

Open letter to George Osborne

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Dear Mr Osborne,

You have spoken a lot of rhetoric about “people who want to work hard and get on”. It sounds fine. Few people would argue with supporting those who want to work hard and get on. But this language automatically excludes as at best insignificant or at worst worthless one particular category of people.

There are some people who, by reason of severe, usually multiple, disabilities, will never be able to be gainfully employed. My daughter is one example. She is in her early thirties and lives in a residential care home. She has quadriparetic cerebral palsy, a learning disability, autism and partial sight. Please don't feel sorry for her. She has a very good quality of life.

I read a policy document which your government has published on the subject of disabled people. It was called “Fulfilling Potential”. In many ways it was a laudable document. It had much to say about enabling disabled people to take their rightful place in society, work in fulfilling jobs, pursue excellence in sport and so on. But there was a glaring omission in this document.

There was no mention at all of those people whose contribution to our society will never be an economic one. How are they to fulfil their potential? My daughter is incapable of carrying on any form of employment. She has to be washed and dressed, supervised while eating and drinking, carefully watched to ensure that she does not do anything injurious as she has no sense of danger, and accompanied everywhere she goes. She cannot stand up or even sit unsupported. These are the things she cannot do.

But the things she can do are wonderful. She can tell you the name of any piece of music she hears, with its composer or artist and also what key it's being played in. She can play on the piano with her right hand any tune she has ever heard even once. She can remember and recall almost anything you might care to ask her about any event in her life. She can express deep affection that is more uplifting to the recipient than you could ever imagine. She can be hilariously funny, with or without words, and she brings immense joy to everyone who has any dealings with her. We recently took her away for a weekend and when we returned her to the care home, the staff said her absence had made them realise how much she influences the atmosphere in the home, that it had been much less fun without her and they had really missed her.

But in your brave new world she is almost a non-person. Her contribution to society is not an economic one. It cannot be measured or quantified. It is, in both senses of the word, an immeasurable one. And for you, that means it does not count. I can assure you she works hard. Every single thing she does requires an exhausting effort. And she wants to get on. She absorbs new information and ideas like a little sponge. She never saw the end of formal education as a reason to stop learning.

When she was a child, everyone thought she was very cute. She sat smiling in her wheelchair with her little pigtails and stole everybody's heart. So how is it that in Tory Britain she has suddenly gone from cute and adorable disabled child to skiving benefit scrounger in one bound?

If you think I'm exaggerating, here are two verifiable facts: Firstly, she has been fined for fraud for trying to claim free prescriptions. This was extremely surprising to me, as she is entitled to free prescriptions. I was asked to provide proof of her benefit, so I contacted the DWP to obtain this proof. I was told that she is not entitled to free prescriptions, as she is on contributions-related ESA instead of income-related ESA, and only the income-related version of the benefit would entitle her to free prescriptions. I pointed out that she has never paid any National Insurance contributions, and should be on the income-related benefit. I innocently suggested that there had been a clerical error. I was assured that this was no clerical error. It was DWP policy to transfer people onto contributions-related ESA even if they were entitled to the income-related version, as the income-related version would normally give them more money. It was for the disabled person to find this out and challenge it if they wanted to be put on the income-related benefit. The lady offered to send me the forms so that I could apply for the income-related benefit for my daughter. She apologised that the form is "about twenty pages long". It turned out to be forty-two pages long. She then checked my daughter's records and told me that I had in fact completed and submitted this form eighteen months ago but it had not been actioned. I asked if they couldn't simply action it now and was told no, after deciding not to action it they had not kept it and I would have to fill it in again. So now who is committing benefit fraud? Not my daughter. It seems the DWP is fraudulently withholding from her a benefit she is entitled to.

Secondly, every time my daughter has an annual review, or applies to go on an assisted, accessible holiday, I am asked if I want to write "Do not resuscitate" on her medical notes. Three social workers and a nurse have told me that this is an NHS requirement. I have two other daughters who are neurotypical – they are physically able and their intellectual function and social understanding are unimpaired. All three of my daughters are in good health, and all three have a normal life expectancy. So why is one of them being singled out for the suggestion that we should write "do not resuscitate" on her medical notes? She is a cheerful young woman with, as I have already indicated, a great sense of humour and wonderful musical ability, and

everyone who works with her falls in love with her. She is a much loved and very valued member of our family. No one would ask my other two daughters to consider refusing resuscitation. I find it offensive that society assumes that disabled young people have such poor quality of life that they should not be given proper care if they become ill. It is the ultimate disability discrimination, giving the message that if someone's life is different and more limited than average, he or she is disposable.

Mr Osborne, bad things happen when people are valued only for their economic contribution. People are of intrinsic value in and of themselves. When we lose sight of this we lose something fundamental of what it is to be human. There are some people who will always cost the country money and will never repay it in taxes, national insurance contributions or in any other way. This is why it is so important that we celebrate the other kinds of contribution they make to society. My daughter provides employment for a small army of carers, and makes their work pleasurable and fulfilling for them. She brings real joy into the lives of everyone who comes into contact with her. She is capable of deep love and fierce loyalty. She makes our great country a better place. And your policy towards disabled people considers her at best a burden and at worst a scrounger. Unless we reverse this terrible way of looking at people, Britain will become a very unpleasant place to live. Please find a way of recognising that, as Jean Vanier recently told an audience in the House of Lords, the strong need the weak, and that people like my daughter make Britain a place worth living and show us that money cannot buy the things that really matter in life.

Yours sincerely,

Rosamund Bayes