sarah's parents to clear up any misunderstandings if needed.

Make it clear to Sarah who she should ask if she has a problem or difficulty with her work.

To be completed by employer:

Any additional rules and routines that Sarah should know:
 Break times are 15 minutes. Sarah will have to stay in the staff room during these breaks, but can leave the shop for her lunch.
 Lunch is 1 hour.
 Sarah will be able to leave her belongings in the staff room, which is locked at all times. There is a code to get in and someone will go with her to the staff room when she needs to use it.
 The staff are all very friendly and will always be available to answer questions and help.
 Sarah will work alongside one of the staff members for her first week so that she can learn what to do and the routine of the day.

Appendix E

This is an example of how the DSA's visual timetable may be used to help outline the daily activities expected of an employee. For more information about the visual timetable, please call the DSA on 0845 230 0372.

The visual timetable interface consists of several components:

- Top Navigation Bar:** A row of icons including a floppy disk, a folder with a document, a printer, a document, a sequence of four circles containing the number 2, a magnifying glass, and a power button.
- Search Bar:** A rectangular input field with a downward arrow on the right side.
- Time Slots:** A row of nine analog clock faces, each with a digital time label below it: 8:15, 9:00, 9:05, 10:00, 11:00, 12:00, 13:00, 13:30, and 14:00. Each clock has small up and down arrows on its left and right sides.
- Activity Images:** A row of nine small images corresponding to the time slots, each with a text label below it:
 - 8:15: A person getting on a bus. Label: "Get the bus"
 - 9:00: A person at a desk. Label: "Arrive at work"
 - 9:05: A person at a computer. Label: "Check emails"
 - 10:00: A person at a photocopier. Label: "Photocopying"
 - 11:00: A person at a shredder. Label: "Shredding"
 - 12:00: A cartoon girl eating. Label: "Lunch"
 - 13:00: A person with a trolley. Label: "Help pack boxes"
 - 13:30: A person at a desk. Label: "Franking mail"
 - 14:00: A person walking out of a building. Label: "Go home"
- Bottom Navigation Bar:** A row of icons including a left-pointing arrow, a sequence of seven small activity images (from "Arrive at work" to "Help pack boxes"), a right-pointing arrow, and a recycling bin.