



Down's Syndrome Scotland

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Constitutional and Welfare Team
2 H Bridge
Victoria Quay
Edinburgh
EH6 6QQ

Friday 13th December 2013

Dear Sir,

Call for Written Evidence – Expert Working Group on Welfare

Down's Syndrome Scotland welcomes the opportunity to respond to this call for evidence from the Expert Working Group on Welfare. As a charity, we work to improve the quality of life for everyone in Scotland with Down's syndrome and their families. Down's syndrome affects approximately 20 per cent of the learning disability population and is the single biggest diagnosed cause of learning disability. Therefore we have a particular interest in the future of the benefits system in Scotland. This evidence is a combination of our professional experience, of the lived experience of our member families, and members of our Policy Panel who were consulted for this submission.

Question 1

What should be the high level purpose(s) of the benefits system in an independent Scotland? What key outcomes should such a system aim to achieve?

Down's Syndrome Scotland welcomes the wide range of issues already discussed by the Group on this topic and supports the Group in establishing essential pillars of a benefits system. We strongly believe that the purpose of a benefits system to act as a 'safety net' is central. Individuals who cannot support themselves need to know that there is a reliable and effective system for them to use when needed, whether it is time-limited support or lifelong help. The protection of the most vulnerable and marginalised service users, like individuals who have Down's syndrome, should thus be guaranteed. People with Down's syndrome may require extra financial support to arrange for specific services to be delivered to meet their needs. For them and their families, access to benefits ensures that their most basic human rights are respected and it significantly improves their quality of life too. These two outcomes should constitute the core of any benefits system.

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Moreover we agree with the argument that a benefits system is in fact a form of social investment. Indeed it enables people with Down's syndrome to take an active part in the life of their community locally and, by supporting people in need, such a system also has the potential to tackle major concerns like inequalities in today's society. The point about supporting citizens' activity other than paid work is also very important as we know for a fact that employment among people with learning disabilities is very low (including in apprenticeships) as indicated in the latest eSAY statistics¹. Down's Syndrome Scotland have members who may not be currently in paid work but certainly are active members of our society and their contributions as citizens should be acknowledged too as it would not only improve their own confidence but also contribute to a more truly inclusive Scottish society.

Although the situation of people with Down's syndrome has significantly improved over the past few years thanks to the implementation of strategies like *The Same As You*², and now *The Keys to Life*³, much work still has to be done to ensure they are treated as equally as any other citizen in Scottish society. Equality should thus represent another key pillar of the benefits system in Scotland. Enabling disabled people to achieve their personal aims and to take part in the society they live in with dignity (at a local and/or national level), like any other citizen, represent key purposes of the benefits system.

Question 2

What are the main principles that should underpin the benefits system?

Down's Syndrome Scotland believes that a future benefits system should be built upon the concept of personalisation. This balanced system (nationally led – see answer to Question 8) should be based on a holistic assessment of individuals which would then determine which benefits the individual is entitled to. This personalisation model would be grounded on a minimum standard of living that everyone would be entitled to and which would take into account various criteria such as location and the status of the individual (e.g. single, couple, family with a disabled child, single parent...). One minimum standard of living should be established for each category. Through this model, the benefits system would be used to top-up the existing income of the individuals so that they reach the minimum standard of

¹ See Scottish Consortium for Learning Disability, *Statistics Release: Adults with learning disabilities known to Scottish local authorities 2012 (eSAY)*, 2013. Available at:

http://www.sclcd.org.uk/sites/default/files/statistics_report_colour_1.pdf.

² See The Scottish Executive, *The same as you: a review of services for people with learning disabilities*, 2000. Available at: <http://www.scotland.gov.uk/Resource/Doc/1095/0001661.pdf>.

³ See The Scottish Government, *The keys to life: Improving quality of life for people with learning disabilities*, Edinburgh – 2013. Available at: <http://www.scotland.gov.uk/Resource/0042/00424389.pdf>.





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living. A benefits system would also need to be flexible enough for benefits to increase or decrease depending on personal circumstances (e.g. new job or loss of a job, illness....).

In terms of more 'practical' principles, we consider that less bureaucracy, more flexibility and a move towards maximising resources would be a great advantage in the management of the benefits system. One of our members describes the current system as 'too big, too bureaucratic and not flexible enough to meet the diverse needs of the current population of the UK in the 21st century'. Many of the families we support complain about having too many forms to fill in, forms which can be complex and lengthy. Some of them also spend many hours over the phone trying to clarify their benefits entitlement. Finally, they often have to attend multiple assessments which can be stressful for both the applicant and their family. They may also have to inform different offices of a change in their circumstances when in fact having a unique single point of contact who would then forward new details to relevant parties would seem more sensible.

Furthermore the system should be designed to encourage and support activities other than paid work. As briefly mentioned above, it remains extremely difficult for people with Down's syndrome to find employment in the current economic climate which has made their situation even worse. The issue of employment should certainly be addressed (see answer to Question 3). However, recognising voluntary work for example and encouraging taking part in unpaid activities may have advantages too. In fact, supporting activities alongside paid work schemes might raise greater awareness of disability issues in the workplace and in the society as a whole. As for employment, one could argue that employers might also be more likely to consider employing people with Down's syndrome if they can learn more about the condition and the challenges and opportunities it may bring to their work place. Better knowledge and awareness would also result in decreasing the myths and preconceptions other members of society may have towards people with learning disabilities. Importantly, supporting all types of activities would also help individuals with Down's syndrome to improve their confidence which is a crucial life skill which aids them not only professionally but also socially.

Finally the benefits system should aim to support and not stigmatise its beneficiaries. As a charity, Down's Syndrome Scotland's ethos is to support families and encourage all people with Down's syndrome to reach their full potential. However the changes currently made to the benefits system are very much focused on what people cannot do⁴. A parent who has a

⁴ See Citizens Advice Bureau, Personal Independence Payment (PIP), 2013. Available at: http://www.adviceguide.org.uk/scotland/benefits_s/benefits_sick_or_disabled_people_and_carers_s/benefits_personal_independence_payment_e/benefits_the_pip_assessment_e/pip_activities_descriptors_and_points.htm.

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young daughter with Down's syndrome has explained to us that 'the current changes result in greater demands for individuals to prove their incapacity' and, according to him, this is the wrong approach for people born with a condition like Down's syndrome. A future benefits system should focus on what people can do and work towards maximising their skills and strengths, not diminishing their ability and confidence. We also need to take service users' views into account and assess their needs when considering any changes to the system.

Question 3

Which areas of policy are fundamental to the delivery of a system that meets the principles you have set out? What evidence do you have to support that view?

In terms of policy, one of our members rightly points out that a key starting point would be for politicians and service providers to fully understand what type of support may be needed for people who have Down's syndrome (as a baby, as a child, as a young adult and as an adult) and the difficulties and challenges families may experience. This would allow them to recognise the positive impact a more flexible benefits system could have on the lives of people with Down's syndrome of working-age and their families.

Employment constitutes the crucial policy to consider when thinking about a future benefits system. Down's Syndrome Scotland knows that many of its members are keen to work and we also recognise how important it is for those who can work to do so for their own wellbeing. Importantly, employment can also give them a sense of belonging and contributing to the society they live in. We therefore strongly urge the Expert Working Group to assess the issue of employment in great detail as it is likely to provide many answers to the feasibility and delivery of the benefits system. The current changes to the benefits system in the UK focus on making work pay; Down's Syndrome Scotland would support a system which 'makes work break even' by enabling people to reach a minimum standard of living that anyone in the society should be entitled to.

Training and unpaid work can provide essential skills for people with learning disabilities, however as one parent said 'these do not pay bills'. Providing better employment opportunities for all as well as the living wage would not only help beneficiaries but it could also reduce the cost of the benefits system since those individuals would then receive an income to support their way of living too. Moreover it is important to remember that, whilst in employment, people with learning disabilities also contribute in taxation and national insurance like any other citizen. Being 'responsible citizens' and 'effective contributors' are defined as key attributes of the Curriculum for Excellence. All pupils, including children with Down's syndrome, are therefore encouraged to develop these attributes throughout their

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education. As a consequence, not being able to participate in society due to a lack of employment opportunities once they left school/colleges can only erode the confidence of young people with Down's syndrome. The contribution of people with learning disabilities to our society is not negligible and should be more widely acknowledged when encouraging employers and society as a whole to give people with Down's syndrome more opportunities to develop their skills and acquire new ones. It is also essential to provide enough support to employment providers. Employers do not receive enough support nowadays which is regrettable as they clearly hold the keys to more opportunities for people with learning disabilities.

Schemes like Access to Work run by the DWP⁵ could also provide useful examples to be included in the future benefits system for Scotland as it is valid for paid work and apprenticeships. The scheme provides practical and financial support to help people with disabilities to start or to keep a job. Importantly, Access to Work can also work with employers offering advice and guidance on the issues of disability and mental health and how best to support their employees.

Examples of policies being considered abroad are also worth considering. We would therefore encourage the Expert Working Group to bear in mind the principles of the Achieving a Better Life Experience (ABLE) Act currently debated in the US Congress⁶. The aim of the bill is to 'ease financial strains faced by individuals with disabilities by making tax-free savings accounts available' without the fear of losing their benefits. This legislation would give disabled people the chance to provide and save for themselves through the same saving tools used by other citizens. Importantly it is also argued that 'the scheme would create incentives to employment for individuals with disabilities by allowing them [...] to seek out employment opportunities without the fear of losing Medicaid [...] because of outdated asset and income limitations'.

Furthermore concerns about losing benefits because of employment shed light on a reality that urgently needs to be addressed. As indicated above, the benefits system should support people with learning disabilities to reach their full potential and this will prove an impossible task if people continue to live in fear of losing their benefits, with its consequent impact on their quality of life, by taking up paid employment. Currently, people can work up to 16 hours a week without losing benefits but Down's Syndrome Scotland is aware that

⁵ See Department for Work and Pensions, *Access to Work Factsheet*, October 2012. Available at: <http://www.dwp.gov.uk/docs/employee-factsheet-atw.pdf>.

⁶ See Sarah Weir & Steve Beck, 'The ABLE Act: Opportunity for Congress to make a difference', *The Hill*, 25 November 2013. Available at: <http://thehill.com/blogs/congress-blog/healthcare/191361-the-able-act-opportunity-for-congress-to-make-a-difference>.

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some of our members prefer to undertake voluntary work instead of paid employment because they do not want to lose the stability of the support they receive through the benefits system. We also know of an adult with Down's syndrome who is working 16 hours for a charity. This person is very happy in their job, however their work place cannot afford to pay them more than 6 hours. As a consequence, that person does the remaining hours as a volunteer for the organisation. At present, there are no other employment opportunities either for them. Moreover, that person does not receive enough money between their job and benefits to cover all expenses. Their mother thus has to work additional hours to enable them to reach a minimum standard of living. Another relevant example is Down's Syndrome Scotland's training project. This project employed adults with Down's syndrome to deliver training courses. What is particularly relevant to note is that parents and carers asked us for the working hours of trainers to be minimal so that their job would not affect their benefits. Last but not least, it has come to our attention that people who get fired also risk losing benefits for a certain period time. It would thus be helpful if the employer's reasons for dismissal could be investigated before benefits are stopped should a similar situation occur for a person with learning disabilities. These experiences emphasise that the issue of benefits and their link to employment is important and of real concern. We would therefore advise the Expert Working Group to consider it in depth.

Along with key policies, Down's Syndrome Scotland is of the view that the consistency and transparency of policies put in place should be evaluated and monitored to guarantee the efficiency and reliability of a new benefits system.

Question 4

Which areas of welfare should be delivered as services and which through cash transfers, and why?

Down's Syndrome Scotland believes that areas such as housing should be delivered as services. At the very least, there should be an option for applicants to choose for the money to go systematically to their landlord instead of cash being transferred to them because not everyone is able to manage a budget.

Question 5

Of these services and/or transfers which should be means-tested support and which should be universal provision?

A new benefits system, whilst sustaining principles of universality, could allow people to opt out of benefits if they do not need them (e.g. free bus travel, free prescriptions, cold winter payments...) rather than donating them to charity.

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Question 6

How important is it that benefits relate directly to the contributions paid by an individual, and if important, which benefits and why?

Down's Syndrome Scotland believes that the benefits system should not be based on the amount of contributions paid by an individual, it should rather focus on guaranteeing a minimum standard of living for all.

As an example, this question raises the case of young people (16-18 years old) who leave school and have not yet had a chance to contribute to the system. If benefits relate directly to the contributions paid by an individual, does this mean that young people (who may struggle to find employment for example) are simply not entitled to any form of support?

Question 7

When considering the cost of welfare in the future, what are the most important considerations which Governments in an independent Scotland should take into account, and why?

Although we recognise the issue associated with costs, saving money should not be the sole objective of a benefits system as is the case with the current Welfare Reform. Instead, Down's Syndrome Scotland argues that improving the services available to people in need and enabling them to achieve more should be the main drivers of any new system.

Crucially, we need a more joined-up approach between various bodies. As of now, one of our parents rightly argues that 'there are too many agencies involved in current policies and this does not lead to clarity'. Down's Syndrome Scotland is also of the view that too much is expected from applicants themselves. As indicated in our answer to Question 2, many parents complain about benefits application forms. As an example, two parents recently spent about 40 hours on one benefits application for their child who has Down's syndrome. Parents would also like to have a single point of contact to discuss benefits, a person who would be able to advise them on which benefits they are entitled to and could help them to complete the necessary forms. Moreover, we would also like to raise the issue of 'digital participation'. As part of the Welfare Reform, claiming Universal Credit is expected to be made on-line and sometimes over the phone; exceptionally claims could be made face-to-face. This raises serious issues for people with learning disabilities who may not be able to complete forms online or over the phone because of their condition. The delivery of Universal Credit clearly does not pay attention to the variety of people claiming benefits and illustrates the importance of identifying potential categories of beneficiaries before setting

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up a system likely to result in a waste of resources and leading to increased costs due to poor planning. One could argue that this is only the tip of the iceberg but it already reveals serious flaws in terms of the efficiency and reliability of the current system. These problems are also likely to lead to a waste of resources and increased costs with various agencies dealing with applications which could in fact be processed through one body. If Scotland is aiming to deliver a cost-effective benefits system, actions must be taken to simplify the application process.

Another option to limit costs would be to ensure the implementation of more systematic rules instead of relying on applicants to fill in ever more forms and to go and ask for support. This does not apply to all but, for people with Down's syndrome for example, forms could be automatically filled in by the relevant authorities as soon as a baby is born. This would not only help new parents during what can be difficult emotional times but it could also be useful in ensuring that the population of individuals with this condition is monitored. This would work towards protecting the future wellbeing and welfare of older adults with Down's syndrome when their parents/carers die for example.

Finally, questions surrounding the costs of a benefits system are linked to employment policies. As one of our parents notes, 'a mix of policies ensuring work is available to those who can work is extremely important to lower the burden for taxpayers and increase the individuals' worth in our society. The Christie Commission's proposal regarding early intervention is very positive. It states that "a recurring theme in the evidence presented to the Commission has been the importance in addressing inequalities of public service interventions that enhance the employability of individuals, and so improve their and their families' life chances. The Commission has received evidence from a range of stakeholders which demonstrates how, and by what mechanisms, assisting individuals to move into training and work delivers positive social and economic impacts and contributes significantly to ending cycles of inequality." This has to be the way we tackle many current inequalities.'

Question 8

How should benefits be delivered in this system? (e.g. Through a new or existing national public body? Through existing public or third sector organisations? Localised delivery based on national guidelines) What would this entail? Are there barriers to such a structure?

With regard to delivery, Down's Syndrome Scotland is of the view that the benefits system should be nationally led and delivered locally. As one parent explains, 'it is important that there are local contact points, so that people can talk to an individual who understands the local economy and area'. It is worth pointing out that a local contact may also know of other

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adults with Down's syndrome living in that area and thus be able to better help families facing similar challenges and signpost appropriate services to them. One needs to understand that 'people who receive benefits will, generally, not be able to move far to work, either because of costs or support networks'. It should however not be left for local authorities to decide how to manage the system as this could lead to beneficiaries facing a postcode lottery in terms of access to services. Benefits should be delivered through one single system which would regroup and facilitate communication between all actors involved, including applicants.

On this note, it is worth considering that changes implemented as part of the current Welfare Reform heavily rely on directives and penalties that can be enforced against beneficiaries if they fail to comply with the rules. Due to their condition, people with Down's syndrome are less likely to be able to strictly abide by these demands, which is different to deliberately breaking them. Down's Syndrome Scotland thus strongly believes that the future delivery of benefits in Scotland ought to be a system which is not grounded on the concept of punishment-led interventions. It should also ensure that staff in charge of assessing applications and delivering benefits truly examine each case in detail instead of assuming that some applicants are simply not eligible for support. These situations can be very distressing for our members and their families. At a time when stigmas surrounding people who claim benefits remain high, such behaviours and attitudes constitute without a doubt significant barriers to the establishment of a successful and reliable benefits system.

Question 9

What are the advantages and challenges of the delivery system you propose? What should its relationship be with e.g. 'job centres', work preparation programmes, and members of society who are unable to work but wish to play a full role in society?

Down's Syndrome Scotland is aware that a national system may lead to significant administrative costs if led by a statutory body and would therefore suggest that a new benefits system could be administered by a third sector organisation (perhaps a new one) which would be more flexible and likely to provide the most cost effective route for the local delivery of benefits. In our view, the option of a third sector organisation would also constitute a guarantee that the rights and interests of people with Down's syndrome are respected throughout Scotland due to the predominantly social values driven ethos of the third sector.

We would also like to emphasise the importance of building relationships and strengthening links between the national system and local job centres and work preparation programmes. As part of their services to people, job centres should check and ensure that benefits

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delivered to beneficiaries are correct and they should also support people to challenge any difficulties they may encounter with their application through a single point of contact.

We trust these comments assist the Expert Working Group on Welfare with its work. Please do not hesitate to contact our office on 0131 313 7452 or by email at rachel@dsscotland.org.uk should you have any question.

Yours sincerely,

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